Should We Embrace our Cyborg Identity?

David Coco, Ph.D.

The unofficial slogan of Austin, Texas is “Keep Austin Weird”

You see, Austinites are fascinated with anything on the cutting edge in music, technology, politics, and people. The weirder the better and you can find this theme on T-shirts and billboards all over town. So I wasn’t surprised to come across a flyer Austin conference called Body Hacking Con 2017.

The bodyhacking conference, held in the early part of the year, was a meeting for a small but growing group of techno-geeks, artists, and academics who view the human body as a work in progress rather than a finished products and have a shared interest is using technology to expand their bodies’ natural capabilities. In short, Body Hacking Con was a gathering of people who aspire to become cybernetic organisms or cyborgs!

While you can’t get any weirder than that, as a late-deafened adult, a cochlear implant user, and self-professed techno-geek, I couldn’t resist the prospect of meeting kindred spirits and procured a conference pass. This marked the beginning of my yearlong exploration in the emerging field of bodyhacking.

I must admit that I was a bit apprehensive at the start. This is because bodyhackers are primarily able-bodied pioneers interested in enhancing their native capabilities rather than disabled consumers trying to overcome their limitations. Would someone, like me, who uses a federally approved cybernetic device as a coping strategy for deafness be accepted by the conference attendees?

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Friends,

Orlando came, went and now all eyes are on Portland. We go from the land of magic in the east to the hipster scene on the west coast. It’s going to be fun; we going to rock! If you haven’t registered, consider doing so soon as time will fly by just too fast.

While not trying to be nostalgic, a few articles about things that happened during at ALDAcon 2017 is found in this issue because it’s the first ALDA News issue following the our party in Orlando.

The feature article, Should We Embrace Our Cyborg Identity, by David Coco is not the script of an upcoming Star Wars film. It’s a summary of his conference workshop that describes several technologies, much like cochlear implant technology, that augment the human experience.

Following David’s article is a heartfelt account of ALDAcon Orlando by Cleo Simmons, who is one of ALDA’s biggest supporters and an original ALDA Chicago board member. Whereas Cleo has never missed an ALDAcon, a newcomer to ALDAcon, Heidi Lovato, wrote about the good time she had and the support from others that she received in A Newbies ALDAcon Experience. The last conference related article comes from Kristin Stansell and her pal Shadow, which is a review of the film Wonderstruck that was a special showing for ALDAcon attendees.

Also included in this issue are mainstay pieces, which includes: President’s News by Sharaine Rawlinson Roberts; ALDA Advocacy Corner by John Waldo; the One of Us profile featuring Barb Martin that was drafted by Karen Krull; an article on making New Year’s resolutions in the Ask the Nurse column by Anne Killilea; Chapter Happenings by Ann Smith; and a list of motions discussed by the board of directors in the ALDA Biz section. Finally, my article on the never-ending pursuit for equity can be found inside.

Before letting you get on with reading, the ALDA News is now accepting articles for the Spring Issue. Although there isn’t a theme, consider sending in stories about something or an accomplishment that you are particularly proud of. It doesn’t have to about deafness itself but it could be if hearing loss has played a role in that pastime.

Deadline for submission is February 20th and recommended length is 750-900 words. Send your contributions to: Editor@ALDA.org. Kindly send a photo with the submission and a brief bio (about two sentences).

All for now!
To my surprise, the answer was YES! I found that abled-bodied bodyhackers are open-minded, friendly, and supportive of their disabled comrades and accepted me as one of their own. I even received multiple offers to try out their favorite implants – especially those not yet approved by the federal Food and Drug Administration (FDA).

Through my interaction with these cybernetic aficionados, I learned that we had more in common than I suspected. This is because both bodyhackers and cochlear implant users are not satisfied with the status quo and are searching for new ways to enhance their capabilities. We also have many common concerns, such as battery lifespans, aging processors, and botched implantation surgeries. Finally, both groups come together around the question: “How will this thing change my life?”

Let me introduce you to a few of the cyborgs that I have encountered, personally and digitally, over the past year.

First is Neil Harbisson who has been color-blind since birth. He implanted an antenna in his skull that allows him to “hear” colors as audible vibrations inside his head. Neil can hear infrared and ultraviolet colors outside the range of normal human eyesight and, since his implant is connected to the Internet, he can hear colors from anywhere in the world. He is the first legally recognized cyborg in the world and can prove it with a British passport that identifies him as a “CYBORG”!

Next is Jonathan Leach, deaf from birth and a native signer who has used ASL all his life, now uses a vibrating vest to sense sounds.

The vest, which is also the acronym that means Versatile Extra-Sensory Transducer, looks like a conventional garment but uses an app to pick up sounds with a microphone and transmit them to more than two-dozen vibrating motors sewn into the vest.

This new device is being developed and tested by a company called Neo-Sensory as a means to provide enough information so that the user can understand speech. Although this device is not yet available to the general public, I had an opportunity to briefly test an early version of this vest being used in clinical trials, and was impressed.

Despite being impressed by this technology, I am not yet ready to trade in my CI for this vest, nevertheless, the fact that it doesn’t require surgery would make it a potentially less costly option for late-deafened adults.

To learn more about this technology, check out the TED talk by Neo-Sensory co-founder David Eagleman for more details. (Subtitles provided.)

The third interesting cyborg is Frank Swain. He is a long-time hearing aid user from the United Kingdom who developed an experimental tool to convert ambient Wi-Fi signals audible signals. Frank’s tool, called the Phantom Terrain, consists of a “jailbroken” (hacked) iPhone and a modified pair of hearing aids.

The iPhone captures and converts the Wi-Fi meta-data into an audio signal that is overlaid with the traditional amplified signals from his hearing aid. The result is that Frank can experience his digital environment in a unique way that no one else can.
There are two aspects of his venture that particularly impressed me. First, Frank actually convinced a mainstream hearing aid company (Starkey) to partner with him on this project, which amazes me since all of the cochlear implant companies were unresponsive when I asked for their position on the bodyhacking movement. The second aspect is that Frank was able to get a small grant to implement this innovative project.

Finally, there was Scott Cohen who has added a sixth sense. The device is called North Sense and it notifies him when his body faces north.

The device is typically attached to the upper chest outside the body and simply vibrates when facing north. But unlike a conventional compass, North Sense is always on and continuously streaming information to the brain.

He developed it not because he is disabled, but because he thinks that this additional sense will allow him to experience the world in new and unpredictable ways.

The idea behind this technology is to incorporate new sensory information into one’s consciousness and see how it changes a person’s perception of the world.

To date, Scott’s company, CyborgNest, has produced and distributed almost 300 of these devices worldwide, plans to develop other sensory-based technology in the future and claims that adding more senses will make us smarter and result in a richer life experience.

These four individuals represent only a small fraction of the bodyhackers who are exploring the possibilities of expanding our sensory capabilities as a way to speed up the human evolutionary process a bit. They should give you some insight into what the bodyhacking movement is about and where it is headed.

Imagine, for a moment, how this bodyhacking movement might affect disabled communities.

We are currently separated into two easily defined groups – able-bodied and disabled – based on how our five senses function relative to statistical norms. But as the bodyhacking movement expands, the classification of “disabled” will become obsolete because it will become possible to add new senses to our repertoire to augment or replace other senses.

In the not too distant future, your decision of which senses to use and how to use them will become a personal choice rather than a consequence of your genes, disease, or accident.

Cyborgs may be weird today but soon they will be the new normal and the City of Austin will have to look elsewhere to maintain its reputation for weirdness.

Dr. David Coco is a late-deafened adult with a passion for science and technology. David is best known in the late-deafened community for his articles in ALDA-News and other publications where he shared his humorous insights into life as a late-deafened adult.

This article is based on a presentation of the same title at ALDAcon 2017
Friends, as I write this, it has been 24 days (I counted!) since ALDAcon 2017 ended. The conference evaluations that we received indicated most attendees found the conference offerings to be very good. Hats off to the entire planning committee for putting on such a successful convention!

I’ve received emails from several ALDA members regarding feeling sad and lonely at home after spending four days in a welcoming environment with fully-accessible communication at ALDAcon 2017. These feelings are normal. We hope that you learned some communication tips at the ALDAcon that you can use to improve communication at home. ALDA’s communication philosophy, “Whatever works!” includes writing, sign language, gestures, mime, speechreading, whatever. If one method is not satisfactorily effective, try another method. Also, please remember you can reach out to ALDAns on our Facebook pages, both the ALDA and ALDAcon 2018 – Portland, OR pages. Members frequently use the latter ALDAcon page (updated annually to reflect the year of the upcoming `con) to communicate with one another and offer suggestions, tips and share plans for the upcoming ALDAcon, and so forth.

In my last column I promised to provide you with more information about ALDA’s most recent advocacy efforts. One of the most exciting outcomes is the press release from The Broadway League on November 6, 2017 announcing Broadway theaters are beginning rollout of new technology that will enable theater goers “who are deaf, or who experience hearing or vision loss” to better enjoy performances. This technology includes captioning that is synchronized with the performances on stage. This outcome is a direct result of ALDA members Tina Childress and John Waldo serving on the Broadway League’s Audience Services Advisory Board along with other representatives from the Hearing Loss Association of America (HLAA), Hearing Accommodation Task Force of New York, and other individuals. Hats off to Tina and John for their tireless work on theatre accessibility.

In other advocacy news, ALDA signed on to official comments filed with the FCC regarding the need to provide compensation to video relay service (VRS) providers that participate in testing of skills-based routing for VRS calls. The test would evaluate the routing of calls based on consumers’ communication preferences and the skills of available VRS interpreters. Skills-based routing is expected to improve the quality of VRS communication. The FCC’s decision not to provide compensation to providers during the trial is what provoked these comments because none of the providers agreed to
participate in the trial. Other organizations and an individual signing on included Telecommunications for the Deaf and Hard of Hearing, Inc., Cerebral Palsy and Deaf
Organization, National Association of the Deaf, and Bryen M. Yunashko.

ALDAcon 2017, ORLANDO

by Cleo Simmons

I can honestly say I am so happy I went to ALDA con this year. My first ALDA con was held at Mercy Hospital in Chicago in 1989 and this one made it my 29th convention. Kathy Schuleter and I have never missed one.

I manage to get my picture taken with I. King Jordan each ALDAcon that he attends. This is a tradition that began at first ALDAcon in Chicago.

It was also nice to see Miguel Aguayo. We go way back to ALDA’s very beginning. He was Treasurer of the first ALDA Chicago board of directors but left Chicago to attend university in Rochester NY and then start a new life in Canada. I took over the treasurer position from him after a gentile nudge by (late) Kathie Hering, who the chapter president at the time.

David Coco’s Workshop, Should We Embrace Cyborg Identity, was so interesting. Of course a lot of what he said went over my head, but I still found it most interesting in trying to keep up with things that are being developed to help improve life for the deaf and hard-of-hearing.

Conferences are always hard on seniors and I worried about being able to do all the walking. My age, balance problems, and use a cane were just a few of my concerns, but happy to say it all worked out.

Thanks to Karen Krull and Carolyn Piper, I had a terrific roommate in Martha Mattox Baker (Marty). We actually had two beautiful rooms thanks to Marty’s motorized wheelchair that would not fit through the standard/regular rooms. Our rooms were on the first floor right next to the swimming pool. Marty took advantage of the pool but I was unable since I do not have a bathing suit and did not want to try skinning dipping.
Sometimes we forget to thank all the people that helped to make it a terrific ALDAcon, especially for making it special for those who need special help – like me! Lois Maroney worked hard to make sure our room was accessible. She and Carolyn worked together to get accessible seating for me at Cirque de Soleil on Thursday evening. Gloria Popp also made sure I got to my seat, which fortunately was next to hers. It was GREAT!

On Saturday, Angie Fugo drove Marty and me to the *Wonderstruck* movie. Angie was great, as always, to take care of me. We sat down about four rows back. That was a big mistake, as we should have sat higher up for a better view. When the movie started, Angie is made a point to move me to the very first row so that tall chairs would not block my view. We sat in the middle and I was able to see the captions clearly. That made the screen was so large that it looked like 3D to me. But I’m still happy I went!

Angie also introduced me to members that I never met. She introduced be to other as a ‘famous ALDAn’. These members already knew my name even though they never met me before. This all made me feel good, as did the long talk in the theater lobby afterwards.

I could keep writing about how everyone hugs me, even if I do not remember names. Seeing Bill Graham, Steve Larew, Larry Littleton, Roy Miller, who at the Reception Party on Wednesday, got up and gave me his seat. (Sometimes there are advantages to getting old/older.)

Sharaine Rawlinson Roberts, our President, who has and is doing a terrific job, goes out of her way with her beautiful smile to give me a hug. Diane Thorpe, who checks to see if I need any help as soon as she sees me. It was good to see Pat Graves because we go back to even before ALDA. Also, Ken Arcia who will always take a picture or two for me with my camera.

Dear reader, I may not have mentioned your name, but please know I’m thinking of all of you even though there is no room for me to mention everyone who has been so special to me. I am Blessed.

*Cleo E. Simmons is one of the earliest ALDA members. She hails from Chicago’s south side, was a member of the first ALDA Chicago Board of Directors and hosts the famous annual ALDA Chicago pool party, which is a Windy City tradition.*
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Susana Flores ’16
B.S. Museum Studies, and immersion in Deaf Studies
Wonderstruck: A review

Kristin Stansell and Shadow

I attended the Wonderstruck movie showing during ALDAcon and my initial feelings about this film is that it’s hard to follow and understand. The term “wonderstruck” is to be affected or overcome with wonder.

I saw no wonder. Instead, the story was more about a strong desire to hike (or wander around) and this is exactly what main characters did in their parallel storylines and the title made absolutely no sense to me.

The girl’s story line was filmed in black and white denoting that was lived is the past and the boy’s story line was set in the 1960s and in color. It wasn’t clear how these two individuals were connected. I kept waiting for these two characters to meet with the girl becoming a mentor to the boy and helping him learn how to communicate with hearing individuals. But this didn’t actually happen in the film.

I also wondered of it was it was more of a historical account of deaf oppression. In both story lines, hearing people around the deaf characters felt a need to keep them in ‘safe harbour’ by not letting them venture out into the world. But it’s hard to say that because there were not enough clues in the film to conclude this.

Maybe it was more about a dream. For example, the recently deafened boy learned the ASL alphabet in just one lesson. As a deafened person, I know it takes a lot more practice to be able to recall the manual alphabet. Furthermore, there was too many coincidences that didn’t make sense like the boy becoming deaf by being indirectly struck by lightning while speaking on the phone and happened to be the grandchild of a deaf woman. This made more since because dreams typically do not make sense.

After the Wonderstruck was over, left the theatre with the impression that this movie was trying the say that those becoming deafened are struck with wonder about how to relate to the hearing world. This I have, personally, felt to be true.

Nevertheless, it was educational to understand how past generations dealt with this very rarely understood trauma. I suppose that I need to watch this movie again to really understand its message.

Kristin Stansell is a member of the ALDA Peach Board of Director and became deaf through a head injury. She is dedicated to use what she has learned from acquiring sudden hearing loss and loss of balance to help others live a positive and happy life.
My last report from the Spring of 2017 focused on ALDA’s advocacy efforts on behalf of its members. Those are ongoing and expanding. Here’s an update on where we are basically at the end of 2017.

**Live-Theater Accessibility**

The lawsuit that ALDA and two of its members, Tina Childress and Mary Stodden, filed against the Fabulous Fox Theatre in St. Louis continues to be unresolved. Back in 2016, Tina requested captioning for the musical “Rent,” which was on the 2017 schedule. Fox said captioning was not part of their plan.

After we filed suit, Fox then began to offer captioning, and Fox decided to transmit the captions wirelessly to portable tablets, making the captions available at every seat. However, Fox limited captioning to one and only one performance of some but not all of its shows.

We objected to that one-performance limitation. We can accept a limited number of performances where the theater needs to set aside specific seats from which the captions are visible. But when theaters can make captioning available from any seat, and when it asks for a request two weeks in advance, there is no reason why the theater cannot make captioning available for any performance when requested.

That’s the impasse at the moment. We’ve asked the court to rule that as a matter of law, we’re right. Fox apparently will ask the court to rule that we’re wrong and they’re right – although as I write this, it’s hard to know what Fox is going to say that it should do. If the court can’t make a decision based on the briefs, we’ll go to trial in April.

By pleasant contrast, the situation with the Broadway Theaters is good and getting better all the time. As I’ve reported previously, the Shubert Group, which owns 17 of the 41 Broadway theaters, is rolling out captioning for every performance and from every seat, using a smart-phone app called GalaPro. The captions are prepared in advance, and displayed in sync with the pace of the production, using a combination of lighting cues and voice-recognition software to time the captions. (Synchronization has been the difficult part of providing every-performance captioning at live theaters, because unlike a movie, which is the same for every show, the pace of a live performance always varies from show to show).
Tina and I were in New York City in November for an industry roll-out of the new system, and we were treated to a show. We were very impressed with the technology – the syncing was flawless, and there were only a couple of dropped lines. But as we said at the rollout, the system needs to be more user-friendly, because we don’t want to hold our phones for the entire performance. The Shubert folks have acknowledged the problem, and are continuing to look for solutions.

**Movie-Theater Access**

The federal regulations requiring virtually all indoor movie theaters to provide caption-viewing equipment go into full effect on June 2 of this year. While we’re still getting spotty reports of malfunctioning equipment, that issue seems to be getting better at the major theater chains like AMC, Regal and Cinemark. There appear to be a number of smaller operations that do not yet offer caption-viewing equipment, and their time is running out. Now would be a good time to start compiling a list of theaters that are not in compliance. ALDA has been a major player in advancing movie-theater captioning, and I hope we continue taking the lead on this.

Movie theaters show more than just movies, though. A company called Fathom Events – a joint venture of AMC, Regal and Cinemark – brings events like Metropolitan Opera performances, classic movies and Broadway and London theatrical performances to movie theaters across the country. Fathom adds content, such as commentary and “behind the scenes” interviews, so with the close-up cameras and extra content, patrons at Fathom Events actually get a better seat that patrons who attend the events live in New York City or London. These events have been well received – movie attendance was down in 2017, but attendance at Fathom Events continues to grow rapidly.
Unfortunately, almost none of that content is captioned. When asked, the content originators like the Metropolitan Opera claim that captioning is the responsibility of the theaters, the theaters claim that it’s not technically possible, and Fathom Events claims that it has no legal obligation to provide captioning.

We disagree. So ALDA and two of its members – Tina Childress and Jerry Bergman from New York City – filed a lawsuit against Fathom and the theater chains in federal court in Seattle. We’re joined by two Washington residents and the Washington State Communication Access Project, and by Roger Townsend, an experienced Seattle class-action lawyer.

This effort is brand new, and we’re hoping that we can put the legal action on hold and simply sit down with the theaters and work this out in a collaborative manner. But Fathom Events are a valuable and exciting addition to public entertainment, and we want to ensure that those of us with hearing challenges are not left behind.

One of Us: Barb Martin
By Karen Krull, Curator

This issue’s interview is with Barbara Martin, who I met in Orlando. Barb was a bubbly, vivacious person, who reminded me very much of one of our Board members, Eleanor Shafer. She seemed to be a kindred soul, and I thought she would produce an interesting interview. I was right. Barb was born in Milwaukee, and raised in the nearby town of Pewaukee, Wisconsin. She left for graduate school in Washington DC, and stayed in the DC area until moving to Gaithersburg, Maryland in 1989. Barb’s hearing loss was “discovered” when she was 6 years old. Her teacher was the first one to notice, and like many of us, no one knows if she lost her hearing around the time of discovery, or if she was born with a hearing loss. Her parents, surprisingly, thought she might have been born with a hearing loss, as they considered her stubborn and disobedient as a child. Barb’s hearing loss has been stable in the 70-80 db. range since she was 6. She feels that being hard of hearing is a weird place to be in the world; somewhere between deaf and hearing.

Barb is married, has two adult children from her first marriage. She also has one adorable 3-year-old granddaughter and another grandbaby on the way. She’s a retired math teacher, with 30 years of experience teaching math at Model Secondary School for the Deaf. She said,” It was my dream job; I’ve always loved teaching math, and still do.” And now for the nitty gritty of the interview:

KK: What book or books do you recommend others read?
**BM:** The latest awesome book I read was Lisa Wingate’s *Before We Were Yours*; *Mountains Beyond Mountains* by Tracy Kidder; *Bonk* by Mary Roach. Other favorite authors are Leif GW Persson (any Swedish author), Anita Shreve, Anne Patchett, Dennis Lehane, and Dava Sobel. The best part about retirement is I can borrow a book from the library and finish it within 3 weeks!

**KK:** You simply cannot live without.....

**BM:** my husband, my granddaughter, my sons, my friends, my sisters, and RUNNING. Running is my Zen time, am actually grateful to be deaf so I can run in silence. There are many reasons to like being deaf!!

**KK:** Your little known talent is:

**BM:** Hate to sound cliché, but I really don’t have one!

**KK:** Hardest thing you’ve done is:

**BM:** Taking spelling tests in elementary school. Taking the Weather course and Calculus 3 course in college from professors I couldn’t understand (I was in college before interpreters became available). I didn’t have the courage to ask for notes. Didn’t want to put anyone out, sigh. If I knew then what I know now...

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

**BM:** I don’t know if this is funny or scary but a few years ago I was waiting to board a Southwest Airlines flight to Milwaukee at DC’s National Airport. At Southwest people board by the number on their boarding pass, and mine was something like A25. It seemed like the right time for my flight to board and people are getting in line (right, I don’t understand the announcements, I just watch).... so I get in line. My boarding pass is scanned (I detected a faint ‘beep’ and figured I didn’t really); I found a seat in the second row. I saw the feet of the people on either side of me, one wearing flip-flops (this was March…. going to MKE…but my students often dressed like it was July even when it was cold out). I got out my book, didn’t bother trying to listen to the flight attendant, as it’s always the same thing ....so I’m all settled in. Maybe an hour, 45 min later I noticed we were flying over water. Lake Michigan isn’t supposed to show up that soon (I’ve flown the DC - MKE route countless times, I know this for sure).... then I saw palm trees .... I asked the flight attendant where we were going.

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Alerts to phone/video phone, smartphone, door and baby cries with flashing lights, vibration and sound.
and she told me Fort Lauderdale! Needless to say, Southwest tripped up and they went all out to get me to MKE ASAP. From Ft Lauderdale I flew to Midway in Chicago, then a cab took me to MKE, arriving about midnight. Ever since then, I never fly without telling the staff I’m deaf, and getting a priority boarding pass!!

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

**BM:** From Wendy Ting and Bernie Palmer. I went to my first ALDAcon in Milwaukee in 2016 because I was hoping to meet deaf people from Wisconsin. I didn’t know any deaf people when I was growing up so I get really, really excited when I meet someone from Wisconsin. Turns out I had a blast and I’m really grateful to have found you all!

**KK:** Have you ever attended an ALDAcon?

**BM:** Milwaukee 2016, Orlando 2017

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

**BM:** It has been fun meeting people like me from all around the country. It has also been heartwarming to meet people who lost their hearing later than I did and share our struggles and successes. Especially fun for me is meeting people from Wisconsin! You know who you are -- it has been a blessing to meet you and get to know you, and see you again in Orlando!

**KK:** Who or what inspires you the most?

**BM:** My youngest son is an emergency physician. I am in awe of him. He is not only smart as a whip; he is one of the kindest people I know. Also, my dad. He taught me what love is.

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

**BM:** I’m passionate about giving blood to the American Red Cross. Yes, it’s a pain, but way less painful than the suffering of the poor person who needs the blood/platelets/etc.! I’ve been blessed with good health, so like to do my share for those less fortunate.

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

**BM:** Students who don’t do what you tell them to do. They eventually have to so why the fuss?

**KK:** What’s your favorite childhood memory?

**BM:** Playing Barbies with my younger sister and best friend Jane.

**KK:** Your favorite saying is:

**BM:** This too shall pass. What goes around comes around.

**KK:** The bottom line is:

**BM:** Be Kind.
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ALDA was born out of inequity. Prior to 1987, deafened people had no support in the world. The hearing people treated us as second class citizens and offered impatience, pity and/or exclusion. Culturally deaf people simply didn’t understand us. In that year, the famous at party that Bill Graham hosted set off a chain of events that led to opportunities to attend social events with deafened peers and gave us a sense of belongingness that didn’t exist for us the hearing and deaf worlds. As we grew closer as reference group, ALDA was created to provide avenues – primarily self-help and ALDAcon – where deafened people could get the support they needed to enhance coping with profound hearing loss. This resulted in ALDA becoming the fastest growing deaf organization of that era.

Fast forward to today; deafened people are still not treated as equals in the hearing world. Despite ALDA’s successes in raising awareness of deafened people as a group, barrier to accessibility that affect us continue to emerge as time goes on. For example, we previously had to fight to get captioning at events, on television programs, in movie theatres, and websites, we now have to push for the functional equivalent when businesses try to cut costs by using technological solutions, such as YouTube’s automatic captioning that tends to provide inaccurate translation of dialogue.

While ALDA does much in the arenas of advocacy and encouraging the business sector to comply with the Americans with Disabilities Act (ADA), accessibility barriers are sneaky critters and emerge in strange places with some of those equity barriers being created by those who consider themselves allies of deafness/hearing loss groups.

I say this because the sheer weight of academic research related to acquired and profound deafness has focused on aural rehabilitation instead of on our psychological and social rehabilitation needs. This is still true today as my study found in a 1999 study on the rehabilitation process for deafened adults that described a revolving door rehabilitation system that provides a hearing aid or cochlear implant to deafened people and then leaves the individual without psycho-social adaptation support. Even employers that purport to embrace diversity do little to ensure holistic inclusion of deafened people in the workforce, which Dr. David Baldridge pointing out in his study of tends in deafened workers’ workplace adaptions. (For more information on his study, see the fall 2017 issue of the ALDA News.)
More recently, an American university issued a call for volunteers related to the aging needs of deaf person and the researchers sought pre-lingual deafened persons who preferred language is American Sign Language (ASL) while ignoring the wide range of diversity among deafened person and persons with other hearing loss levels, as well as the wide-range of communication preferences. (Does this mean we are valued less because ASL is not our primary language?!) While the jury is still out, the researchers seem to have walked back on the selection criteria after Judy Vera and Marylyn Howe, with support from Larry Littleton and me, reached out to the university to express our concerns.

What this experience emphasizes that even though ALDA and deafened people have come a long way since that bash in Bill’s Livingroom, we still have yet a long way to go before being treated on equal footing.

**A Newbie’s ALDAcon Experience**

*By Heidi Lovato*

I really had no expectation about attending ALDAcon 2017 in Orlando, Florida. I went with an open mind and for the experience. What better place than being around the magic of Disney, right?!

But even before my plane landed at the Orlando International Airport, I had already joined the ALDAcon 2017 group on Facebook and welcomed with virtual open arms. Through this online group I became familiar with the names of people whom I would meet and learned about the various planned activities that would be held before, during and after the convention. I admit that I didn’t commit to many activities because I wasn’t sure how I would feel about being there; however, I decided that I would attend the private viewing of the “Wonderstruck” film.

As soon as I arrived at the registration table, I was greeted with a warm, personal welcome. I was handed all kinds of goodies as I set out to attend the newcomer’s welcome breakfast, which was a great opportunity to meet all of the first-timers to ALDAcon. It made us “newbies” not feel so alone.

We played a game that allowed us to interact and get to know each other – a perfect icebreaker! The newcomer’s breakfast was a great way to start the convention because from there, I was able to see familiar faces and engage with others. I never had a feeling like I was alone or didn’t know anyone.

I enjoyed all of the workshops and gained out of each what I had hoped – I especially enjoyed the two sign language workshops, they were very interactive and I learned a lot
in two sessions! I also enjoyed the one outing I signed up for, the movie “Wonderstruck”.

Getting out as a group in public, watching a great movie together, and being part of a ‘tribe’ of deafened people was pretty awesome. Having said that, I will definitely be signing up for more activities next time around!

I can’t end this without mentioning the infamous Karaoke night that closes out the whole ALDAcon experience. I got the T-shirt to prove it! Although I was kind of skeptical about how the evening would unfold, the karaoke was strangely therapeutic for me as I was able to let loose, sing out of tune, and dance like a wild woman. I especially enjoyed how the evening ended, but I won’t give away all the fun and leave that for the future “newbies” to find out when they attend ALDAcon 2018 in Portland!

Heidi Lovato and lives in Chandler, Arizona and lost her hearing six years ago. She is Assistant to the Executive Director of the Arizona Commission for the Deaf and the Hard of Hearing. Heidi also leads a support group for working adults with hearing loss in the Phoenix area and blogs about her personal journey with hearing loss journey which ALDAns can visit at: www.decibelmemos.com.

ALDAcon provides late-deafened adults and theirs supporters exposure to renowned speakers and informative workshops. Most importantly, it provides barrier-free interaction with their peers as ALL activities have sign language interpretation and/or CART (Communication Access Realtime Translation) as well as extensive technical support for all types of hearing assistance.

Save the Date
ALDAcon 2018
Portland, Oregon
October 10-14

For More Information:
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Francine Stieglitz reports that ALDA Boston has had a busy fall in spite of a blip or two. Our September 9 event with Jonathan O’Dell, Assistive Technology Manager/Training Specialist at the Massachusetts Commission for the Deaf and Hard of Hearing, had to be canceled that morning because of a water main break next to the library. Fortunately, we were able to contact everyone before they drove to the library. Jonathan’s presentation has been rescheduled to March 10.

On Saturday afternoon, October 28, historical interpreter Patricia Perry gave a presentation of witchcraft from the perspective of the accused and the accusers. ALDA member Lydia Kaufman was accused and found guilty of being a witch, but we managed to save her with some delicious treats that members had brought to the presentation.

Preparations are underway for our Annual ALDA Boston Holiday Party on Saturday, December 9. As we do every year, ALDA provides the main course, side dishes, and drinks. Members bring appetizers and desserts. Special thanks to ALDA member Ann Tanona, who has again graciously offered her home for a fabulous sit-down dinner.

Monthly tours for ALDA and HLAA members at the Museum of Fine Arts ended for the year with a superb tour of Conservation in Action on November 18. A few pictures have been posted on the ALDA Boston Facebook page. January and February are iffy months because of our fickle New England weather, so tours will resume in March. But there are lots of accessible theater productions to take advantage of.

Lastly, as of January 1, 2018, ALDA Boston dues will be going up. We have held individual dues at $15.00 for fifteen years, but increased costs for CART, the website, and other operating expenses justify the increase. The new rates for individual members will be $20 and $30 for professional members.

ALDA Peach gathered at the Georgia Aquarium in October. Members enjoyed the various exhibits. A dolphin performance was a highlight of the tour, and the penguins put on their own spontaneous show. Allison Freshley, a student in the Interpreter Training Program at Perimeter College, joined us and interpreted during the dolphin performance. Later, she and two other students produced and presented a PowerPoint program about ALDA for their class. They did a good job of presenting the origins and mission of ALDA, Inc.
2017 Motions Passed by the ALDA Board

Below is a list of motions passed by the ALDA board of directors during the second half of 2017. For a list of motions passed during the first half, see the summer issue of *ALDA News*.

**July 2017 Motions**

Through email discussions and electronic voting, the board passed three motions to accept an updated travel policy. It reads:
“It is the policy of ALDA that in principle all members of the ALDA board of directors are entitled to be reimbursed for transportation, lodging, and meals incurred in order to attend regular and special meetings of the board of directors and executive committee.

However, in practice, reimbursement for travel expenses is always contingent on funds availability, and this policy may be temporarily suspended for a specified length of time by a two-thirds (2/3) vote of the full board in times of fiscal exigency. In order to ensure that board members have sufficient advance notice of policy changes that might affect their travel plans to the next board meeting, this policy cannot be suspended within sixty (60) of a board meeting except by unanimous consent of all board members.

“Procedure:

1. To claim reimbursement for travel expenses, a Travel Expense Voucher must be completed by the board member and submitted to the treasurer within 30 calendar days after the relevant travel has ended. In situations where payments must be made in advance, as for plane tickets, reimbursements may be requested immediately from the treasurer and must be accompanied by a receipt. Any board member may choose not to request reimbursement for any or all of their travel expenses to a board meeting.

2. The treasurer, in consultation with the President, will review the expense vouchers and issue reimbursement as soon as possible upon receipt of travel vouchers.

3. Whenever possible, taking into consideration time, cost, and essential board requirements, all travel shall be by the most economical mode of transportation available. For example, when transportation by airport limousine or bus is available and convenient, it shall be used in lieu of a taxi. Modes of transportation authorized for ALDA board travel include personal autos, airlines, railroads, buses, taxis, and other usual means of conveyance.

4. Any board member using a personal auto for travel to board meetings will be reimbursed at the rate of $.54 per mile.

5. Incidental transportation expenses which are eligible for reimbursement include the costs of parking, ferries, bridge, road, and tunnel tolls, and miscellaneous airline fees, such as luggage fees.”

6. When a board member’s approved travel includes staying overnight away from home, the actual cost of such lodgings will be reimbursed up to a maximum of $70 per night. It is the responsibility of each board member to request lodging accommodations at the lowest available rate at the time of making reservations. An exception to this rule will be made whenever lodging accommodations are arranged centrally for board members by an individual designated by the board to do so.
7. When a board meeting is held in conjunction with an ALDA convention (ALDacon), board members are entitled to be reimbursed for their travel expenses as follows:

   a) Board members are entitled to full reimbursement for their transportation expenses to and from the meeting site.

   b) Board members are entitled to reimbursement for half ($\frac{1}{2}$) the cost of their hotel room for two (2) nights, the night before the board meeting and the night after the board meeting.

   c) Board members are entitled to reimbursement for three (3) days of per diem to cover the costs of their meals on two (2) travel days and the day of the board meeting. The per diem rate is $65 per day, minus the cost of any meals that are provided by ALDA. Board members are entitled to the full per diem for any part or full day that they are traveling to or from a board meeting. The per diem deductions for centrally provided meals are $15 for breakfast, $20 for lunch, and $30 for dinner.

   d) Board members are not entitled to reimbursement for their ALDacon registration fee or any other costs specifically encountered during attendance at ALDacon.”

**August 2017 Motions**

No ALDA business motions were passed in August.

**September 2017 Motions**

The board approved the location of ALDAcon 2019 as Overland Park, Kansas.

The board approved the following recipients of the designated awards: I. King Jordan Distinguished Achievement- David Baldridge; ALDA Angel Award - Kathy Schlueter; Able ALDAan Award - Sarah Wegley; Cheryl Heppner Advocacy Award - John Waldo; and the Brainstorm Award - Miguel Aguayo.

**October 2017 Motions**

The board approved a listing of ALDA’s name as a Link on the “Supportive Care Matters” website.

Approval was given for ALDA to sign on to a case against Fathom Events, a business that brings the Metropolitan Opera, London theatre and classic movie reruns to a theatre near you. None of the offerings are captioned.

The board also approved joining the Telecommunications Relay Service Consortium as a partner rather than a member.
Katherine Schlueter and Karen Krull were approved as planning co-chairs for ALDAcon 2018. Tina Childress was approved as program chair.

The board approved exhibiting at the Successful Aging Expo in Florida, in February of 2018.

**November 2017 Motions**

**ADDENDUM**

During the online board meeting on November 1, no motions were passed.

Through email discussions, the following motions were passed.

**November 8** – A move to amend an original motion to correct the full registration rate from $315 to $310. **It** passed unanimously.

**November 10** – The board accepted the amended motion for ALDAcon 2018 registration fees to be $250 as the holiday rate, $280 as the early bird rate, $310 as the full rate and $340 as the on-site rate.

**On November 12,** Steve reported that the election ballots would be distributed electronically at 6 a.m. (EST) the next morning.

**November 13** – A motion for ALDA to sign on to a lawsuit being filed by John Waldo and Tina Childress against Fox Theatre in St. Louis, Missouri, asking that it provide captioning during its live performances passed unanimously.

Following online discussion, it was decided by the board to send a letter to Centers for Disease Control and Prevention (CDC) expressing concern over its discriminatory practices in regards to deafened employees. The letter was sent on November 13.

Online discussions also were conducted to determine the listing on our website of organizations and associations that provide services and resources to deafened people. The majority of board members agreed that ALDA should be listed first.

The board agreed in its entirety to sign on to a letter to the Federal Communications Commission, urging it to make the social, cultural and communication benefits of video games accessible to all consumers who are deaf or hard of hearing.

**December 2017 Motions**

During the regular monthly meeting, no business motions were passed.

Through email discussions and voting, the following motions were passed:
ADDENDUM

December 7 – The board voted to transfer the remaining balance of $750.00 from the Carolina chapter fund to the Ray of Sunshine Restricted account.

December 14 – The board voted to sign on to the FCC filing the Consumer Groups Draft for FCC Communications Services 911 Docket, per Blake Reid’s request.

December 21 – A vote for ALDA to pay the $250 dues to remain members of the Deaf and Hard of Hearing Consumer Action Network passed with eight in favor and one abstention.

ADDENDUM

December 7 – A motion to transfer the remaining balance of $750.00 from the Carolina chapter fund to the Ray of Sunshine Restricted account passed unanimously.

December 14 – The board approved a motion for ALDA to sign on to the FCC filing of the Consumer Groups Draft for FCC Communications Services 911 Docket passed with seven in favor and two abstentions.

December 21 – A motion for ALDA to pay the $250 dues to remain members of the Deaf and Hard of Hearing Consumer Action Network passed with eight in favor and one abstention.