CART in the Land of Oz
Bill Graham, ALDA co-founder

I took part in a panel at the National Court Reporters Association (NCRA) conference last week. The topic was “Capturing the Flavor of the Room”—how captioners can use parenthetical words to go beyond the verbatim text they provide and give clients a better feel for what is happening or said.

Preparing for the panel made me realize how much the captioning industry has changed and grown through the years. I co-founded the Association of Late Deafened Adults (ALDA) in Chicago in 1987. At that time cochlear implants were not yet widespread and deafened adults were not recognized as a distinct population in the deaf and hard of hearing communities, with special communication (and psycho-social) challenges. To meet as a group, we needed to overcome the fact that we couldn’t hear what others said and almost none of us could sign or lipread effectively. But we all knew how to read, so text seemed the greatest common denominator for communicating with each other. Coping strategy for deafness be accepted by the conference attendees?

Realtime captioning was in its infancy and unknown outside television. The word CART was not yet invented. Our first approach to group discussions in ALDA was to have a hearing person use a manual typewriter and type what we said. She had four carbons in the typewriter and every ten minutes or so would pass the carbon copies around so people could catch up on what they missed.

Continued on page 4
ALDA NEWS
Publisher:
ALDA, Inc.
8038 MacIntosh Lane, Suite 2
Rockford, IL 61107
ALDA VOICE/TTY : 815-332-1515 or
866-402-ALDA (866-402-2532)
FAX: 877-907-1738
Contact ALDA: ALDA.org/contact/
WEBSITE: ALDA.org
Interim Editor: Sharaine Rawlinson Roberts (editor@alda.org)
Layout Editor: Paul Wummer
Editorial Review Board:
Terri Singer
Randall K. Roberts
Technology Director:
Ken Arcia
Chapter Happenings & GA to SK
Ann Smith
Advertising Inquiries:
Matt Ferrara (treasurer@alda.org)
V/TTY: 815-332-1515

The views and opinions expressed in these articles are those of the authors and do not necessarily reflect the views or official policies of ALDA, Inc.

This publication contains copyrighted material and may not be reproduced in whole or in part in any form without written permission of the Association of Late-Deafened Adults, Inc.

ALDA 2018
Board of Directors
Sharaine Rawlinson Roberts, President
Steve Larew, Past President
Paul Wummer, Vice President
Kim Mettache, Secretary
Matt Ferrara, Treasurer
Wendy Ting, Region 1 Director
Tina Childress, Region 2 Director
Chris Littlewood, Region 3 Director
Roy Miller, Region 4 Director

Communicate with ALDA at:
www.alda.org/contact

Advertising Information
Full page (7.5 x 9.5) ……………………….. $200.00
Half page (7.5 x 4.5) ……………………….. $150.00
Quarter page (3.5 x 4.5)…………………….. $75.00
Eighth page (3.5 x 22.5) …………………… $45.00

Ads should be submitted electronically via pdf file and should conform to the sizes listed above. Payment in full is due when submitting the ad. Additional charges will be added for not meeting size conformity, ALDA dies not endorse any product or service advertised herein. Advertisers assume full liability for the content of ads.
This issue of ALDA News is full of interesting articles. The aforementioned bill, H.R. 620, ADA Education Reform and Act, is further covered in John Waldo’s column, ALDA’s Advocacy Corner, in this issue of ALDA News. This bill could have several unintended consequences that could undermine our rights to communication access and I believe it is important that ALDAns stay abreast of this bill.

If you have attended an ALDacon, you’ve seen firsthand CART (Communication Access Realtime Translation) services. ALDA’s co-founder, Bill Graham, has provided an interesting column about the first days of realtime captioning in his article, CART in the Land of Oz. Captioning has evolved so much since ALDA’s beginnings. We should all be grateful for the services of captioners.

In One of Us, curator Karen Krull introduces Nawaraj Bhattarai, a new member of ALDA from Nepal. He attended his first ALDacon in Orlando last year and, like many first-timers, came away very happy to have met other people like himself.

We have a second review of the movie, Wonderstruck, by Carl Sjobeck. He offers a different perspective on the movie from the review that was in the Winter 2018 ALDA News.

Did you catch the flu this winter? If so, you are not alone. In her column, Call the Nurse, Anne Marie Killilea writes about proper handwashing methods provides that help prevent becoming sick or spreading germs.

Special to this issue, we have a second Call the Nurse column about setting new year’s resolutions. This column was inadvertently left out of the Winter 2018 ALDA News. We regret the error.

We hope you enjoy this issue of ALDA News.

PUBLISHING ALDA NEWS

ALDA wants to publish YOU!

The themes for the next issue will cover Empathetic Support. For the Summer issue, tell us what your stories related to empathy and its effect on yourself and others. Please share with your fellow ALDAns!

The deadline for the summer issue is May 25th.

With each item sent, please include your city and state, a head shot and permission to print those, and your email address if you want to grant it.

Send your contribution TODAY!

ALDAeditor@gmail.com
After a while our CGO (chief geek officer) Steve Wilhelm was able to connect a computer keyboard to a monitor so the typist’s output was visible immediately (this was no easy feat back then—it took weeks of experimenting with parts from Radio Shack to get the system to work). We thought this system—which we later referred to as ALDA Crude—was remarkably cool.

Stories about our efforts spread and eventually reached Jerry Miller, then president of NCRA (then NSRA), who worked in Chicago. Jerry brought me to a courtroom downtown and showed me how a court reporter could make spoken words appear in realtime as verbatim text on a laptop screen. To a deafened, communication inept person (me), this was positively magical, like first casting eyes on the Land of Oz.

Thus began ALDA’s close relationship with NCRA. At ALDA’s first “national” conference, held in a hospital with 38 attendees, three presidents of NCRA came, as well as the organization’s top administrator. Live-event captioning was a promising new field for court reporters. Our meetings at our itty bitty conference were captioned by Marty Block, the first person to caption live television and a founder of VITAC, now the nation’s leading broadcast captioning company. Marty sat in a cramped space in the hospital’s auditorium and his captions—full of mistranslates, which came with the territory then—were projected onto a blackboard. But hey, this was Oz back then. The next year ALDA’s conference moved to a hotel and attendees numbered over 200. Ours was the first major conference in which all plenary and workshop sessions were captioned. And the term CART had been introduced, although almost nobody but Marty (who helped coin the term) knew what it meant.

After the Americans with Disabilities Act (ADA) was enacted in 1990, captioning and CART grew dramatically. I then used CART for many meetings at work—at first onsite and then remotely. Without it I would have struggled mightily, no question. Captioning has been essential to my success at work, just as it has been essential in helping me more fully partake in the family event known as television.

At the NCRA convention, other panelists mentioned matter-of-factly the benchmarks for quality CART skills—225 words/minute or more with 98+ percent accuracy. Visible mistranslates are rare, and there are many ingenious ways that captioning can be displayed other than on a blackboard. The captioning industry has come a long, long way from the days of ALDA Crude, but I never forget how important captioning has been and is to my life and the lives of so many other deaf and hard of hearing people. As the CEO of a captioning company, I do my best to keep that in mind and ensure our customers are served as I myself would expect to be. I also make a point of thanking the captioners for their important and indeed life-changing work, as well as those who coordinate captioning services for others. The Land of Oz doesn’t just happen.

Bill is founder and CEO of CaptionAccess, which provides live and post-production captioning services and VRI (video remote interpreting). He has been a relentless advocate for captioning since becoming deafened as an adult. He co-founded the Association of Late-Deafened Adults (ALDA) and has served on numerous national boards and committees related to captioning and disability, as well as the Gallaudet University Board of Trustees. He is featured in the book Great Deaf Americans. Bill also spent a decade as a manager at Microsoft Corporation. He’d be a cross-country ski bum if he had the time.
My Fellow ALDAns,

It’s hard to believe that March has come and gone, leaving us with just nine months in 2018. Where did the time go?! While time does seem to fly by, there is one good thing we can focus on – that we will be together again at ALDAcon 2018 in Portland, Oregon, October 10-14. The planning committee is working hard under the guidance of co-chairs Karen Krull and Kathy Schlueter. Steve Larew, ALDA’s Past President, is once again chairing the program committee and several proposals have been received. If you want to present and have not yet submitted your proposal, please do so ASAP. The deadline for submitting proposals is April 30, 2018. We encourage you to submit a workshop proposal using the Call for Proposals (CFP) form found online at: ALDAcon 2018 - CFP.

While we are talking about ALDAcon 2018, have you registered? The Early Bird rate of $280 is good through June 30, 2018. After that, the rate will increase to $310. So, save some money and get yourself registered today! Here’s a link to our online registration form: ALDAcon 2018 Registration. For those who wish to pay by check, a registration form is included in this ALDA News.

The ALDA Board of Directors continues to work on various advocacy efforts. On February 9, 2018 we sent a letter to the Rehabilitation Engineering Research Center on Technologies to Support Successful Aging with Disability (TechSAge) at Georgia Tech University regarding research project #90RE5016. This project is focused on studying the challenges of senior citizens who are Deaf or Hard of Hearing (D/HH). ALDA is concerned that the study is limited to only D/HH persons who use American Sign Language (ASL) and does not include ALL persons who lose their hearing later in life. I am happy to report that we received a response from the co-Director of the TechSAge project acknowledging our concerns. In her letter, she stated that if they receive a second round of funding from the National Institute on Disability, Independent Living, and Rehabilitation Research they welcome ALDA’s participation and will include deafened adults in their research.

ALDA continues to be involved in the Deaf and Hard of Hearing Community Action Network (DHHCAN) that is located in Washington, DC. Our involvement with DHHCAN has given us greater visibility with our sister organizations from across the U.S. that advocate for the accessibility rights of people with hearing loss and deafness. On March 7, members of DHHCAN met with representatives from three Congressional Representatives’ offices to go over several issues including H.R. 620, the so-called ADA Education Reform and Act. Initial reports following this event indicate that DHHCAN’s efforts are having some positive impact.

Until next time, have a marvelous spring!
“Wonderstruck” is a film about two individuals, Rose and Ben, who are both deaf for what appear to be separate causes. The film centers on pre-teen Ben in 1977; and at the same time, Rose as a pre-teen in 1927.

We are introduced to their tragedies, unhappiness and lack of family love using flash-backs and flash-forwards. The use of these cinematic devices helps build tension and explains many of the plot intricacies, while using little dialogue. This seems appropriate for a story about the lives of two deaf people.

What we see are two separate tales: one of a boy, Ben; and another of a girl, Rose, each, who, despite their deafness, overcomes their miserable environment and life pattern by running away from home. Despite the fact that neither character has any sign language or speech-reading training, they manage to succeed on their own. Their determination and resolve give them the fighting power to achieve their separate quests.

Julianne Moore and Michelle Williams portray the two main adult characters in a very natural manner. The actors portraying the two preteens are relatively unknown; however, they are truly the stars of the production.

There aren’t many movies that use the subject of deafness in a realistic manner. Often, deafness is used as a comic effect for laughs, or a reason for mental fuge. I believe that this movie has effectively portrayed two deaf individuals striving to find answers to their diverse needs, including their shared need to communicate. The conclusion of the movie ties together the loose ends of these two stories in an amazing show of love.

I recommend this movie: it’s an excellent vehicle to introduce hearing loss to a broad audience and reveal its effects on the deaf individual, as well as on others in the same environment.

Carl Sjobeck is no stranger to the hearing loss world. He has been active since his first group meeting in Minneapolis, MN, back in the 1980’s. In the 1990’s he relocated to the Fort Lauderdale, FL, area, and participated in many other groups.

At this time he lives in Winter Haven, FL with his partner, Larry Kavanaugh. Both men are active in the local Expos and social groups.

Carl is a graduate of Gustavus Adolphus College, St. Peter, MN, and is now retired after working in finance in the medical field, book publishing, and government.

In the early days he wore a body hearing aid; later a BTE in each ear; and in 2002, opted for a cochlear implant.
On Feb. 15, the United States House of Representatives voted to pass the so-called “ADA Education and Reform Act, a bill seen as hostile to the interests of people with disabilities.” This bill would amend the Americans with Disabilities Act to require that before anyone can file a lawsuit for the failure of a business to remove architectural barriers, the person who encountered the barrier must provide written notice to the business, give the business 60 days to respond and another 120 days to make “substantial progress,” whatever that may be, towards eliminating the barrier.

The stated objective of the bill is to eliminate so-called “drive-by” lawsuits in which, supposedly, people who have never actually patronized a business file a lawsuit claiming lack of access, then offer to settle for less than it would cost the business to either fix the problem or hire a lawyer to defend the case. The unfortunate truth is that some suits like that do exist, particularly in California, where state law allows for money damages.

In part, the problem arises from the extraordinary level of specificity in those provisions of the ADA dealing with people in wheelchairs. Businesses are given precise instructions as to where light switches must be, how parking lots must be striped and graded, how bathrooms are to be configured, and so forth. While businesses may appreciate that guidance, the downside is that minute variances can lead to lawsuits.

Although there are some legitimate concerns, the bill is, at the very least, gross overkill. It removes any incentive that businesses might have to make their establishments ADA compliant – they can simply wait until they get a notice. While that could arguably lead to appropriate corrective action at businesses that are patronized repeatedly, this advance-notice concept seems completely useless in providing businesses that people patronize only on very rare occasions, like funeral homes, with any incentive to provide accessibility.

Note that this bill, as written, does not seem to impact those of us with hearing loss, who ask for aids and services like captioning or better assistive-listening systems like t-coil compatible loops. The ADA requires businesses to provide “effective communication,” but provides virtually no specific guidance on how that should be done. Some businesses have argued – occasionally successfully – that they should not be
required to do anything to accommodate us because there are no specific federal regulations.

The concern is that the bill undermines some of the important concepts driving the ADA, and some of the compromises that were made to get the initial legislation passed. The ADA generally does not permit money damages, although some state disability laws do. Basically, all we get by filing an ADA lawsuit is a directive that the business must provide access in the future. Attorneys who bring successful ADA actions may also recover reasonable fees from the business and, in reality, the only incentive businesses have to provide access before being sued is to avoid paying attorneys. Making fee recovery more difficult is going to make private enforcement problematic.

The vote to approve the bill in the House of Representatives was 225-192. By and large, it was a party-line vote – 12 Democrats voted for the bill (and against the interests of the disability-rights community), and 19 Republicans voted against it.

The Senate may save us. Senate rules basically require 60 votes to bring any bill to the floor for the debate. Sen. Tammy Duckworth of Illinois circulated a letter expressing opposition to the House bill and asked other senators to sign on. At last count, 42 Senators – all Democrats – had done so, suggesting that the House bill may never actually be introduced in the Senate.

Beyond the specific provisions, what is disturbing about the proposed law is the seeming breakdown of congressional consensus about the purpose and value of the ADA. The conceptual problem ADA tried to address is how to integrate people with disabilities into the mainstream of public life – employment, education and access to businesses open to the public. As Congress recognized, the existence of a disability has nothing to do with fault – it’s not the fault of a movie theater that I can’t hear well enough to understand the dialogue, but it’s not my fault either. So, who should bear the cost of including us in public life?

At the one extreme, the argument we hear frequently is that we should bear the costs – that hearing loss or other disabilities are just our tough luck, and that if we can’t enjoy movies or the theater, that’s too darned bad. Another possible approach is to say that society as a whole should underwrite the costs of inclusion – essentially that the government should pay for the necessary measures. ADA took a middle ground. It basically said that the cost of measures needed to include us is a cost of doing business, like the cost of electricity or insurance, to be borne by all customers, not just those of us with the disabilities. (Society as a whole does participate somewhat through a small tax break available to small businesses.)
My concern is that we may be seeing that general consensus break down, as the “tough luck” theory is gaining strength. The original ADA and 2008 amendments to overrule some highly restrictive court interpretations of ADA were adopted almost unanimously. The fact that there was such a strong vote to weaken ADA is alarming. Moreover, support for disability rights seems no longer to be a bipartisan issue, with efforts to weaken the ADA coming from Republicans and support coming almost completely from Democrats.

This is not to suggest that ADA does not have some unintended consequences. Extortionate lawsuits filed by unscrupulous lawyers are a problem, although that problem is by no means unique to the disability-rights field. There are constructive ways to deal with that problem without doing widespread damage to the good ADA has done for millions of us. We stand ready to participate in genuine efforts at making this vital statute even better and not just a way to get a quick payout.
One of Us: Nawaraj Bhattarai

By Karen Krull, Curator

This issue’s spotlight is on Nawaraj Bhattarai. Those of you who attended last year’s ALDAcon in Orlando probably met this very congenial man from Nepal. Nawaraj is a married teacher of deaf students, with a secondary job of auditing. English is his secondary language, but I’ll let him tell you in his own words why, even though he lives a world away, he is one of us. He speaks from the heart.

About Myself

By profession, I am a registered auditor and Secondary Level teacher in a government school. But for me a job is meaningless for the disabled community of Nepal until a majority of the disabled people of Nepal can overcome the challenges of daily livelihood. Most of the deaf and disabled today are still living without minimum facilities in their daily life in our country. Today I live in Birtamod Municipality, Jhapa District. But I’m getting ahead of my story. Let me start at the beginning.

I was born on November 30, 1972, at Phidim V.D.C., Panchthar District, a far eastern and very remote part of Nepal. There was no motorcar accessible road. There was only radio as mass media and not all families owned one. Only some rich villagers had it. The radio covered only Radio Nepal's frequency. Villagers used to listen to news of Radio Nepal and folk songs, gathering in a public location. Printed media, telephone and television like as today were out of imagination. There was a secondary level school for education and a health post for medical treatment. There was no college for higher education and medical doctors also were not available in the health post. There was an assistant or clerk to run the health post almost all of the year. His boss used to visit only one or two times a year.

My family belongs to the lower middle class as per the economics status of our country. There was no option but to adopt a traditional agriculture profession as a livelihood for my parents. My father inherited some agricultural land from my grandfather on which he worked hard, ploughed by ox, and dug by homemade iron kodalo (a Nepalese spade). He grew grains like maize, millet and rice, too. There was not enough land for us to cultivate. It was difficult for my father to feed 7 family members for the whole year with limited harvesting.

I grew up fetching grass for cattle and firewood for the kitchen from the forest, helping my parents to dig the plot and plant it. I had to go with my elder brother and sister to fetch a huge bundle of straw from the bottom of the hill near a river and to climb up almost 2 hours for home. Although I was deprived from the modern facilities of life and economic scarcity was forever in my family, my childhood was filled with joy and happiness, roaming the forest, hills and rice fields such as Gadi hill, Gairi field, Sabrang
and Lalikharka with my friends, and swimming in nearby rivers like Hokma, Thangsang and Hewakhola.

But this happiness ended when I became hearing impaired. When I was in grade seven I suddenly suffered diarrhea and vomiting. I could not close my eyes because if I did, vomiting always started. I was in bed for several days due to this awful sickness, later diagnosed as meningitis. It was a miracle that I survived after being attacked by such a dangerous disease in that village where medical doctors visited only for a few days a year. Due to the side effect of medicine, I gradually lost my hearing and became deaf within a week. My family tried their best to restore my hearing ability by applying spiritual healer's treatment, folk tantric (Dhani-Jhankri) and worshiping God & Goddess, but all in vain. My father sold a portion of his land and took me to Siliguri, Kolkata and Patna (India) for medical treatment. I was also taken for Ayurvedic Baidhya (a treatment tradition of eastern culture from the ancient time), Kunfen (Tibetan method of treatment) and several Ear-Nose-Throat health camps in various places, but no fruitful outcome appeared.

My happiness disappeared as all the surroundings around me became unique and voiceless. Even my friends became unfamiliar as I could not communicate with them as before. Suddenly my broad society became a narrow course of road with a monotonous scene. There was no music, no dance and no exchange of thoughts in my life. There I had only eyes to see and roll down the tears. My environment was not joyful like before. There was a flood of misfortune which left me only sorrow. A man born deaf may enjoy his life as it is because he never heard or spoke. He is habituated to live without voice and he does not suffer with difficulties caused by hearing loss. The late-deafened person always misses the moments of hearing. I cannot speak as before, laugh as before, and behave as before. Today I always feel a gap between reality seen by my eyes and materiality of environmental feelings.

I never got the chance to study in a school for the deaf. I went to a normal school in my village. I was an average student when I was hearing. After becoming deaf I was alone. I had no friends to speak with, no friends to play with and no friends to walk with. So, I devoted myself to study. I was always immersed in books. I had only school work to read and write. What knowledge I gained in school or college was through my self-study. I could not hear a word in the classroom when the teacher was giving the lecture and teaching us. However, I earned the top placement in the class and gradually teachers showed compassion and affection toward me. I also topped the District in School Leaving Certificate Examination (S. L. C.) and earned eighth rank out of top ten in Intermediate of Commerce (I.Com.) Examination. After studying in common school while being a deaf student, this was an amazing achievement!

Later on, I graduated from Tribhuvan University without attending the class because the Mechi Campus in Bhadrapur was far away from my home and my family. I could not afford rent and the studying cost if I left home. I also completed my Master of Business Administration Degree from Degree Campus, Biratnagar, by working hard and almost solely based on self-study.
My family and I were unaware there was any sign language for the deaf to communicate. When I finished my MBA degree in the city of Biratnagar and was in search of a job, only then did I learn about sign language. I also came to know that there was a school for the deaf in Kathmandu and it was the only school for the deaf in our country.

Our society is not so educated and the attitude towards deaf and disabled is not favorable. Most disabled people are neglected and boycotted by their own family. Superstition is one of the traditional cultures of such a society. Many people think that being deaf and disabled is the result of a curse by the Gods. Parents treat the deaf or disabled person as a burden in their family. Some of the families have the idea that it is better if their family member with disability would die an immediate normal death. They do not want the deaf or disabled children to be exposed to society and keep them inside the home and out of others’ eyesight. Parents have no hope that their disabled son or daughter will earn a living in the future by using their capacities, so parents do not want to expend monies on the education or health for their disabled child. Thus, persons with disabilities in our society are totally deprived of minimum human rights, proper education and adequate employment. Their lives are worse than pet animals.

Deaf and disabled people are marginalized at all sectors of the society. They are discriminated against economically, politically, socially, educationally. Less than .01 percent of all disabled people in our country have the opportunities of education and gaining a higher level of academic qualification, talent and proper skill. These educated people are capable to handle the task and bear enough responsibility in their respective field. But they are still deprived from the proper employment because policies and laws made by others are inadequate and based on merely an estimate and guess.

There is lack of representation of persons with disabilities in the policy-making level of the state. Although some regulations and directives are made in favor of persons with disabilities, these are prepared from the normal peoples' point of view and are not enough. First of all, these are not right-based, but passion-oriented. Second, these are not practiced from a grassroots level. Thus, persons with disabilities are compelled to walk down the road designed for normal people who have not experienced the difficulties faced in daily life by disabled people. There are yet to be prepared and practiced policies of the disabled, for the disabled and by the disabled. These are needed so that persons with differences will be able to think for themselves, speak for themselves and act by themselves to ensure their comfortable future and betterment of their lives, and to create an inclusive society with equal rights for all.

Here are some other insights that came up in the interview:

KK: What book or books do you recommend others read?
NB: I did not read any English book except course (text) books, but I have read many Nepalese books of stories, novels, autobiographies, poems, essays.
KK: You simply cannot live without.....
BM: Deaf friends and books.
**KK:** Your little known talent is:

**NB:** I have written several articles and stories. Some of them are published even in Kantipur National Daily, leading newspaper of Nepal.

**KK:** Hardest thing you’ve done is:

**NB:** Completion of MBA degree without any support of sign language interpreter or other kinds of hearing devices.

**KK:** Your funniest hearing loss moment is:

**NB:** Hearing loss always creates deep sorrow for me and there is no funny moment.

**KK:** When and how did you learn about ALDA?

**NB:** I searched deaf program and organization in Google and found ALDA.

**KK:** In what ways has ALDA enhanced your life?

**NB:** It gives me feelings that I am not alone in the world.

**KK:** People would be surprised to learn that you……

**NB:** I am deaf and have a Masters' Degree!

**KK:** Your biggest pet peeve is:

**NB:** When I am busy at my work, gossiping nearby me is very disturbing.

**KK:** Your favorite childhood memory is:

**NB:** I used to go to a yearly fair called Yuwa Mela, where exhibition of agro products and various creations and miniatures of many service provider offices attracted me.

**KK:** Your favorite saying is:

**NB:** Let your work speak louder than your words.

**KK:** The bottom line is:

**NB:** Innovation is created in a mind not in the minds of crowd.
Call the Nurse:  
Making New Year’s Resolutions  

By Anne Marie Killilea, MSN, RN, EdDc

Happy New Year to All My Fellow ALDAns!

My thoughts for this column for the winter edition were going to be on creating attainable and logical New Year’s resolutions. This seemed like a good idea for a column to begin the new year with, but some circumstances have caught me by surprise, have changed my way of thinking about making resolutions, and I wanted to share it with you.

Up in the Northeast, as in the rest of the country, we have been hit with a terrible strain of the flu. People have been out of work for weeks and there are others who have sadly succumbed to the disease. Even though I’m a nurse and know that covering coughs and frequently washing hands are two of the best ways to ward off germs, I fell prey to flu and required several ER visits.

During one such ER visit, a young physician was sent in to assess my condition and prescribe treatment. I needed a nebulizer treatment to improve my breathing and antibiotics to treat the infection in my sinuses. But, because I’m allergic to so many different antibiotics, prescribing a certain drug had to be done with care. After waiting an hour, another older, seasoned physician came in and stated to me, “I know you! You were the nurse who taught me how to be careful when prescribing antibiotics because you became deaf immediately after taking one several years ago. And, it’s because of you and our conversation that I am conducting research and presenting it to a pharmaceutical forum on the perils and affects of antibiotics.” I sat there and smiled. Somewhere in the past I spoke my mind, gave him the facts, and he listened to me. Not only did he listen, but he’s now taking it to higher ground where those who create the drug and those who prescribe the drug will hear what devastation certain medications do to people.

On another note, I have also been sworn in as a member of the Commission on Disabilities in our city. I am thrilled to be on this Commission as their main goal is to assess the city for any areas where it is not accessible to those with disabilities. I’m the only one with hearing loss and can bring forth areas where I’m concerned about the lack of accommodations for those who need services in areas of the city.

One such concern I had was with crosswalks. I said that on some days I can hear the buzz well, and on others I can’t. It was described to me that some crosswalks have a hand stimulator which shakes and points in the direction in which the person can walk. I didn’t know this was already in place. But what occurred to me was that I could use my disability to find other areas where hearing and communication are not adequate and try to find accommodations to fix the problems.
On one such occasion, a young firefighter came up to me and asked me to come to one of the fire stations. As we were talking, I could hear the blast of the emergency alarm and noted how it interfered with my communication. I asked the young firefighter if this was a problem for other firefighters, and he did say that most firefighters are concerned that this constant blast of high frequency noise could be causing some type of hearing loss in the future. I immediately brought this up to the commission and we will be examining what other type of emergency response noise can be used to alert firefighters while preserving their hearing.

Why am I bringing up these two situations? In both situations, I’ve used my hearing loss to teach others different things about life and hearing loss.

For the physician, I taught him that antibiotics can and do cause harm to some individuals. While antibiotics save many lives by destroying the bacteria that causes illnesses, accurately assessing each patient to determine the need for antibiotic treatment is first and foremost. And, instead of me becoming angry for having lost my hearing due to an antibiotic, I chose to teach him that it did happen. I lived through the loss, and now lead a full life as a late-deafened individual.

As for the Commission on Disabilities, we are there as a group because we are considered disabled. Through living with our disabilities, we understand the needs of those who cannot speak up for themselves. We address issues and parts of the city where accommodations would make life a lot easier. In addressing the ear-piercing alarm system of the fire station, how different it would be for that firefighter if I didn’t “hear” the blast of the emergency alarm! Who else would have the most effect upon an audience bringing up the issue of hearing loss and the blast of emergency alarms in a fire station? I use my hearing loss to address issues to protect those from losing their hearing. I’m teaching others to pay attention to noise levels that can and do destroy hearing.

Now, let’s get back to making New Year’s resolutions — the ones that seem to be so important. I’ve made some resolutions to lose weight, or not spend money on frivolous things. While I could stand to eat less ice cream or learn to put some money away for rainy days, I do try to make these resolutions with good intentions to keep them. That is, until I get sick, or am comforting a friend, or some church organization has had a crisis. Out the window these resolutions go. But, the ones I do NOT make, which are the ones of true worth, are — teaching others about living a life with hearing loss. It comes naturally and from the heart. And, I found that through my two experiences that instead of looking for ways to improve myself, I should just look for ways to teach others about myself.

During this time of year when people are searching in themselves to make resolutions, dig a bit deeper to find in yourself the true gift you already have: teaching the hearing community how to live a life with hearing loss. Each day we are living proof that hearing loss does not have to isolate us. We work, we play, we enjoy each other, and we live! It is time to make a resolution which is positive and teaches others that our way of life, living with hearing loss, is different, but truly perfect in every way.

Anne Marie Killilea, MSN, RN, EdD lives in Boston, Mass.

Write her at ALDAeditor@gmail.com
Confidence Over the Phone

Enjoy phone conversations again, confident you’ll catch every word. Trust CapTel® Captioned Telephones to show you captions of everything your caller says. It’s like captions on TV — for your phone!

• Built-in answering machine shows captions of your messages
• Extra large display screen with variable font sizes and colors
• 40dB amplification – hear what you can, read what you need to!

CapTel® is a registered trademark of Ultratec. Bluetooth® is a trademark of Bluetooth SIG, Inc.
Call the Nurse:  
What’s the Big Deal About Handwashing?  
By Anne Marie Killilea, MSN, RN, EdDc

Ever since childhood, I can remember how all of us were taught to wash our hands before we ate. I can remember singing “Happy Birthday” twice to wash hands long enough to get rid of germs. Even in nursing school, handwashing is taught to be an important part of nursing care that helps protect our patients, and ourselves, against acquiring illnesses. Simple handwashing breaks the infection cycle.

But, let’s investigate why handwashing is so important for everyone to do.

As an example, some of us travel to work via mass transit. We board the train, touching everything that so many others did before us. We grab onto the handrails and seats. If we are lucky we find a seat to sit down on, a seat that someone else sat on. As the train stops at our destination, we grab onto the handrail that someone else touched before us to get up off our seat. We push our way through several people who are coughing, blowing their nose, and scratching their eyes. We made it to our destination. But, look at all the germs we have collected from touching public objects on the mass transit!

Then, we grab a coffee and donut. Without washing our hands, we gobble down our “breakfast” and all the germs we picked up along our way.

What happens next? If we are strong enough, we may be able to fight off the germs we ingested. But, if our immune system is compromised in any manner, we will get sick.

How can we protect ourselves?
According to the Center for Disease Control (CDC) (2017) handwashing is the most effective way in which to protect yourself from getting sick. The CDC (2017) further states that there are five parts of handwashing that are important:

1. wet your hands;
2. lather your hands with soap;
3. scrub all areas of both hands for at least 20 seconds (the amount time it takes to sing “Happy Birthday” twice);
4. rinse all the soap off; and
5. dry both hands completely.

Washing hands in this order is one of the easiest ways to protects ourselves and others from the spread of germs. It’s also better to use an antimicrobial soap rather than plain soap, according to a study by Fischler, et. Al. (2007).

When should you wash your hands?
According to the CDC (2016), you should wash your hands:
Before: preparing food, eating food, caring for an ill person, or treating a cut or wound.
After: changing diapers, blowing your nose, coughing, or sneezing, going to the bathroom, taking care of animal food or waste and touching garbage.
While this short list of when to wash your hands is important to know, you should always think: “What have I touched that could make me sick?” Anytime your hands are dirty, you should always wash your hands. And, anytime you feel that you have touched something that could make you sick, wash your hands. It’s simple and helps to protect you from getting sick.

What to do when we do not have soap and water?
If your hands are not visibly dirty, it is important to use a hand sanitizer solution. There are several different types of hand sanitizers on the market that work well to destroy most germs on our hands. The CDC (2016) recommends a hand sanitizer should have at least 60 percent alcohol base in its product preparation to reduce the number of germs on your hands.

According to a study by Edmunds, et. al., (2010) the higher the alcohol content, the better the action of getting rid of germs on hands when using hand sanitizer. Remember, hand sanitizers do not get rid of all the germs and chemicals that our hands come in contact with. The CDC (2017) states that hand sanitizers do not get rid of pesticides and heavy metals. And, it is important to know that when we have used a hand sanitizer a few times we should wash this off of our hands because sometimes the hand sanitizer can get rid of both good and bad bacteria, leaving us with fungal organisms that can cause problems with the nail beds and palms of our hands.

How should we apply hand sanitizer?
The CDC (2016) states that we should first apply the correct amount of hand sanitizer to the palms of our hands. We then should rub our hands together, getting into the areas in between our fingers. Lastly, we should rub our hands together long enough to dry the solution on our hands.

The winter season is a tough time of year for many of us. We see an increase in the amount of colds and flu spread from one person to the next. To help reduce the spread of infections, handwashing is one important way that we can protect ourselves from getting and spreading infections. Handwashing is a big deal, and each one of us needs to learn about and practice good handwashing techniques to break the chain of transmitting germs from one person to another.

Anne Marie Killilea, MSN, RN, EdDc lives in Boston, Mass. Write her at ALDAeditor@gmail.com

References:

Phonak has partnered with Advanced Bionics to develop a new microphone technology, MultiBeam Technology, that will help people with hearing aids and cochlear implants hear better in noise. By utilizing multiple microphones in six directions, MultiBeam Technology captures speech from 360 degrees, which is then calculated and compared. The direction with the best signal-to-noise ratio is automatically selected. Phonak said the technological processing complexity is almost 10 times higher than its previous technology, and the power consumption was reduced more than one-third with MultiBeam Technology, which has been in development since 2009. In a study conducted at the University of Dallas involving 10 participants, speech understanding improved up to 61 percent in a group conversation in 75 dBA of noise compared with that when using hearing aids alone in the same setting. Linda Thibodeau, PhD, who led the research, said this new technology will allow people with hearing challenges who have resigned from attending social functions, family gatherings, and business meetings to experience significant improvements in speech recognition. "This could ultimately lead to improved quality of life as they confidently reconnect with others using discreet, convenient, and highly versatile technology," she said. To read the full article, go to The Hearing Journal: Breaking News.

From New Mexico Commission for Deaf and Hard of Hearing

A Hearing Loss Technology Conference is being put on May 9, 2018 in Albuquerque by the State of New Mexico Governor’s Committee on Disability and the New Mexico Commission for Deaf and Hard of Hearing. Topics include “Hearing Loss – What You Should Know,” “Assistive Listening Systems Review,” “Hearing Loss Support Groups Review,” “Adjusting Telecoils for Hearing Loop Use,” and “Psychological Implications of Hearing Loss”. There will also be demonstrations of Assistive Technology and a panel of individuals with hearing loss. For more information go to: Hearing Loss: Technology Conference.

Francine Stieglitz has been a member of ALDA since she received her first cochlear implant about fifteen years ago. She has been the president of ALDA Boston for eight years, and in 2013, she received the Bob Hawley Fearless Leader Award. She started losing her hearing about 20 years ago and tried using hearing aids but not very consistently or successfully. Her first implant worked well for several years until she realized she was missing a lot of what was being said. Seven years ago she received a second implant. Both implants together work well, but a lot of auditory training is still needed on a regular basis. When she is not advocating for better hearing accommodations and encouraging people with hearing loss to actively speak up, she is working on encouraging the public to use microphones at meetings and events. As a member of the Commission on Disability for the Town of Lexington, she has made it a priority to make people aware of our hidden disability, but educating people is not always easy. Just because you don’t see it doesn’t mean it isn’t there.
Chapter Happenings
By Ann Smith, Curator

ALDA-Boston’s Francine Stieglitz reports: The weather played havoc with some of ALDA Boston’s scheduled events.

The ALDA-Boston Holiday Party on December 9 had to be canceled because of a snowstorm.

Our annual New Year’s Brunch on January 7 was probably one of the coldest days of the season with frigid winds. Nevertheless, about 30 hardy ALDA members braved the cold. (Another 15 members who had planned to attend had to cancel because of illness.) Former Region 1 Director Eleanor McPherson Shafer came down from New Hampshire with new member Joan Marcoux, and new member Sandy Speckman and her husband Hyman came up from Plymouth, MA. Commissioner Heidi Reed, Mass Commission for the Deaf and Hard of Hearing, welcomed everyone and brought us up-to-date about what MCDHH is doing, including helping those with traumatic hearing loss and victims of crime.

Deaf and Hard of Hearing Constituents’ Annual Day was scheduled for March 8, but it had to be rescheduled due to a snowstorm. The event has been rescheduled for May 17, 10 a.m.-12 noon, at the State House, Boston. The event is a gathering of Statewide Advisory Council members, community members, legislators, and state agency directors. Afternoon legislative visits to discuss community concerns and bills of interest can be scheduled in the afternoon.

Between snow storms, there was a large turnout on Saturday, March 10. Jonathan O’Dell, Assistive Technology Manager/Training Specialist at the Massachusetts Commission for the Deaf and Hard of Hearing, gave a thought-provoking presentation on “Coping with Hearing Loss.” After doing Unconscious Bias Trainings, O’Dell realized “how deeply entrenched we are in our cultural environment and how much of an effort it takes to reframe our narrative of how we see ourselves, how we are seen by others, and how we can and must upend both in order to get beyond the coping perspective.” A very thought-provoking talk.

ALDA-Boston will celebrate its 29 Birthday on Saturday, April 21 at the Framingham Public Library. Ellen Perkins will be presenting on Assistive Technology. CART will be provided. The Annual Business Meeting and Election of Officers will also take place at that time. The schedule of events for the second half of the year will be planned at the meeting including details of our signature events, the Annual 4th of July picnic and barbecue, and the Holiday Party. In between those two events we’ll be planning for other ALDA-Boston events.

“ART in Bloom,” the Museum of Fine Art’s annual festival of fine art and flowers, will take place on Saturday April 28 – Monday, April 30. ALDA /HLAA members will be treated to a special tour with ALDs on Friday, April 27.

Wishing you all a warm spring!
Linda Belice reports on ALDA-Chicago’s activities. ALDA-Chicago recently held its annual election to fill three open seats on the organization's Board of Directors. Linda Belice, Michelle Donnelly and Marsha Swetin were elected to serve a two-year term (2018-2019). The new Board of Directors for 2018 is: Marsha Swetin, President; Joe Linder, Vice President; Linda Belice, Treasurer; and Karen Krull, acting Secretary. Board Trustees are: Michelle Donnelly, Debra Flowers, and Tom Garvey.

ALDA-Chicago also expressed appreciation for the services of Sara Wegley, Joe Linder, and Tom Garvey.

The Chicago chapter had three special events planned for February and March. Tom and Laura Garvey hosted a gathering in their home after our first Board of Directors meeting of the year on Saturday, February 3. While most of us socialized, Tom’s wife showed 10 interested individuals how to make candles.

On February 24, we head to Fitz’s Spare Keys to bowl, play some billiards, watch sports on multiple TVs and generally stuff our faces in between all that! It was a lot fun!

On March 10, we attended a captioned “live” theater performance of “Anna Karenina,” followed by dinner at a nearby restaurant called Leona’s. Both are in the north end of downtown Chicago. Many of our members enjoy going to captioned plays and our Social Committee (Dawn Linder and Donna Punzio) aims to please (smile).

On April 15, we are celebrating ALDA's 30th birthday with a party at the William Tell restaurant in Countryside, Illinois, from 1-5 p.m. Our menu is the "All American Buffet" with three different salads, pot roast, baked chicken, mashed potatoes and gravy, green beans almandine, rolls and butter, an assortment of homemade pies and the ALDA birthday cake. Beverages include coffee, tea and water with a cash bar for soda or alcoholic beverages nearby. The birthday party is always a lot of fun, with a few raffles, as well as one or two nice surprises thrown in by our Social Committee. The menu will feature an All-American buffet.
**Sara Hartman** reports: **ALDA-Peach Atlanta** meets bimonthly and was scheduled to meet in December for our annual holiday luncheon. However, the board agreed that the December meeting should be postponed due to inclement weather. As a result, Peach members met for a nice lunch on January 13, 2018 at Red Lobster. Several new members attended and the luncheon became an information gathering/sharing and social event. The January planning session and annual board election were postponed until February 13. We did have time for our annual Unbirthday celebration with a chocolate cake served after the meal. The Unbirthday celebration is Peach’s way of honoring the birthdays of all chapter members.

The ALDA-Peach Atlanta group intended to meet on February 13 to have elections and a planning meeting. However, our President **Marge Tamas** was contacted by a researcher who offered to speak to the group about everyday technology use among deaf senior adults. Consequently, the planning meeting and election were postponed to the next meeting, which will be in April. The group welcomed several new people to the meeting, including two who have a vision impairment.

The special presentation was given by a researcher at the Center for Assistive Technology and Environmental Access at Georgia Tech. Her group is studying issues dealing with older adults with disabilities. The five-year grant the group has is for three populations: Blind, Deaf/Hard of Hearing, and Impaired Mobility. The research discussed was based on an online survey through the National Association of the Deaf (NAD) and Deaf Seniors of America. There were 109 participants, most of whom had early onset deafness and considered themselves deaf, as opposed to hard of hearing or late-deafened. The researcher explained that the survey will be modified and given to larger, more diverse groups.

**Jim Laffer reports: ALDA-San Jose** remains firmly committed to social events. We have only had one meeting in the last few months and that was our annual "group maintenance" meeting where all board members were reconfirmed in their respective rolls. Since December the group has had several social events though including our Holiday Party which was a big success and attended by nearly 20 people. Sadly, a few regulars had other plans, but it was a great group with lots of socializing and food at a member’s house. We’ve also had two dinner/movie outings including seeing Black Panther on the opening weekend in February and The Last Jedi in mid-January. Both were well-attended and the members had a great time. We tried to do another Super Bowl party, this time in San Jose, but only a few members attended. We may have to rethink this and go another direction in the future. It hasn't really taken off the way we hoped. Still it was fun with some homemade pizza and other goodies to nosh on. We'll be returning to one of our most popular group events in April a potluck picnic at a local winery which tends to draw as many people as the Holiday party does or even more.

The Mid-March social got pushed back due to St Patrick’s Day and bad weather, but it’s not a big deal since March has 5 Saturdays and looking forward to being able to plan an early April brunch since Easter does not conflict this year.
Our membership remains steady and we've had some great success with our Facebook group page helping spread the word and keeping members connected. Hoping to have another meeting in early June with a presentation on hearing dogs, but we're just in the planning stages. Over the summer we have a few annual social events that come back every year - a bowling outing with brunch and a trip to a local minor league baseball game. Updates on those after they happen.

Debbe Hagner reports on ALDA-Suncoast: We are in the process of reviewing the chapter bylaws. We would like to know what is happening in the other chapters and to see what is in their bylaws. ALDA Suncoast has recently elected new officers. Tammy Carrier is new president, Tracy Kasch is new vice president, Judith Greaves is new secretary and Debbe Hagner is treasurer. Chris Littlewood is past President.

On April 10 we will have a guest speaker. Her name is Bette Washburn-Neiman, and she is a friend and supporter of ALDA Suncoasters. She is a paralegal in Clearwater, Florida and will speak about what a paralegal can do for you and when you would need a lawyer. Bring along your questions.

We meet the second Tuesday each month in the Fellowship Hall at Our Savior Lutheran Church, 4825 East Bay Drive, in Clearwater. CART (live captioning) is provided, and meetings are interpreted. All are welcome!

Kim Mettache reports: The ALDA-NW Indiana group recently hosted the captioned play, Steel Magnolias, at the Munster Performing Arts Center. We continue to advocate for those with hearing loss and offer socials throughout the year.
What is ALDA? ALDA is the Association of Late-Deafened Adults and was established for people who are hard of hearing or deaf, or who have lost some or all of their hearing usually after acquiring the ability to use speech. Late-deafened people may have lost their hearing, suddenly or gradually, as a result of inherited causes, accident, illness, medications, surgery, noise, or unknown causes. ALDA also welcomes family, friends and professionals who support late-deafened adults.

Join us in Portland, Oregon, as ALDA hosts its 30th annual international convention (better known as ALDAcon) on October 10-14, 2018 at the Sheraton Portland Airport Hotel. It’s an experience you won’t forget and will want to attend annually!

The theme of the convention is “ALDA: Bridging the Gap,” referencing the many bridges in Portland and the “gap” between hearing and deafness.

ALDAcon offers world renowned speakers, workshops, karaoke and, most importantly, barrier-free interaction with peers. All workshops, luncheons, and banquet are fully communicatively accessible via CART (Communication Access Realtime Translation – a form of captioning) and sign language interpretation, as well as assistive listening systems and pen & paper. These services allow everyone to understand what is going on and to participate fully.

**ALDA Member Registration:**
Early Bird (1/16/18 to 6/30/18) $280
Regular (7/1/18 to 10/1/18) $310

**Non-Member Registration:**
Early Bird (11/1/17 to 6/30/18) $310
Regular (7/1/18 to 10/1/18) $340

**Military Veteran Registration:**
11/1/17 to 10/1/18 $260

For more information visit: ALDA.org/ALDAcon 2018 For hotel reservations call the Sheraton Portland Airport Hotel at 503-281-2500 or 800-325-3535. Ask for the ALDAcon 2018 group block and mention the group code: AJ06AD.