

ABILITY

JOHN ROBISON
Neurodiversity

REBELLE RALLY
Karah Behrend

WANG LU
China's Hand

TOBY FORREST
He's the Man

JUDY HEUMANN
Pull Back the Curtain

*National Press Club
Accessible Winnebago*

MARILEE

talkington

ACTOR
ADVOCATE
ARTIST



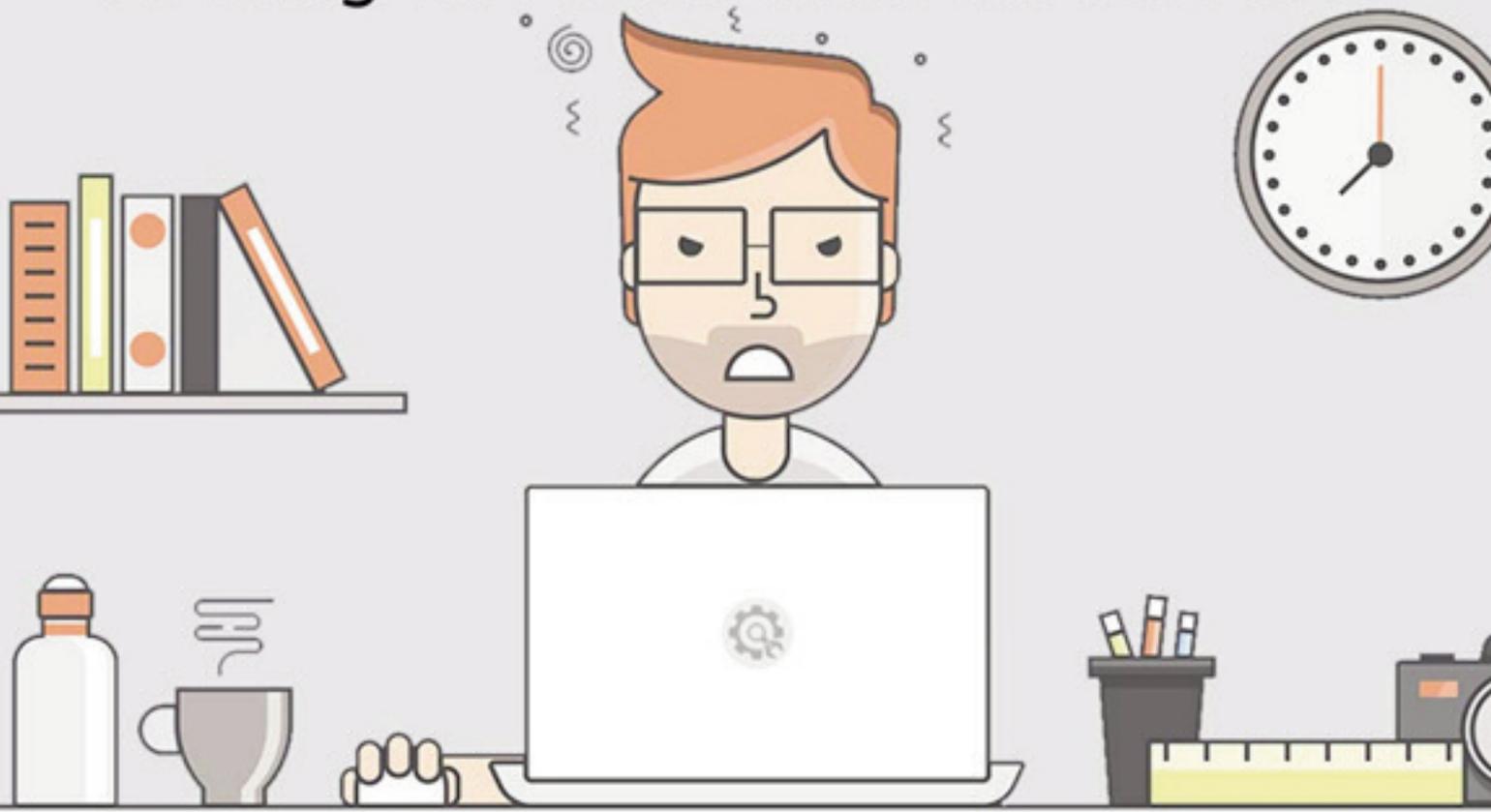
A Revolution in Captioning & Subtitling Web Video

- Join Ted Talks, PBS NewsHour, Udacity, Mozilla, and many other organizations
- Drastically reduce your cost of captioning
- Engage your community *or* tap into Amara's
- Access the easiest way to caption web video

Get in touch - Enterprise@[Amara.org](mailto:Enterprise@Amara.org)

 Winner, 2011
AAA Chairman's Award for Accessibility

Looking for Actors with disABILITIES?



There Must be a Better Way!

abilityE

disABILITY Talent Source for the ENTERTAINMENT Industry



Rebelle Rally's Karah Behrend and Mitsubishi p. 22



Marilee Talkington p. 50



Toby Forrest p. 60



Winnebago p. 36

- 8 HUMOR – It's a Date
- 10 CHINA'S – Wang Lu
- 16 LONG HAUL PAUL – 400,000 Miles
- 20 JUDY HEUMANN – Pulling Back the Curtain
- 22 KARAH BEHREND – Rebelle Rally Winner
- 28 NATIONAL PRESS CLUB – John Williams Gathers disABILITY Advocates
- 36 WINNEBAGO – Accessible Road Trips
- 42 JOHN ROBISON – Neurodiversity Advocate
- 52 MARILEE TALKINGTON – Actress Teaching Blind Actors
- 62 TOBY FORREST – He's the Man
- 68 ABILITY'S CROSSWORD PUZZLE
- 72 EVENTS

ADVERTISING

For advertising information e-mail advertising@abilitymagazine.com 949.854.8700

DISTRIBUTION

Faxon-RoweCom Library Services
Ebsco - Library Services
Swets Blackwell

CORPORATE SHIPPING

ABILITY Magazine
8941 Atlanta Ave.
Huntington Beach, CA 92646
Tel 949.854.8700

ABILITY Magazine is published bimonthly by CR Cooper
8941 Atlanta Ave, HB, CA 92646 (ISSN 1062-5321) All Rights Reserved
Membership: \$29.70 per 1 year (6 issues)
Send address changes to ABILITY Magazine, Attention: Subscriptions Manager
PO Box 10878, Costa Mesa, CA 92627; Marilee Talkington Issue Dec/Jan 2019-20

Published in USA

MANAGING EDITOR
Gillian Friedman, MD

MANAGING HEALTH EDITOR
E. Thomas Chappell, MD

HUMOR WRITERS
Jeff Charlebois
George Covington, JD

EDITORS

Melinda Chilton
Paula Fitzgerald
Pamela K. Johnson
Carol Brown
Sylvia Martirosyan
Lia Limón Martirosyan
Josh Pate, PhD
Maya Sabatello, PhD, JD
John Williams

HEALTH EDITORS

Moses deGraft-Johnson, MD
Larry Goldstein, MD

CONTRIBUTING WRITERS

Ashley Fiolek
Eileen Grubba
Geri Jewell
Regina Hall
Myles Mellor (Crossword Puzzle)
Paul Pelland (Long Haul Paul)
David Zimmerman

WEB EDITORS

Marge Plasmier
Mary Shafizadeh
Bob Williams (Interactive Puzzle)

MULTI-MEDIA

Helki Frantzen

GRAPHIC ART / ILLUSTRATION

Scott Johnson
Melissa Murphy (Medical Illustration)

PHOTOGRAPHY

Wang Lu
Toby Forrest
Paul Pelland
Nancy Villere

TRANSCRIPTIONIST

Sandy Grabowski

TRANSLATOR

Jing Hu

MARKETING/PROMOTIONS

SOCIAL MEDIA
Lia Limón Martirosyan
Shelly Rohe
Tamay Shannon

ABILITYJOBS.COM

Sabrina Bertucci
Vicky Dupree
Marge Plasmier
Casey Mims
Yesmeen Mikhail

EDITORIAL

editorial@abilitymagazine.com

PUBLISHER / EDITOR-IN-CHIEF

Chet Cooper

The views expressed in this issue may not be those of ABILITY Magazine

Library of Congress
Washington D.C. ISSN 1062-5321

© Copyright 1990-2020 ABILITY Magazine



**LISTEN TO TEXT
ANYWHERE,
ANY TIME,
on
ANY DEVICE**

**Sign up
for a
FREE trial**

RATHER LISTEN THAN READ?

Read aloud tools give those with reading difficulties **autonomy** and better **understanding**, whether it's a web page, a document, an image, or even text as it's written.

Try ReadSpeaker TextAid for yourself with our free 14-day trial.

ReadSpeaker
THE POWER OF SPEECH

[HTTP://TEXTAID.READSPEAKER.COM](http://textaid.readspeaker.com)
+1 (703) 657 7801

GET USED TO SEEING ME UP HERE

2 **START YOUR IMPOSSIBLE** 3

TOYOTA



Worldwide
Olympic Partner



Worldwide
Paralympic Partner

WHEN WE ARE FREE TO MOVE, ANYTHING IS POSSIBLE.

Welcome everyone



Since 2010 we work with clients, hoteliers and engineers to provide better experiences for all. Your accessible journey begins on an accessible website, perhaps as accessible as NATIVE's, where you can browse the Internet without looking at the screen, without touching the keyboard and without talking to the computer. Simply by blowing, touching any key or emitting a sound. It's not magic, it's technology for everyone.

We would like to offer our revolutionary solutions to hotels and any kind of accommodation worldwide. NATIVE is a nonprofit entity, an NGO, and we look for global hospitality brands ready to go forward with the comfort and safety of millions of customers. Thanks to our alert wristwatch, deaf customers in the event of fire during the night should not be in danger of dying. Deaf customers should also be able to laugh at a joke cracked at table thanks to a portable loop. Blind customers should not use body lotion instead of shampoo. Our Hotel Signage Pack is a great help. The QR code of Chef's Voice system in 12 languages helps blind customers and everyone to choose a menu. It also filters allergens avoiding surprises in the restaurant.

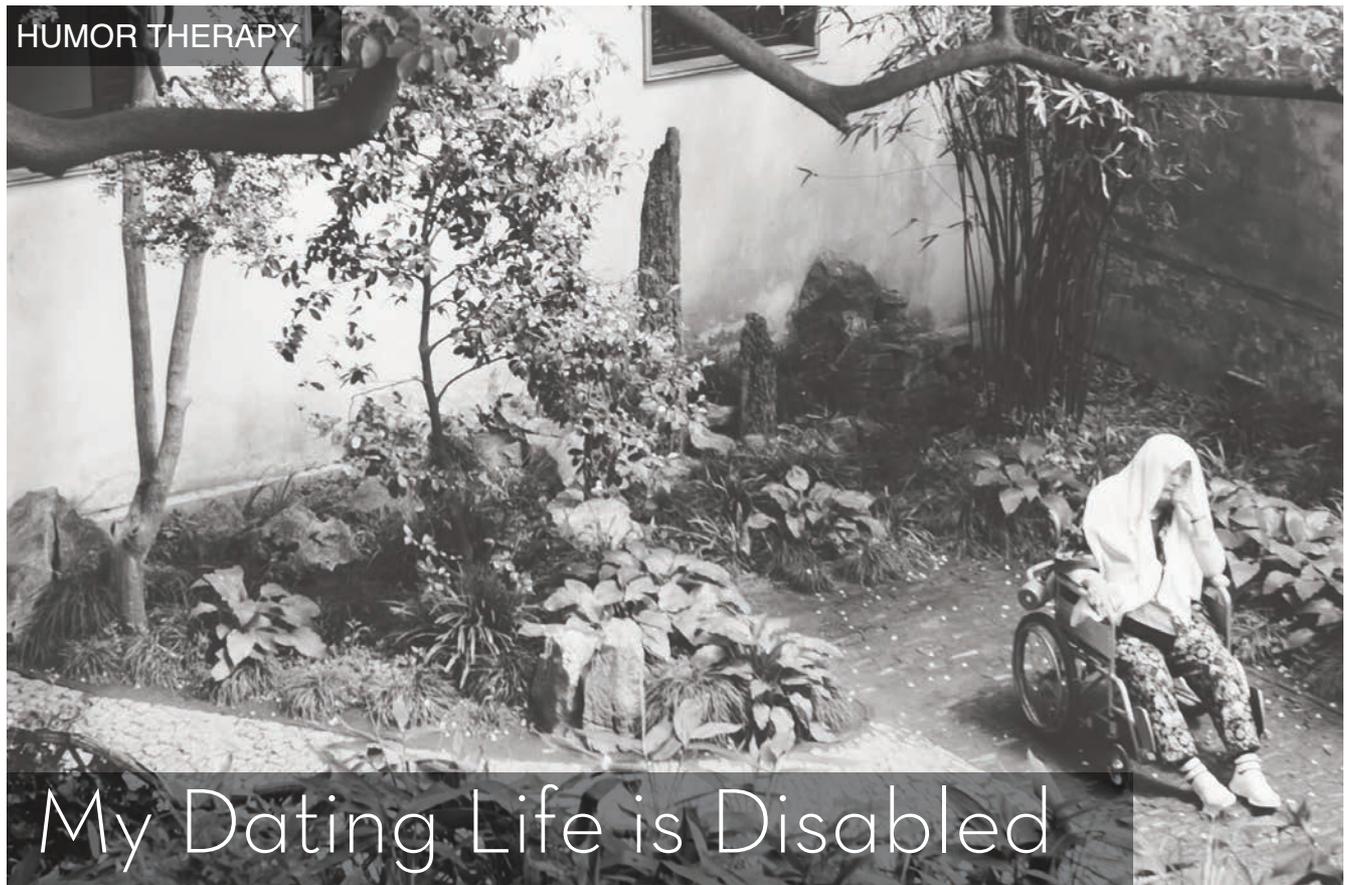
And ... how about enjoying a trek riding a camel with your wheelchair in the desert?

nativehotels.org



Hotels & Accessible Tourism





My Dating Life is Disabled

Dying is easy, dating is hard; pretending that you're always happy, keeping up that easy-going facade, coming up with lies that everything is great in your life, trying to take off wrinkles with sandpaper, etc. The nuisances are endless. It's almost not worth the trouble to find someone special. Now throw on top of all those hassles and anxieties the dilemma of being disabled. There's only small clan of special people in the world that are willing take on questionable goods.

I know, it's hard to believe and probably everyone who is reading this is saying, "Oh I'm not like that." Nobody wants to admit that dating someone with a disability is at the top of their ideal qualities they look for in a partner. It's probably somewhere between "one who still lives with their mother" and "one who uses a bicycle as their main mode of transportation." Some may say that it's shallow. As a disabled person in a wheelchair, I don't know if I would label it shallowness, maybe it just a matter of taste. I happen to like brunettes better than blondes. Most of us have an idea of our perfect mate we would like to spend our life with. A guy who uses a respirator and firing off leg spasms is not typically thought of as a fine catch. But most won't admit it. They'll claim I'll give anyone a fair chance if they are attentive, caring and kind. It sounds nice. It makes you look good. The only problem is it's not true.

I was on this dating site before and I just had a headshot and my profile didn't mention anything about a disability. This cat was hit up by oodles of eager women. When

I say oodles, I mean oodles of lovely ladies. I don't use the word oodles lightly. That made me feel good because just the day before I was looking at myself in the mirror and the next thing I know, my mirror spit on me. After that, my confidence level had gone down a few notches. Anyway, I would strike up a conversation with the ones I was attracted to by text or email and all was well. I'd get responses back like "I was thinking about you all day" and "when are we gonna meet?" I could feel their interest in me. Then, after I got to know them a little, I'd dropped the D bomb. I would be assured that I could tell them anything and it wouldn't affect the relationship. "So, I don't know if I told you this yet but, I'm disabled in a wheelchair. Crazy, isn't it?" It would usually be a day or two before I'd a response back, perhaps they needed time to digest the explosive news that just put a crowbar into their bicycle wheel. Some never responded back but most replied, "Oh really, that doesn't bother me." But it clearly did because I would no longer get four or five emails or texts a day as I had become accustomed to. For some strange reason, they quickly tapered off. I'm a big boy, I can handle it. At least they weren't as rude as my mirror. I don't make any judgments on it. Some might say I was false advertising and should put that pertinent info upfront. Maybe, but maybe I just wanted to feel good for a little while. I guess I could liken it to dating a woman and after a month of romantic dinners and movies she throws out, "Did I tell you I have seven kids? Oh, and I have herpes, too."

I've seen calendars like the twelve sexiest firemen—they have a helmet on, holding a hose and their shirts buttoned half-opened revealing a well-oiled glistening chest. I've yet to see a calendar of hot men in wheelchairs popping a wheelie with oiled glisten chests and maybe holding a leg bag. I think it's safe to say, at least for now, the disabled person is not really viewed as a sex symbol, even if he or she rides around in a really cool sporty wheelchair.

In all honesty, being in a wheelchair myself, I'm not sure if I could date someone in a wheelchair. I have a hard enough time taking care of me. Sex could be a little difficult. Somebody should be able to do the heavy lifting in the bedroom, right? If I became intimate with another person in a wheelchair it would be quite complicated. I'd be afraid we would just end up lying in bed, smoking cigarettes, and talking about how great it could've been.

I would think a guy in a wheelchair would be a good catch for many reasons. You can always push him around; you don't have to worry about ever standing him up and he won't walk out on you. Plus, he has that parking placard. Perfect for your shopping day at the mall. You get to board a plane first. If you go to Disneyland, they move you to the front of the ride lines. How about when you get in an argument with them? He can't really getaway to fast giving you ample time to unload slew of criticisms "Don't think you're gonna roll away from me! And another thing..." Also, if you're really upset, you can always just go upstairs for some alone time. Or, heck, not to throw out more sick ideas, but if he really pisses you off, wait 'til he's asleep then move his wheelchair into another room. These are just a few perks of dating someone in a wheelchair and the fun you can have together.

Of course, whether you're disabled or not, it's never easy for anyone to find the right somebody. Can I get an

amen? I mean it's difficult to find someone who can deal with you, the whole you; you're annoying mannerisms, you're pissy moods, snoring, you're body odor, smelly feet, who knows, but believe me, you got some stuff going on and it ain't pretty. I'll throw in bad breath too. Can I get another amen?

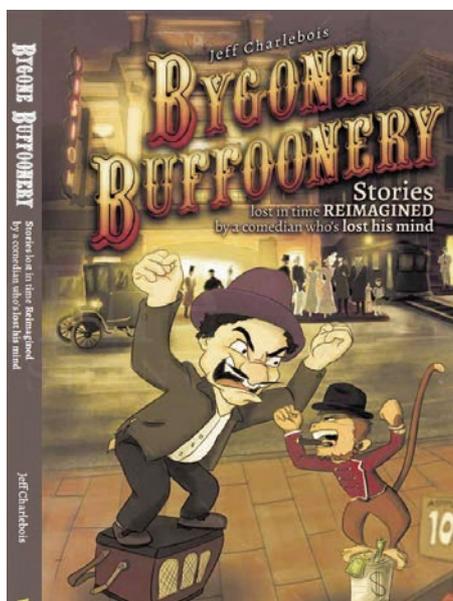
Can there be compatibility with disability? My best relationships in life were with that one who looked past my disability and saw the me inside of me. That scared little boy who is dying to grab you and kiss you goodnight then be invited into your place for a night cap and enjoy a nice breakfast in bed. I don't like when people see the disability part unless I need to use it to get out of something I don't want to do—like clean out the cat's litterbox, go pick up the Chinese food or do the dishes. "Honey, can't you see I'm disabled!" The good thing about dating someone who is willing to look past your disability is you don't have to go on a lot of dates to find out that they're special and a keeper. They are the ones who don't huff or make irritating perturbed noises while you're taking an hour to button your shirt or put on your shoes. That's a quad reference.

Wouldn't it be great if you could just be happy dating yourself? Save a lot of time trying to find the right person. You'd probably have a lot in common. Talk about love at first sight. Could you imagine if you didn't get along? Like everything you did pissed off yourself. What could you do? You can't leave the relationship. That's definitely a "til death do you part" situation. No two ways about it. What if you caught yourself cheating on yourself? You going to make yourself sleep on the couch? I have trouble forgiving myself after eating a candy bar.

I'm going to keep swinging for the fence. There's got to be someone out there for me, somewhere. I'll bet if, instead of baseball cards, I put dollar bills in my wheelchair spokes I'd get some interest. Everyone tells me to just be myself. I've tried that enough.

Wasn't it Einstein that said, the definition of stupidity was doing the same thing over and over and expecting a different result? The crazy thing is I've been through this routine before in my life. I search, I find, I begin a relationship then I spend most of the time wondering how I'm going to get out of this thing. Breaking up is hard. That's a whole new article. Right now, I'm just focused on finding that perfect compatible lover that can fill my needs until we break up. ■ **ABILITY**

by Jeff Charlebois



Did you know that mankind was nearly doomed when treasonous animals on Noah's Ark attempted a mutiny? Or that the entire Roman Empire nearly unraveled when a crackpot Caesar swooned for—and married—his horse? Were you aware that a flamboyant cowboy subdued bloodthirsty gunslingers with a two-step? What about the vaudevilain hack juggler who received his first standing ovation in a coma? Don't freak if all this comes as news. In *Bygone Buffoonery*, Jeff Charlebois provides centuries of laughs as he rewrites the past in witty, short stories you won't find in any dusty library.

"From the moment I picked your book up until I laid it down I convulsed with laughter. Someday I intend reading it!"

Groucho Marx



About the Author

Jeff Charlebois is a professional comedian and writer. He's performed for audiences across the country, published previous humor books, including *Medical Secrets Revealed* and *Life Is A Funny Thing*, and written columns for *Ability Magazine*. He is currently at work on his debut novel. Charlebois, originally from America's crab capital, Maryland, resides in the Los Angeles area.



ISBN 978-1-54674-031-5
9 781646 740315

LitFire PUBLISHING





王璐：断掌少女“有一手”

Wang Lu and Her “Upper Hand” in Talk Shows

“Because no matter what script I came up with, the audience would cast an eye over my right hand.” So Lu changed her strategy: “Instead of having them wonder about my hand, it would be better just to ‘wave it off’ with a few explanations. Only then could I get their attention back to what I had to say next.”

Wang Lu, a Chinese citizen born with right hand deformities in Baoding City, Hebei Province in 1997 and a performer on *Rock & Roast* Season 2, one of the most popular internet talk shows in China.

On August 13 Wang Lu tweeted “Happy Left Handers Day,” to which her fans replied: Haha, an “unnatural” left hander!

Lu was born with a right hand that has no digits. Where it’s perfect to “give me five,” “all I can say is ‘give me zero.’” Her right hand, which resembles a common Chinese baby toy called “rattle-drum,” has won her a nickname: Palm Girl.

Lu is a plumpish young lady with wavy hair and a pair

of round spectacles, quite well-known after her appearance on *Rock & Roast*. It is also this online show that has opened up the world for the life of “Palm Girl.”

“I’ve finished my fingers off”

A few years back a time came when Lu, at her uncle’s home, watched the 80’s *Talk Show*, which was claimed to be China’s first TV program of its kind representing the lives of the younger generation by way of Western-style humor, with Wang Zijian as the anchorman. Only a few minutes into the show, Lu began to rock back and forth with laughter. Seeing this, her uncle chipped in, “You might as well do that, too.” Surprised, Lu rejected, “I can’t. No way for me to do that,” though she somehow did wish to try it.

Since then Lu had become a fan of this program. Watching it wasn’t merely enough for her; she also made herself a “follower.” She was getting to know Wang Zijian as well as the increasingly popular figures in the talk show business, such as Li Dan and Wang Jianguo. Later she learned that Wang’s style is strictly not that of talk

shows, but rather of stand-up comedy. It was only for the sake of promotion that they called it “talk show,” a more popular name among the audience.

When she was in college in 2017 Lu saw from the 80’s Talk Show crew an ad about a talk show training class. Signups required videos of the candidates performing. Lu felt excited about this. At first she worried that her disability might discredit her, but then on a second thought she braced herself and filmed a piece about the hand.

No phone call followed from the admission staff, but Lu saw a message in the online fans’ group. “Perhaps Li Dan saw my video and directly asked in the group: Who’s this girl without a hand? Did she sign up?” The entire group mentioned her name. This came as a big surprise for her as she had not expected to get Li Dan’s attention. Or to put it another way: she could be easily remembered just because her hand looks different.

To attend the training, Lu traveled to Shanghai for the first time. With other trainees, she studied theoretical approaches during the day and practiced stage performance in turns at night. “Now it is still quite awkward to watch those videos.” Disability became the first label by which she was recognized, but she didn’t feel uncomfortable at the time. “On the contrary I found this hand quite helpful.” She crafted her first comic piece about the hand. “I have a little brother who is a kindergarten. He loves to suck his fingers. To correct him, I say, look, I used to do that a lot, too, and now I’ve finished my fingers off!”

Out of her training class Lu plunged right into talk show theaters in the real world, shuttling between Shanghai and Beijing for small performing opportunities. Acting simply as a hostess also delighted her. The audience, mostly young people, would pay two or so dollars (10 to 20 yuan) for a bit of novelty and leisure a talk show promised. They would not expect much or mind bangles. For Lu, this relaxing atmosphere was an ideal proving ground. “The audience got all the ‘ha ha points.’ They only had a minimal idea of what a talk show is, so no one intentionally threw eggs at you.” Not only was there a cheerful audience; the performers also lauded one another. “Not bad today!” “Punchlines were quite intense.” “Nice audience connection.” To these rosy-sounding comments, she referred deprecatingly as the “false prosperity” of interpersonal relationships.

When the lights went up, Lu walked onto the stage, mic in her left hand. “Hello, my name is Wang Lu.” With this she raised her right hand and waved it before the audience. “And I need to tell you that I was born with a hand like this.” This was her opening cliché because “no matter what script I came up with, the audience would cast an eye over my right hand.” So Lu changed her strategy: “Instead of having them wonder about my hand, it would be better just to ‘wave it off’ with a few

explanations. Only then could I get their attention back to what I had to say next.”

The first season of *Rock & Roast* was a huge success. Season 2 expanded candidacy creating an opportunity for land-based performers like Lu. Out of seven contestants, one who overcame the Cruel Open Mic challenge with top votes would be entitled to a TV production along with the title of “Hot Comedian.”

Still with a mic in the left hand and the right hand held high in the air, Lu zoomed through and won the opportunity to face the national audience on TV.

“I only had one week of fame”

“She sprinted over full of vigor and verve.” To panelist Wu Xin’s comment, another popular comedian named Yu Qian nodded, “She came out with an aura of the-atics.” Lu beamed under the spotlight, feeling both excited and nervous, trying to hold her tongue, somewhat over herself inwardly. “Actually this is how I walk, sashaying along.”

“Sashaying along” was her way as a first-timer to repel fear and keep cool-headed on a stage too brightly lit for the performers to remain focused. She opted to do as many stage rehearsals as possible. When the other performers left, she could only practice with a white spotlight and a water bottle, which she fetched from her room as a substitute for the official mic. She would keep drilling until the security guards came to clear the site.

She valued this hard-earned opportunity. According to her instructor, she remembered, the creative fountain for talk show performers is a relentless dig at the difficult, the horrendous, the stupid, and the bizarre, four underlying aspects of life that provoke negative emotions, before packing it all up with humor. Going too deep is unbearable on the performer’s side, but too shallow a dig can hardly move the audience. An outstanding performance is somewhere in between. This is what talk show performers need to do – digging long into their souls and taking out to the audience all that sounds freshly alive.

“Hand” was where Lu constantly dug into. According to her, what should you do when a child asks his mother about your hand? “Wave it so he can see more clearly.” Could a disabled guy take five able-bodied friends to Disneyland without having to wait in line? “Obviously, those five people want to go there no less than that disabled guy!” What would you say if your team lost a video game? “Blame my hand if you ask me!” When you were lauded for your comic work, “that’s because they don’t have an “upper hand” as I do.”

This script Lu had repeated countless times, knowing without thinking which line could make the audience laugh and at which she should pause to wait for laughs.



Mobility Reimagined

Imagine being able to independently and safely sit, stand and navigate environments that were once inaccessible – all while standing at eye level. Tek RMD is easy to board, and is done unassisted, providing you greater independence. With just a gentle pull, the gas spring mechanism brings you to a standing position, while the joystick control gives you the freedom to take your own path. Tek RMD. Upright mobility, greater accessibility and an improved perspective.

ShopNumotion.com

numotion
Mobility starts here.

“The key is to be error-free”

When her show was over, Lu seemed more willing to let go. Unlike other performers, who would judge the shows as good or bad, Lu minded more the fact that “it’s finally over,” having blurted out all that she had learned. She said that stage performance is like sitting for an important exam when you have certain disabilities. It is very rare that disabled people tease their own bodily defects in public. As compared with the mere use of common laughingstock, Lu’s appearance takes on new meaning.

When her show was broadcast, she felt that she had shot to fame. “When I went to the bathroom during a job interview, someone waited holding the door frame curtains for me. “Like this thing could ever have happened to me earlier!” A leisure walk on the street sometimes also involved a photo-op with fans. “The first thing people wanted to do after they had recognized me was take a look at my hand.” So she had to “show proof of her identity” over and over with passersby. Later when Lu found that she was not included in the list of performers who had performed in that talk show program and who had built their own fan clubs, she felt a little disappointed. “A week later it looked like I was already a ‘has-been.’”

Many of the private messages Lu has received on Weibo, the Chinese equivalent of Twitter, are from people with

disabilities asking her how to be as resilient and strong as she is. To this, she cannot offer much advice, for she doesn’t see herself as disabled at all. “I got my disability card upon my mother’s request. Not much to feel about.” As she said in the show, “Many people say I’m strong, but I don’t want to be strong.”

“No one looks at my hand anymore”

Though a one-timer in the show, Lu made a good social circle. Once in the performers’ WeChat group she replied with a Chinese emoticon of one hand folded in the other, implying a masculine appreciation of what had been discussed. Following were many responses that conveyed a similar “wish to see Lu physically make that gesture herself.” As it turned out, the wish was granted when Lu actually did that in the last episode of *Rock & Roast*.

What Lu had not expected, however, was controversy against her performance. Some netizens thought that joking about disability was “cruel.” Some even went so far as to accuse her of exploiting loopholes and sponging off Disneyland. “If I don’t talk about my hand, there must be doubts if you have an issue about your disability. If not, why do you keep silent about it? If I talk about my hand, there must be some thinking that I’m here to win cheap sympathy. No way out of this as if you were on a boat.”



Wang Lu on stage

What others say about you is as good as a passing cloud. The truest is how you feel at your worst. Lu had enjoyed herself ever since she stepped into the talk show community. Earlier, Fridays always involved commutes to Beijing and Sundays back to Tangshan. The alternative would be a full stretch of school vacation working as an intern in Beijing. All was for more opportunities to perform in big cities. “I was quite broke at that time and could barely afford the travels. So I also was a part-time volunteer plus worked as a hostess at other venues to cover at least part of my travel expenses.” After the show, Lu worried about where she could spend the night. “I have slept at the homes of many fellow performers.”

Lu has a relative who owns a small company in Beijing. “I slept on the couch there at night and before the staff arrived the next morning, I had to make it look like no one had been there. Now looking back, the situation really seems dismal, but I felt so happy back then.” Lu particularly dislikes it when her story is seen as a prototype of success. “A lot of people love to send me success stories about some people with disability because they think that my hand is abnormal. Whenever they do

that, I would like to send them the ‘girl-with-small-boobs-can-also-be-a-model’ sort of thing.”

As *Rock & Roast* Season 2 drew to an end, so did the limelight on Lu. But she still envisions her future career in comedy. Even writing comedies would not be so bad as long as it could make ends meet. Now Lu still manages to get a number of performances a month at small theaters. “But so far this industry doesn’t look like a place to make big money. The first thing is to scratch out a living.” Despite that, she’s found herself so well-known among the audiences at those theaters that no one stares at her hand anymore. This may be a great opportunity to make a change for herself. “I can create better comedies for them.” ■ ABILITY

by Bai Fan



This story is part of a series of articles published as an exclusive editorial exchange between *China Press for People with Disabilities & Spring Breeze* and *ABILITY Magazine*

60+

地球一小时



垃圾分类，因好手艺而美丽。
唤醒每个人心中的环保家，从“地球一小时”开始。

2012年3月31日 星期六 20:30 至 21:30

www.earthhour.org.cn



400,000 MILES FOR MS

Drizzly, cold and dark was never my favorite way to embark on a thousand mile day on the bike, even when I was riding to an event I had been looking forward to. I was heading to Newnan Georgia to share my Ural in the Iron Butt Rally story to a large group of Harley Davidson riders. It was November, we had just changed the clocks to steal away another hour of precious daylight and although I was heading south, I was headed for an even colder morning. About 200 miles into my ride, with my heated gear working to fool my core by keeping the chills away, I was making good time. I wondered where I stood in my million mile quest for Multiple Sclerosis and I knew I was getting very close to the big 400,000 milestone. I poked at my cellphone with my stylus which failed to wake it's brain. I then activated the voice command to open my bike maintenance app.





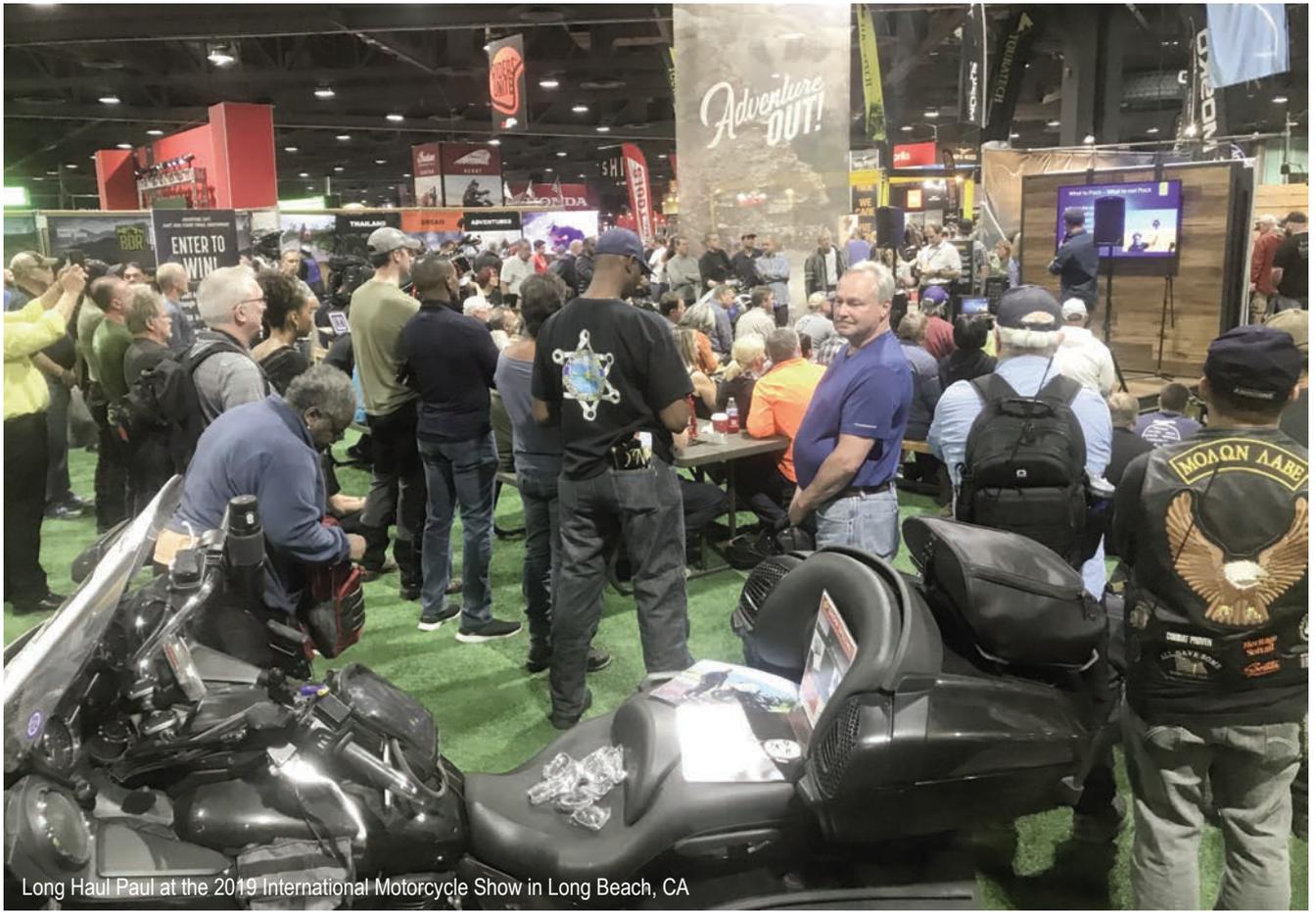
The mileage page opened up reminding me I was 6,000 miles overdue for an oil change and then it scrolled to the records page. A quick mathematical calculation made me realize I would reach a major milestone in the next four or five hours.

300 miles never took so long to rack up.

The sun was up and the temperature stopped dropping and ever so slowly started to rise. Soon it would climb above freezing and maybe in a few hours I could even lift my helmet visor briefly to take a sip of water off my Camelback. Winter weather was here, although the calendar disagreed. I watched the bike's odometer click up to 79,900 and without any fireworks or party horns to celebrate, I settled for a simple smile that creased my cheeks against the thick padding of the helmet. I had documented 400,000 miles *Chasing the Cure*.

After seven years traveling the country as a patient advocate for Multiple Sclerosis I know my adventure is really going somewhere. This particular trip started in Atlanta where the Harley riders welcomed me with open arms, trading a plate at their annual Thanksgiving luncheon for my inspiring presentation. Although I wasn't paid to be a speaker, they passed the hat and raised \$1200 for the MS charity I work with. I then rode across the United States to do a second presentation in Costa Mesa, California. This event, held in a high school auditorium was organized by a fellow long distance rider who invited family and friends to hear me speak. Again, donations were collected and approximately another \$1000 was raised for the charity.

From Costa Mesa I made my way the short distance to Long Beach, CA where I would spend about 30 hours



Long Haul Paul at the 2019 International Motorcycle Show in Long Beach, CA

working at the International Motorcycle Show. My bike and I were on display for the tens of thousands of attendees. At their press conference, Yamaha announced a brand new smaller adventure bike called the 700 Tenere. They also introduced me and renewed their continued support of me and my journey. They ended by telling the motorcycle world that they were going to give me one of the new bikes!

I can't wait as the new bike is similar to my old Tenere, but smaller and really capable off road. It will be quite a change from what I am riding now, but will allow me to explore even more of the back roads and rural parts of this country. I am also very excited that Yamaha is stepping up and continuing to support me in my journey *Chasing the Cure!*

As ridiculous as it may sound, getting diagnosed with MS has created so many opportunities and opened so many doors for me. Although my disease has been stable and manageable, I also know others who are not responding to treatment and who's disease continues to progress. Dedicating the next 600,000 miles to them, I will not slow down, and I will not stop until we have a cure.

■ ABILITY

longhaulpaul.com



PULLING BACK THE CURTAIN

When I was five years old, I was deemed a fire hazard. Like millions of American children that year, I was entering kindergarten. It was 1952 in Brooklyn, NY and my mother was taking me to my neighborhood school to make sure everything would go smoothly on the big first day. It didn't. The principal who personally "greeted" my mother and me at the school entrance informed us that my wheelchair, the one I'd used since I had polio at 18 months old, made me fire hazard because I could not independently exit the building. I was told to go home and stay home and not to worry because a teacher would be sent to me, segregating me from my peers.

This episode became a template for the experiences I would have throughout my life. My high school principal, for example, didn't want me on the stage with the other graduates. Later, as a prospective teacher, examiners asked me humiliating questions about how I go to the bathroom. Still to this day, flight attendants talk to my colleagues about me rather than talking to me directly. Through these challenges I have learned a painful, but important lesson: my life was constricted not by my disability, but by the stories others told themselves about what disabled people are capable of.

Looking back, I'm struck by a simple question: What if those who barred my entrance to school, asked inappropriate questions at a medical exam, or otherwise expressed their ideas about disability, had been taught to understand disability differently? What if they'd had the benefit of learning, from popular media, from the TV, films, and news programming that are central to our lives, that disability—which affects more than 56 million Americans of all race, class, and gender identity—is simply another way of being human?

Consider the way our understanding—and the media representation—of other historically marginalized groups has changed. The characters portrayed in Ryan Coogler's "Black Panther," for example, depart type from characters who populated 1970s Blaxploitation films, like Gordon Parks' "Shaft". Constance Wu and Henry Golding, who delighted audiences in *Crazy Rich Asians*, don't look much like the characters portrayed in earlier movies like "Thoroughly Modern Millie" or Mickey Rooney's character in "Breakfast at Tiffany's."

However, these efforts to diversify popular media hasn't extended to disabled people. As a child, I rarely ever saw myself—or anyone like me—represented in movies or TV shows. The few disabled stereotypes I did see — facially disfigured James Bond villains or the powerless victim of Lenny in *Of Mice and Men* — were rarely real people facing the same kinds of challenges non-disabled people face, including the struggle to find love, build a career, deal with financial turmoil, or cope with family illness. More often they were disabled characters as one dimensional as a cardboard cutout, positioned like props for entertainment purposes. It's 2019 and this week, Ali Stroker was the first wheelchair riding actor to be nominated for a Tony. While progress is being made there is so much more that must be done.

Although we constitute about one-quarter of the population in the US, just 2.1% of the primetime broadcast TV series regulars are disabled, according to GLAAD's *Where We Are on TV '18-'19* report. An Annenberg Foundation and USC Annenberg Center report found that 2.5% of the top 100 grossing films over the past decade included disabled characters. And, the Ruderman Foundation found that in 95 percent of these examples, these characters were not played by actors with

actual disabilities. This means that audiences have few opportunities to learn about us or our experiences, and have few examples to change their common thinking that disabled people are somehow broken, abnormal or in need of repair.

Late night show host Trevor Noah, speaking about the prevalence of non-disabled actors playing disabled characters, touched on how jarringly strange this phenomenon is when seen from a different perspective.

Noah cited a disabled actor who addressed the problem in a conversation online by explaining that, currently, the issue is not that disabled actors like him don't get these parts but that they don't even get called to audition for them. "As someone who is not in a wheelchair, I never thought of it that way," Noah told his Daily Show audience. "It's powerful because you [usually] don't think about representation, you don't think about how important it is for people to see themselves on screen in a real way."

This is more than a missed opportunity. It's a blight on the progress we're making on the issue of diversity in media. When we talk about diverse representation in media, we need to include people with disabilities in the diversity conversation.

Remember the unspeakable video of Donald Trump mocking a disabled reporter? The President's display provided an excellent example of the worst, most mean-spirited kind of misrepresentation—and misunderstanding—of people with disabilities who live, flourish and contribute to our diverse and ever-changing world.

What if people were to realize that many of their best

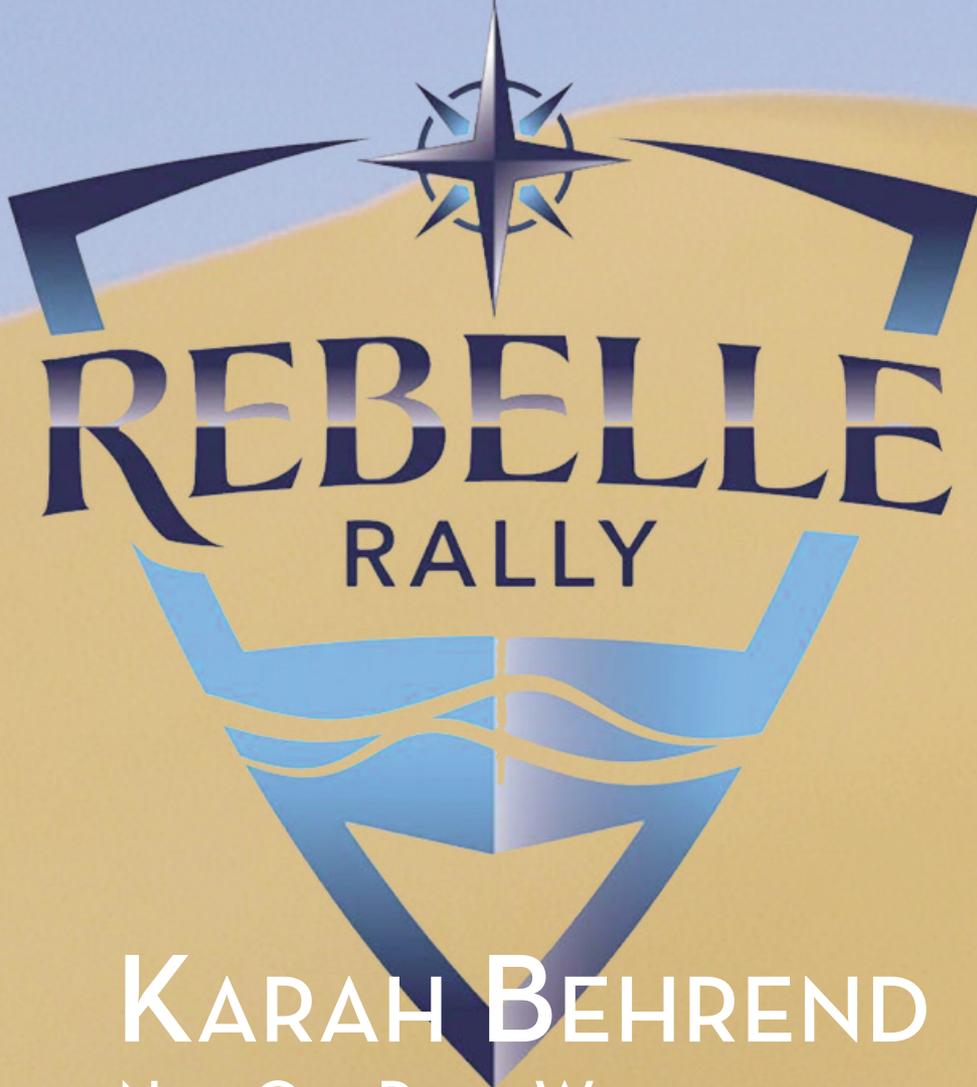
friends, closest relatives, dearest loved ones, and most valued colleagues have some form of a disability, and perhaps one we cannot see? What if they were to experience the inner lives of disabled people through storytelling, to learn about the social injustices disabled people face as well as how our day to day lives are like theirs?

Never before has our society made such a concerted effort towards inclusivity. From the political sphere—with Congress now made up of a more diverse group of representatives than ever before—to award shows like The Oscars and The Tony's—that have suddenly become a celebration of diversity, a veritable rainbow coalition of black, white Asian, LGBTQI performers. Yet, in a world of increasing inclusivity, it seems particularly odd that popular media still excludes one very large section of the population. Meaningful change begins with starting a conversation about changing the way disability is represented in the media and taking the necessary collective actions which finally results in authentic and meaningful inclusion of disabled people. One girl in a wheelchair presents far less of a hazard than does a culture that denies the truth of a prominent portion of its constituents. ■ ABILITY

by Judy Heumann

• • •

Judy Heumann is an internationally recognized leader in the disability rights community and a lifelong civil rights advocate. She has been involved on the national and international front working with disabled people's organizations and governments in the U.S. and around the world.



KARAH BEHREND

NEW OFF-ROAD WARRIOR

Karah Behrend is all about breaking down barriers. She's an adaptive athlete who not only completed the grueling eight-day, off-road Rebelle Rally—her first time ever—but the medically retired Air Force veteran placed second. With Behrend behind the wheel of a Mitsubishi Eclipse Cross, made accessible with hand controls to accommodate her, and her teammate Rachael Ridenour serving as navigator, the duo raced from Lake Tahoe to an endpoint near Mexico. With basic navigation tools and coordinates, they barreled through the wilderness, confronting dense forests, rugged scrublands and stark sand dunes. During the last section of the rally, Behrend met up with ABILITY to talk about her career as an adaptive athlete, her love of sports and her warrior's spirit.

ABILITY: Since retiring from the Air Force what do you do?

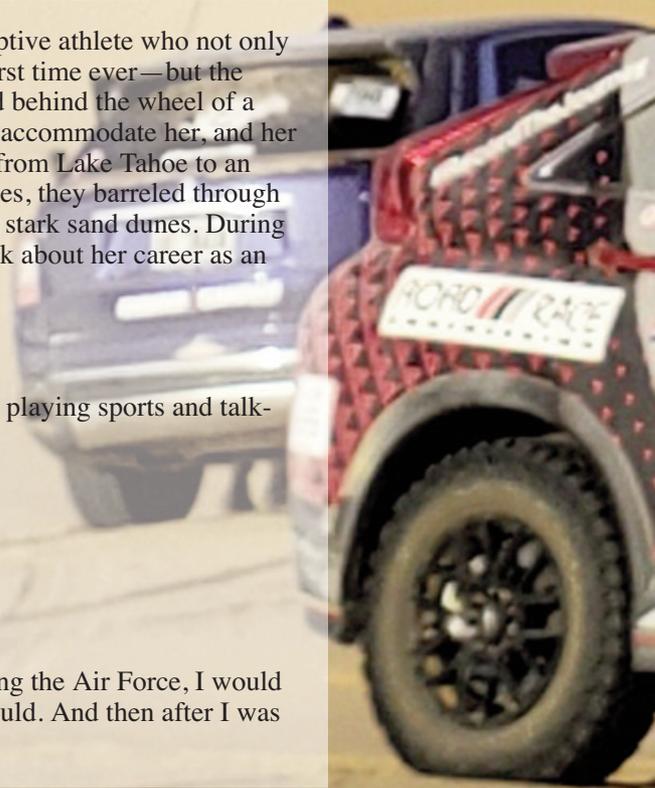
Karah Behrend: I play wheelchair rugby, and I travel the country playing sports and talking to people.

ABILITY: How long were you in the Air Force?

Behrend: Six years and four months. Not that I'm counting.

ABILITY: (laughs) You've always been an athlete?

Behrend: Before I joined the Air Force I was a cheerleader. During the Air Force, I would do unit sports and play sports with my friends or whatever we could. And then after I was hurt, I found adaptive sports, and that was my new drive.







Rebelle Rally cross over winners Rolls Royce and Mitsubishi — placing 1st & 2nd respectively

ABILITY: How'd you get into rugby?

Behrend: It kind of fell into my lap. I was in an event where they had me try it out, and I fell in love with it. I ended up contacting a team called Oscar Mike's to see if I could play with them for the season, and they had me try out. They took me last year, and I've been playing ever since.

ABILITY: Did you see the movie *Murderball*?

Behrend: No. Somebody got me into a rugby chair and had me hit somebody, and I was like, "Whoa! That's an adrenalin rush I haven't had in a while! How do I get that again?" As somebody with a quadriplegic function level, it's difficult to feel free, it's difficult to feel like you're able to be as aggressive as you want, to be able to do the things you used to do and be empowered. Wheelchair rugby has given that back to me.

ABILITY: Will you try out for the Paralympics?

Behrend: I'll try to. This is my second season now, so eventually I'm hoping to be the first or second female on the Olympic rugby team.

ABILITY: I never thought about male-female when it came to rugby.

Behrend: The sport is four percent female.

ABILITY: So you said you'd be the second—

Behrend: I want to be the first or the second. There's a girl who's really close to making it, and I really, really hope she makes it.

ABILITY: Oh, not first and second in the sport, but in

getting onto the team?

Behrend: For the country. We've never had a female on the Paralympic team.

ABILITY: Oh, that is what you were saying. But there are other females on other teams around the world?

Behrend: Yes. Australia has a female, and I believe Japan, Canada, and Britain each have one. I don't know who else. But I know there are quite a few females playing.

ABILITY: What did you do in the Air Force?

Behrend: I was a communications signals intelligence analyst.

ABILITY: You had high level clearance?

Behrend: (laughs) That's literally all I can tell you.

ABILITY: Can you talk about how you got involved with the rally.

Behrend: It's a really long, funny story. This guy broke up with me because, you know, things—

ABILITY: Life.

Behrend: Yeah, life. People aren't always okay with the chair and whatever. So this guy broke up with me, and my friend was like, "Hey, let's go mudding."

ABILITY: Wait, what, mudding?

Behrend: Mudding. We took some ATVs out and we went mudding out at this park in Texas. We got really

stuck. I was waist-deep in mud. If I had gotten out of the buggy, I would have been swimming to get out. So I took a really dumb video and I put it up on my Instagram, and my rally partner, Rachael Ridenour, saw it. She had been following the #adaptiveathlete for a little while. They had known that they wanted to find an adaptive athlete to do this race. And when she saw a sarcastic video of a quadriplegic stuck in mud, literally can't get out to do anything, just making the best of it, she said, "That's who I want my next partner to be."

ABILITY: Nice! That wasn't that long of a story. Make it longer!

Behrend: (laughs) I don't know how. That's literally what happened.

ABILITY: So she was already doing rallies?

Behrend: This is her fourth. She's an original Rebelle. She has done the rally every single year.

ABILITY: How was it with modifying the vehicle?

Behrend: It was awesome! A nonprofit called Control The Road stepped in and helped us find a person in California where the Mitsubishi was who would install hand controls and do all of that. I flew out on the first of October, a couple weeks ago, and same-day install. They hooked it up and made sure that everything was in there properly and made it so that it would be safe for the rally. It was all off-road, and the wear and tear on hand controls is kind of hard. They really did a great job.

ABILITY: And so far it's held up?

Behrend: We haven't had a single issue. Knock on wood. It's been awesome.

ABILITY: Let's go back a bit. Tell me how the rally works and the rules. It's all women in the rally? There's a whole story behind that.

Behrend: Sure. The Rebelle Rally is an all-female navigation rally. There is no GPS allowed. It's straight compass and map navigation with lat-long coordinates you're given. Sometimes you're not even given coordinates, you're given a degree from a certain point and you have to do all of the math and triangulate a specific meter point on the train you're on.

ABILITY: All in longhand?

Behrend: Oh, yeah. Everything is compass, map, ruler—you're literally calculating where on the map you are and then using terrain associations and headings to find where you are. You then click a tracker to click in and get your points.

ABILITY: If you get to a point early, do you get points

taken away?

Behrend: It depends on what part of the rally you're on. For the timed enduros, yes, you would get points taken away on that specific event. But during the checkpoints you have a certain close-out time and you have to hit your tracker on that point before that close-out time. Today we had some pretty aggressive close-out times. We had three points that closed within an hour and a half, five that closed within three hours, four that closed within seven, two within nine, two within ten, and four within eleven. You have to use time management throughout your whole day with everything and trying to think ahead of the terrain so that you can get where you need to be in time.

ABILITY: Do you have any idea other than knowing that you're coming—did you even know you were coming to the end?

Behrend: I did know, because it is traditionally the last day of the rally.

ABILITY: Other than that, do you know what type of terrain that you're going to hit? Do you know if you'll be in a rocky, muddy or sandy area?

Behrend: No, you have no idea where you are. They do a really, really good job of keeping it fair and making sure nobody has any idea of where we'll be so no one can go and do their homework. On the morning the race starts, they'll give you a piece of paper with your lat and long coordinates, your azimuths, whatever you need, and they'll hand it to you two hours before you start. You have to clock all of these points on the map and plan a route and find the washes, these weird little roads. You have to literally read the map and figure out where you have to go.

ABILITY: Are you all doing the same thing, and that way you follow tracks?

Behrend: No. There are a few different routes. They make it so you can't team up and—

ABILITY: —follow somebody?

Behrend: Yeah. You can't do that.

ABILITY: So everyone's on their own?

Behrend: For the most part everybody has their own stuff. We do collaborate when we have the chance, just because the whole point of the rally is female empowerment and empowering each other and making sure that we are able to accomplish our goals together. We're not going to leave somebody behind, but we're also not going to give them the answers. We make sure they do the work.

ABILITY: And there are different classes, different



Karah driving a Mitsubishi Cross Over in Glamis Dunes

types of vehicles?

Behrend: There are two classes. There's the 4x4 class. They have the different gears for control. We're in the crossover class. We're taking a normal stock street vehicle and—

ABILITY: Is that what “crossover” means?

Behrend: Yeah. It's a straight street car, something you normally wouldn't taking off-roading, and we take it off-road and race it.

ABILITY: What are you driving?

Behrend: We're in a 2017 Mitsubishi Eclipse Cross.

ABILITY: What size engine?

Behrend: It's 1.7 or 1.6, I believe.

ABILITY: So it's four-wheel, automatic?

Behrend: This one is all-wheel drive, smart all-wheel control. There are three settings. One is auto, for your regular ground. One is gravel, for anything slippery. Rough terrain is rock. And then you have your snow setting for wet terrain—water and ice.

ABILITY: When you're in the really sandy condition like the dunes, what do you use?

Behrend: It depends on what we're doing. If we're riding the dunes, I'd probably keep it on snow. But if we're going to try to get ourselves unstuck, we'd stick it in gravel, just to get a little more torque on the wheels.

ABILITY: And what will you be doing with air pressure?

Behrend: We drop it down to 13. We have some really awesome tires and wheels on the Mitsubishi. We have Vision off-road wheels and BFGoodrich KO2 All-Ter-

rain tires that we're running, and they have been fantastic. We've had multiple competitors pop tire after tire after tire and we haven't.

ABILITY: Is that because you're shooting their tires?

Behrend: (laughs) No. That's because I'm picking my lines and my tires are amazing.

ABILITY: That's really cool. So you had some prior driving experience in the sense of doing this type of race, or is this brand-new to you?

Behrend: It's a mix of both. I've done off-roading, that's normally just the cars that I run. You just take them off-road if you can. But other than that, I haven't had a whole lot of actual off-road racing experience. This is my first off-road race.

ABILITY: Tell me about the chair you're using. Do you know the history of these things?

Behrend: I'm in the GRIT Freedom Chair. I love this thing. It uses a bike—a ratcheting system so you can propel yourself forward through really rocky, rough terrain. I can get up over hills and embankments and stuff like that without—

ABILITY: Using your upper body muscles?

Behrend: Exactly. You just do kind of a push-up motion and it propels you forward.

ABILITY: Do you know its history and who invented it?

Behrend: I do not. I could find out.

ABILITY: They were PhD students who came out of MIT. We did a story on them. They went to Africa to test off roading.

Behrend: I'm testing this for off-road stuff for them too,

like where the best mounting points would be and what we need to do to keep it stable and safe. We strapped it down wrong, and the weight of off-roading and bouncing it around bent some things. We got that fixed, and we've figured out how to keep it stable.

ABILITY: I think they chose Kenya. They wanted to make something like this that had torque and to go off-road on terrain, but also be able to have materials that could be fixed in a bicycle shop.

Behrend: Exactly. Which is perfect. A lot of us don't have many options for wheelchair repair either, so even just having the option of going to a bike shop for this rally for one of my tires—we didn't have tubes or anything, we'd be in trouble.

ABILITY: I was surprised to see you in this chair. I think it's a great idea.

Behrend: I love it. It's a little rough.

ABILITY: You have to have some body conditioning.

Behrend: You do have to be in condition, but that's true of anything you're doing. It's not something you just jump into. It's something you need to work on.

ABILITY: Where do you live?

Behrend: I live in Houston, Texas.

ABILITY: So most of your time is spent doing sports now?

Behrend: Yeah, and the Wounded Warrior Games. Anything I can get my hands on I try to do.

ABILITY: Tell me about some of the tattoos. You mentioned an owl earlier.

Behrend: I have a bunch of tattoos. This is one actually about my disease.

ABILITY: Tell me about the disease.

Behrend: It's called reflux sympathetic dystrophy (RSD). It's a malfunction between your brain and your limbs that causes the signals to be messed up, I guess. Normally it just causes a lot of pain. For some reason it paralyzed me. We're not really sure why, but here we are.

ABILITY: That tattoo is an image is what?

Behrend: It's a ribbon of fire. That's normally what you feel with RSD; you feel like you're on fire. The original ribbon is this orange ribbon with a fist with flames coming out of it. I had it made more personal to me.

ABILITY: The owl you were mentioning, for wisdom?

Behrend: Yeah, I have an owl on my arm to remind me to listen to the wisdom of those who have come before me.

ABILITY: What other ones do you have?

Behrend: Those are two of my buddies who passed away. The nickname for my disease is the "suicide disease."

ABILITY: I didn't know that. I've heard of the disease, but I've never heard the nickname.

Behrend: Yeah. The last study I read said that four out of five people end up taking their life. That's something I try to fight against.

ABILITY: Is that partly—

Behrend: —the pain.

ABILITY: —also connected to depression?

Behrend: Probably. Any major change in your life that takes away something you thought you were going to do can cause depression and anxiety. I can see how that would drive people to that. Unfortunately, it's a really rough road. But it's a disease that's not very well known. There's barely any research going into it. There's no treatment. What else am I supposed to do? I chose sports. Other people, unfortunately, haven't gone that way.

ABILITY: They need an owl on their arm. Any other tattoos?

Behrend: I have a tattoo on my ankle that says, "I heard you care about me." My little brother is autistic and he was in Hawaii and he wrote a note on the window of the car hoping I would see it. My mom put a piece of paper up to it and took a picture of it and sent it to me and I went and got it tattooed on me. (laughs) It's his handwriting.

ABILITY: Did he get to see it?

Behrend: Oh, yeah.

ABILITY: Does he understand it's his hand writing?

Behrend: Yeah. He's high-functioning. He's ridiculously smart. He's just a little socially awkward. He loves it. He thinks it's the coolest thing ever.

Behrend: Thank you. And on my ribs it says in French "Into your own life you bring the sunshine." It's to remind me to bring my own light to life. ■ ABILITY

rebellerally.com
controltheroad.com
gogrit.us

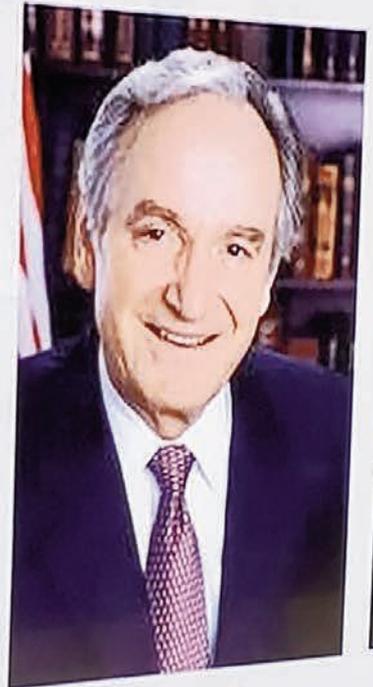
Driving Economic Growth Through As



Chet Cooper
Founder,
ABILITYMagazine



Dr. Gregg Vanderheiden
Professor & Director,
Trace R&D Center at
University of
Maryland



**Former
Sen. Tom Harkin**
Author &
Chief Sponsor,
Americans with
Disabilities Act of 1990

Vi
F
D
th

IONAL
CLUB

Assistive Tech & Workplace Inclusivity



Vinton Cerf
founder and
developer of
the Internet



Kim Charlson
Executive Director,
Perkins Library



Rob Wong
CEO,
Control Bionics

JOHN WILLIAMS

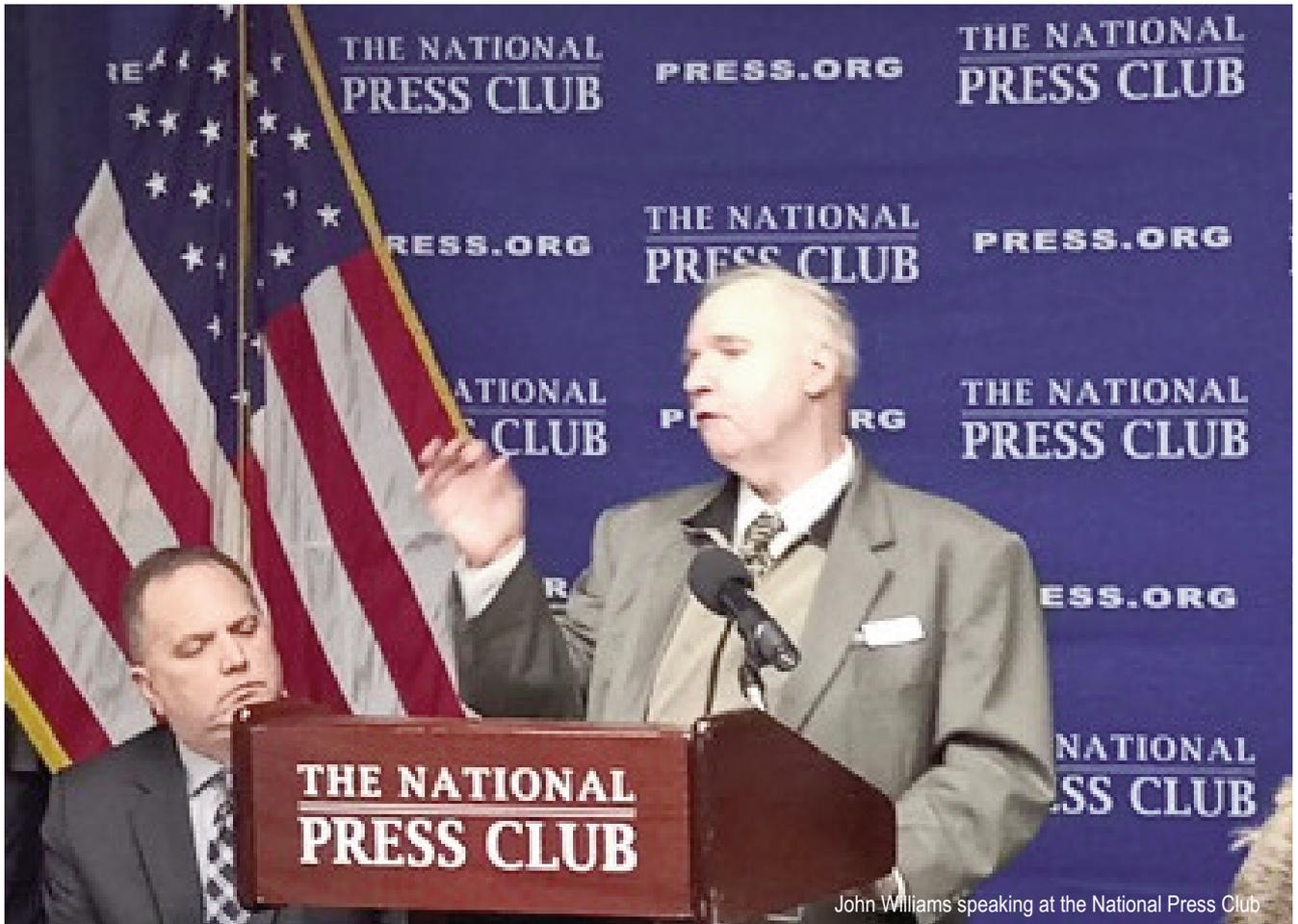
Gathering the Change Agents

During a recent, historical news maker's event at the National Press Club, former U.S. Senator Tom Harkin (D-IA), Vinton Cerf, Rob Wong, Chet Cooper, Kim Charlson and Gregg Vanderheiden discussed "Driving Economic Growth Through Assistive Technology and Workplace Inclusivity."

The country must find a way to significantly reduce the 11 million unemployed adults with disabilities in the United States. The disability population is the largest minority group in the United States.

Despite the strength of the U.S. labor market, persons with disabilities are strikingly underemployed. As of July 2018, only 29 percent of Americans with disabilities between ages 16 and 64 were employed, compared with 75 percent of Americans without a disability.

The speakers offered ideas to reduce the 11 million unemployed adults with disabilities.



John Williams speaking at the National Press Club

Their ideas were based on their past and present experiences in assisting people with disabilities secure employment. During the presentations it was evident that education, access to universally designed assistive technology and inclusion are the tools needed to get more people with disabilities employed. None of the speakers mentioned enforcing the Americans with Disabilities Act and other Federal anti-discrimination laws.

Harkin set the tone for the event. He called the 11 million unemployed people with disabilities a blot on America's history. According to Harkin, when President George Bush signed the Americans with Disabilities Act (ADA) on July 20, 1990, there were four goals associated with the law. The goals were full participation, equal opportunity, independent living and economic self-sufficiency. Harkin introduced the ADA to the Senate and guided it through the legislative process so the Senate would pass it.

Harkin said the country has done well in three of the goals, but in achieving economic self-sufficiency, the needle has not moved in 29 years. Wanting to put a positive spin on employing people with disabilities, Harkin cited data from a recently release four-year study by Accenture.

Headquartered in Dublin (Ireland), Accenture offers ser-

vices in communications, media and technology, financial services, products, resources, health and global resources.

New research from Accenture, in partnership with Disability: IN and the American Association of People with Disabilities (AAPD), reveals companies who embrace best practices for employing and supporting more persons with disabilities in their workforce have outperformed their peers. In large part, companies haven't leveraged the talents of persons with disabilities for three reasons: a lack of understanding of the scope of the talent available, a lack of understanding of the potential benefits, and misconceptions about the cost versus the Return on Investment (ROI) regarding disability inclusion.

The speakers unanimously agreed that the three reasons mentioned above are barriers to employing people with disabilities.

The report found that companies with a disability inclusion policy achieved tangible financial benefits. For example, the research shows that leading companies with inclusion policies, on average, were twice more likely to have higher total shareholder returns than those of their peers.

Despite the strength of the U.S. labor market, as of July 2018, only 29 percent of Americans with disabilities between ages 16 and 64 were employed, compared with 75 percent of Americans without a disability. In 2017, the unemployment rate for persons with disabilities was more than twice that for those without a disability—9.2 percent versus 4.2 percent.

The research also revealed employers achieved – on average – 28 percent higher revenue, double the net income and 30 percent higher economic profit margin.

The U.S. Office of Disability Employment Policy categorizes persons with disabilities as the third-largest market segment in the U.S., after Hispanics and African-Americans. The discretionary income for working age persons with disabilities is \$21 billion—greater than that of the African-American and Hispanic segments combined.

The speakers were policy makers, advocates, educators, and business representatives. They all have the same goal to increase education and employment opportunities for people with disabilities worldwide. Each provided their strategy.

THE AWARDS

Before the event started, each one of the six speakers received an award from people with disabilities. The money to pay for the awards came from about 80 people with disabilities. Each inscription on the award honored the recipient in their area of specialty.

THE POLICY MAKER

Harkin discussed the work of The Harkin's Institute for Public Policy and Citizen Engagement at Drake University, Des Moines, IA. Its mission is to persuade employers worldwide to hire people with disabilities in a competitive integrated environment. That is equal pay for equal work. Another solution is for employers to set a goal over a 10-year span to employ twice the number of people with disabilities working for them.

“If two percent of your employees have disabilities, hire an additional two percent. If the number is four percent, make it eight percent,” Harkin said. He has strong sentiments that doubling the number of employees with disabilities in a decade is doable.

The Harkin Institute for Public Policy and Citizen Engagement has sponsored four summits with more than 600 people from 50 countries attending. Harkin says, “The people from other countries who attended the summits left knowing that people with disabilities can be educated, employed and can compete with their able-bodied peers, Harkin emphasized.

Harkin is a strong supporter of people with physical



Mental Health Careers IN CORRECTIONAL HEALTH

Nationwide Opportunities Available!



Join our team and
make a **Difference.**

Apply Online

www.jobs.geogroup.com

The GEO Group, INC (GEO) is committed to providing leading, evidence-based rehabilitation programs to inmates while in-custody and post-release into the community.



Questions? Contact Michele Dobos
Toll Free 866 301 4436 ext 5863

EQUAL OPPORTUNITY EMPLOYER



Kim Charlson, Rob Wong, Gregg Vanderheiden, Chet Cooper and Vint Cerf

disabilities having access to assistive technologies. Assistive technologies are defined as “any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of a child with a disability.”

Assistive technologies eliminate physical and attitudinal barriers that for thousands of years have prevented people with disabilities from being included in their communities.

Harkin speaks from experience when he says that.

Harkin’s enthusiasm for assistive technologies creating opportunities for people with disabilities showed when he read an article that appeared in the Minneapolis Star Tribune about Almed Ali, a 21-year-old Somali American with Cerebral Palsy who is speechless. It was Almed’s dream to give a speech when he graduated from high school. How could he make the dream happen? With the assistance of a text to speech synthesizer, Almed gave the speech he had wanted to give for years. When asked how he felt about giving the speech, Almed said, “It was one of the happiest moments of my life.”

Harkin urged employers to familiarize themselves with assistive technology products. He suggested that employers consider the purchase of assistive technology as a capital investment and as a tax reduction; He encouraged the developers of hardware and software to make them so everybody can use them and not a select few who understand the intricacies of technology.

THE CORPORATE VIEW

Vinton Cerf is known as one of the two founding fathers of the Internet. He is hearing impaired and wears a hearing aid. He works for Google. As IBM, Google,

Microsoft, HP, Amazon, Verizon other companies move into the accessibility area, Cerf supports Harkin’s view that when engineers start developing hardware and software, they need to ask themselves: “How can I make this product useable for everyone?” Speaking from experience Cerf said, “I tell my engineers at Google that it is easier to make interfaces hard to use. It is harder to make interfaces easy to use.”

Cerf challenges some of the vocabulary used in the disability field. He would replace accessible with usability. To Cerf, usability implies technology can be used everyone. He favors changing the word disability to cool abilities. He believes the term disabled has a negative connotation associated with it. He is certain that if everyone in their life experienced a temporary disability and had to overcome physical and attitudinal barriers, they would have a more positive attitude regarding the challenges a person with a disability faces.

Cerf said that Google is working on developing usability products. He pulled out a handheld usability transcriber from his coat pocket and said, “This transcriber has recorded every word I said since I started speaking. It can do so in 70 languages” Transcriber Live was developed by a Russian friend who is deaf and is difficult to understand.

Cerf supports the inclusion of people with disabilities in the job market. He believes inclusion is good for the person with a disability’s self worth, the economy and country. He says, “People with disabilities who are working bring out of the box thinking to the job.” He sees them as problem solvers. He knows that many people with disabilities have started their own companies in the assistive technology field and are successful.

Looking to the future, Cerf sees the importance of edu-

cating people on new technologies. “If people don’t learn to use new technologies they will be left behind,” he said.

A forward-looking teacher, Cerf said, “The model we have today for living is learn a little, earn a little and retire. That model will not survive as the world becomes more technologically advanced. Learn a lot. Learn a lot. Learn a lot is the replacement. People must want to learn and learn.”

THE EDUCATOR

Starting where Cerf stopped, Dr Gregg Vanderheiden—always the teacher—and with 47 years of experience in the assistive work, strengthened Cerf’s comment on the rewards of learning about and mastering technologies. He commented on a serious problem “of our own making” that can only be eradicated by hardware and software developers making products usable by everyone.

Vanderheiden says, “People do not understand how to use modern technologies. This includes computers, cell phones and other communications devices. Today’s technology is too complex for most people to understand and operate. This complexity is creating an educational barrier even among the most intelligent people.”

A problem solver, Vanderheiden went looking for a solution that would make it easier for students to operate a computer. His solution is a program called Morphic. Morphic is an extension of a computer’s operating system. The program unlocks the flexibility, power and simplicity of a computer. A benefit of Morphic is you can take the settings with you and when using another computer. Vanderheiden believes we must start learning about tomorrow’s technology now and the technology must be universally designed so everyone can use it. He created the term Technology Quotient (TQ). TQ is applied to people who know and understand technology. He says people who understand technology will succeed and those people who don’t will not. This includes half the world’s population. He believes that as the technology revolutionizes, people will be spending more time learning.

Vanderheiden has been working with technology for people with disability for 47 years. He is a Professor at the School of Information Studies (School) and Director of the Trace Research and Development Center at the University of Maryland, College Park, MD. He is the principal investigator of the Rehabilitation Engineering Research Center on Information Technology Access.

THE ADVOCATES

It is quite possible that Chet Cooper’s name and face are recognized worldwide for his 30 years of advocacy work on behalf of people with disabilities. Cooper has been advocating for inclusiveness, housing and employ-



Williams and Senator Tom Harkin

ment issues on behalf of people with disabilities for three decades. He wants to eradicate myths and stereotypes associated with people with disabilities.

Creating a positive image for people with disabilities is one of his lifetime goals. Like Cerf, Cooper wants to see a more positive vocabulary when dealing with disability issues. Cooper believes that people hear the word disabled in so many different contexts, including the media with its repetition of “disabled” (disabled car, disabled truck, disabled link, and disabled bridge), that subconsciously they have developed a bias against disabled people.

His activism in raising the awareness of the abilities and needs of people with disabilities can be seen in many of his activities. In 1990 he launched *ABILITY Magazine*, which gave a fresh look at the abilities of people with disabilities. It continues to do so today.

In his speech Cooper gave examples of his efforts to persuade employers to look at a person’s ability and not disability. Cooper created a specialized career system for job seekers with disabilities so companies could find this untapped talent. In 1995, he assisted in creating the first employment website for people with disabilities called JobAccess.org/ABILITYJobs.com. Since its inception it has helped hundreds of thousands job seekers with disabilities connect with thousands of employers.

He also developed *ABILITY Awareness*, dedicated to enhancing volunteer opportunities for people with disabilities, showcasing employability. Cooper also co-founded *ABILITY Corps* expanding partnerships with NGO’s around the world. His activism can be emulated worldwide.

A BLIND ADVOCATE

Kim Charlson is blind. She is the executive director of the Perkins School, a division of the international NGO Perkins School for the Blind. She is recognized worldwide as a strong advocate for the blind community's right to be treated as first class citizens. She was the first woman president of the American Council for the Blind from 2013 to 2019. Charlson said, "The Perkins' School has long recognized the value of educating employers on disability issues and awareness. Eliminating attitudinal barriers are the most difficult barriers to eliminate. Education is the way to accomplish jobs and inclusion for people with disabilities."

The Perkins School has a number of tools to help people with disabilities obtain jobs. Charlson says, "One path the school has selected is working with Harvard Extension School." Perkins developed a 12-week, free education program titled Ed Ex. The program creates an awareness of disability issues that tell employers what they need to know in hiring a person with a disability.

Speaking from personal experience, she discussed the challenges facing her and other blind people when an on-line website is not accessible. Inaccessibility to websites means a blind person isn't able to find information needed to complete forms, apply for jobs or respond to e-mails. She uses a screen reader to carry out her duties. Without her screen reader, she would be unemployed. Screen readers are software programs that allow blind or visually impaired users to read the text that is displayed on the computer screen with a speech synthesizer or Braille display. A screen reader is the interface between the computer's operating system, its applications, and the user.

Charlson mentioned how important having the proper infrastructure such as buses and subway trains. It is extremely important for blind and visually impaired people to move around a city like Washington, DC. To ease travel for blind and visually impaired people, Perkins School developed a two-way communications device funded by Google, that takes a blind person within four feet of a bus stop. The program Blind Ways is being tested in Washington, DC in 10 Metro Stations and 20 bus stops.

As an advocate, she is working on legislation that will allow blind people to use an autonomous car. An autonomous car is a vehicle that can guide itself without human conduction. This kind of vehicle has become a concrete reality and may pave the way for future systems where computers take over the art of driving.

Charlson sees Blind Ways and the autonomous car as increasing independence and job opportunities for blind and visually impaired persons.

She echoed the opinions of the other five speakers that

in building a website you put accessibility apps at the beginning of the project and not later. She mentioned that the W3 and Access Board have guidelines on making websites accessible. She said accessibility to the web is vitally important for blind and visually impaired people in filling out job application, in securing other data.

As a blind person, she could not understand why Domino's does not want to make its websites accessible to blind and visually impaired people. She added, "Making their web sites accessible to everyone will increase their business."

THE BUSINESS VIEW

Rob Wong is the CEO of Control Bionics. His company manufactures the NeuroNode 3.0 Trilogy, combining touch, eye, EMG and motion control. NeuroNode Trilogy addresses the needs of people with ALS / MND, spinal muscular atrophy syndrome. He has seen technology change a person with a disability's entire life. He holds the opinion that technology is the great equalizer for people with disabilities.

Wong advocated getting assistive technologies into schools so children with severe disabilities can be educated and employed. His focus was on the results assistive technologies provide the user. Wong believes "A mind is a terrible thing to waste."

He is committed to developing newer, less expensive and easier to use assistive technology. Making technology easier to use will expand markets, create new businesses and unlock the ingenuity of people with disabilities.

The plans suggested by the speakers to increase jobs and inclusion can be adopted by anyone. It is important that people are working on programs to change the status quo. The speakers are certain that education, inclusion and access to usable technology will create opportunities for everyone.

I was also was a recipient of an award from the disability community for which I am thankful. ■ **ABILITY**

by John M. Williams

John M. Williams is an award-winning writer who has been writing about disability issues for 40 years. He coined the phrase "assistive technology".



NEW!

READY IN 60 SECONDS ELBOWS

1 pouch Barilla Ready Pasta
1 amazing lunch
1 "want to be just like Mom" moment

ALWAYS AL DENTE, ALWAYS PERFECT

60 Seconds to Wonderful



PERFECT PASTA IN 60 SECONDS

MADE WITH
3 SIMPLE INGREDIENTS: PASTA,
SEA SALT & EXTRA VIRGIN OLIVE OIL
FIND IT IN THE DRY PASTA AISLE



THE CHOICE OF ITALY®



ROAD TRIP!

Access to the Real World

Watching travel shows, or reading articles on vacation destinations can't take the place of being out in the real world. For many the open road has been an accessible challenge. According to the U.S. Census Bureau, 2012 report, there are around 3.6 million people over the age of 15 who use a wheelchair, with an additional 11.6 million people using a cane, crutches or a walker.

For the last four decades, RV buyers have approached Winnebago Industries to customize their personal coaches to make them easier to use for their family members using wheelchairs, or others who have special mobility requirements. While the company serviced their requests, Winnebago has taken their commitment a step further with a product line that addressed 40 percent of the total floor plans for accessibility.

A Win for RV Wannabes with Winnebago's New Wheelchair-Friendly RV Line

Winnebago now offers standardized floor plans with wheelchair lifts, roll-in showers, wider hallways and more.



Nerissa Cannon



ADAE 30T F2B Interior

For those who use a wheelchair or have special mobility requirements, it is now possible to visit a dealer and actually see and experience the vehicle, when in the past, every order was a custom order. Customers can see first-hand how these new Class A AE coaches meet a broad range of unique needs and requirements that allow mobility challenged individuals to begin or continue living the RV lifestyle.

A welcome and needed travel option for these individuals, Winnebago now offers three accessibility-enhanced motorhomes, the Intent 30R AE, Adventurer 30T AE, and Forza 34T AE. These three new Class A motorhomes are produced at Winnebago's production facility in Forest City, Iowa. All three offer standardized floor plans, and more importantly, these AE motorhomes are currently featured in the inventory at select dealer lots, including Lazy Days, Stoltzfus RV, and U.S. Adventure RV.

Real World Knowledge

To create the standard designs, Winnebago leveraged knowledge gained through fulfilling custom order requests over the past 40 years and designed these three standard AE models to accommodate the most common requests.

All floor plans feature a platform wheelchair lift with an 800-pound lifting capacity; expanded hallways; electric adjustable queen beds; thermostatically or remote-control roof vents; wall-mounted light and generator

switches; and lower installation of the systems monitor panel.

There was also a lot of thought put into providing greater accessibility in bathroom areas. Each model features a large roll-in shower with an assist bar and available folding bench seat; extended lever faucet controls and adjustable shower head; raised toilet with assist bars; and a roll-under sink.

The new 2020 models, introduced in September at America's Largest RV Show in Hershey, PA, now include remote controlled, air-assisted doors for wheelchair lifts. In addition, the new door provides an improved sound and thermal barrier. Should a power failure ever occur, this door can be easily opened manually. Additionally, the new Intent 30R AE includes a power Murphy bed providing additional living space when not in use, while the 2020 30T AE Adventurer boasts a sofa-bed, to accommodate additional passengers.

Beyond these standard options, further customization on a Winnebago AE RV is available, including bed and toilet height specification, placement of handrails, ceiling track system installation for mobility without a wheelchair, specific furniture requirements, cabinetry, and aesthetic changes.

Real World Experience

Regardless of the features, customer experience and satisfaction is the number one priority for the team at



Patrick Freeman inside their RV

Winnebago. These vehicles reduce the need for extra planning related to out of town or local travel, provide more options for service animals, and give owners comfort in knowing they'll always have a wheelchair-friendly bathroom and sleeping arrangement.

And for people like the Freeman family, the Winnebago AE was a literal life-changing method of travel. Always the outdoor adventurers, the family was dealt a tragic blow in 2013. Their 23-year-old son Patrick was hit by a car that was running a red light as he was crossing a Los Angeles city street. Patrick suffered a severe, traumatic brain injury and lost the use of his legs. The accident was devastating to both Patrick and his family.

After the accident, Mike Freeman and his wife Cheri moved to Southern California to support their son with his recovery and rehabilitation. Patrick's mobility issues, and the size of his wheelchair made any travel difficult, even with the accessibility van the family purchased. Long-distance trips proved extremely challenging and stressful. So, while taking care of his son and planning for future travel that could help support Patrick in his rehabilitation, Mike began searching for a vehicle that could more effectively accommodate their needs.

In March 2018, the family purchased a Forza 34T AE, which Winnebago custom-fitted with a motorized wheelchair lift, a roll-up door on the lift opening, and a specialized ceiling lift system to help Patrick move from one position to another. The Freemans also customized the bath with a relocated toilet and enlarged roll-in

shower due to Patrick's height; as well as customized bed placement with a power unit that raises the head of the bed so nurses can easily provide care.

Mike says acquiring the Forza was life-changing for Patrick and his family

"Before our accessibility-enhanced Winnebago, the thought of going on vacation was more stressful than just staying at home," said Freeman. "Most people take for granted the ability to hop in a car, plane, train at will to take a vacation, visit friends and family, or explore a new destination. Our accessibility-enhanced RV has opened up a wider and richer world for our whole family and even makes day trips easier. We can leave the house with confidence and excitement rather than anxiety and stress. I hope more people like us will discover their freedom and adventure with Winnebago's new offerings."

In the summer of 2018, the Freemans traveled in the Forza from California back to Indiana, where Patrick was born and raised, and where most of his extended family lives.

"Taking this trip in the Forza helped with positive life activities," Mike says. "Being back in Indiana, where most of our family is, and where Patrick grew up, he blossomed, his demeanor was better, and his cognition and ability to do things improved."



Nerissa Cannon & Kelsom Owens in front of their RV.

Last summer, disability advocate and outdoor enthusiast Nerissa Cannon took a trip across the United States in an AE Winnebago with her partner of two and a half years, Kelsom Owens. More than an RV enthusiast, Nerissa is well-known for climbing, and with the help of 27 friends and fellow hikers, climbed to the summit of the 14,000-ft peak of Mount Bierstadt in Colorado.

Cannon’s journey, from the Winnebago factory in Forest City, Iowa to the No Barriers Summit in Lake Tahoe, California, covered 2,300 miles, six states, three national parks, and multiple states and federal recreation areas. The No Barriers Summit is a multi-day festival that motivates individuals of all capabilities to give their best to the world through inspiring speakers and accessible recreation. Participants choose from dozens of adaptive activities that help them and their families break through barriers and connect in new ways with a welcoming and inclusive community.

Traveling around the country, Cannon says, forced her well outside of her comfort zone. Activities like kayaking, hiking, and rock climbing—both with and without the aid of her wheelchair—helped her continue to push the boundaries of what she can accomplish.

“I discovered that RV travel fosters a sense of closeness and community that is unmatched in other methods of

travel. One of the sweetest benefits on the trip was the togetherness and camaraderie I built with fellow travelers on the road. I often have uncertainty and a fear of being a burden on others, especially when I travel, but this innovative RV and the support and encouragement from the team at No Barriers allowed me to stand (pun intended) equal to those around me. In a world that doesn’t always feel designed for me, having a community of like-minded friends—and, on this trip, a comfortable place to inhabit while I adventured with loved ones—was priceless,” said Cannon.

Real World Innovation

“Our accessibility-enhanced customers are looking for the same freedom from home that many RV owners seek, and in many cases, the ability to travel is much more meaningful.” said Ashis Bhattacharya, Vice President, Strategic Planning and Specialty Vehicles. “RV dealers across North America count on Winnebago for superior quality and innovation, and we look forward to making these options easier to stock and obtain as we understand options for accessibility that are available to drive off the lot are hard to find in the broader industry.” ■ ABILITY

by L. Ann

winnebagoind.com/product-classes/accessibility-enhanced



The key to this motorhome can unlock a world of possibilities.

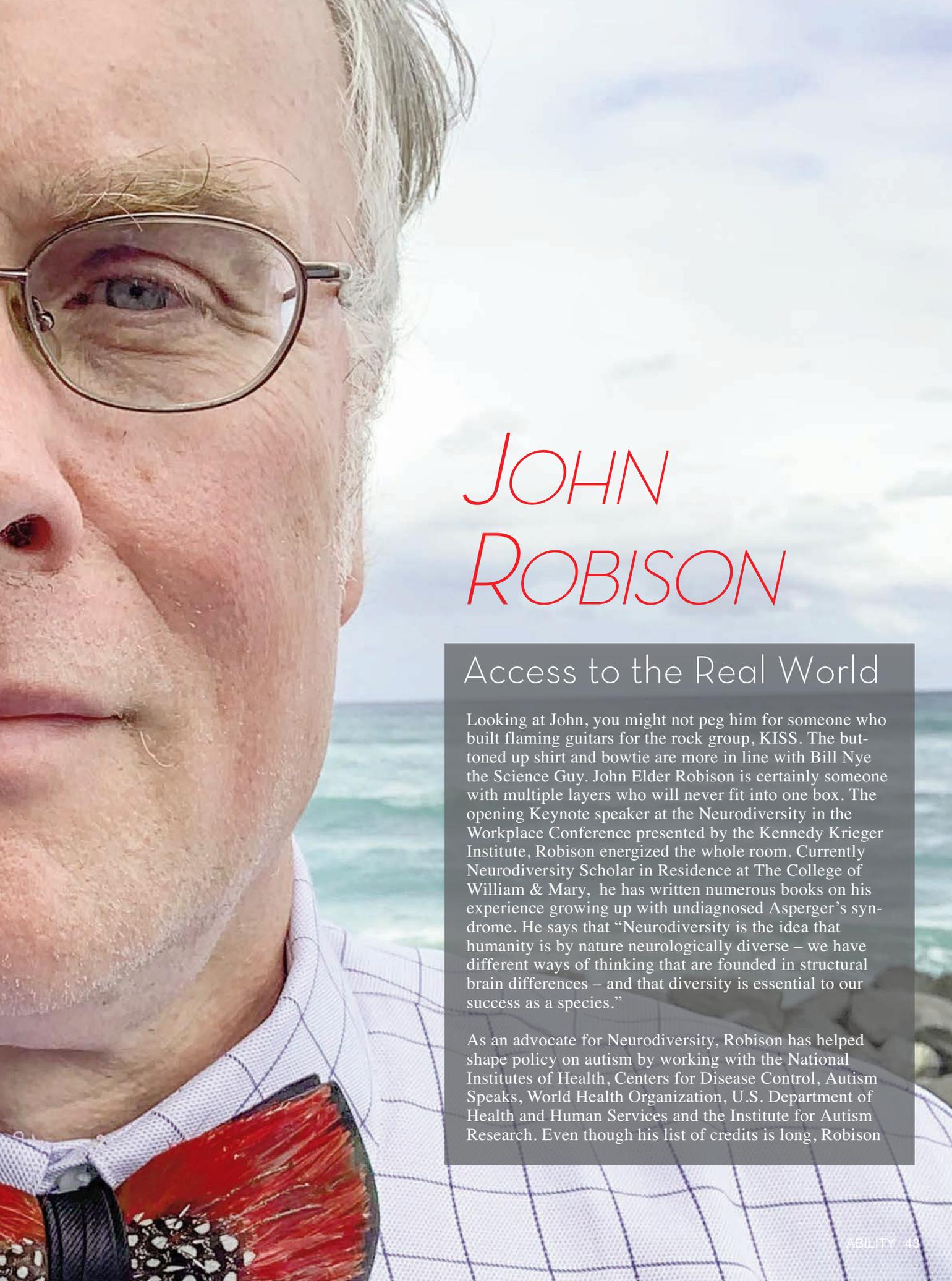
Winnebago's Accessibility Enhanced motorhomes offer wheelchair travelers exceptional comfort, with thoughtfully designed living spaces and features that make travel more enjoyable and day-to-day living more effortless.

With plenty of room, comfortable furnishings, a full galley, and your own private roll-in bath, they also serve as a quiet retreat when you arrive.

Learn more about
Winnebago's lineup of
Accessibility Enhanced
motorhomes here or
call 800-492-9135.







JOHN ROBISON

Access to the Real World

Looking at John, you might not peg him for someone who built flaming guitars for the rock group, KISS. The buttoned up shirt and bowtie are more in line with Bill Nye the Science Guy. John Elder Robison is certainly someone with multiple layers who will never fit into one box. The opening Keynote speaker at the Neurodiversity in the Workplace Conference presented by the Kennedy Krieger Institute, Robison energized the whole room. Currently Neurodiversity Scholar in Residence at The College of William & Mary, he has written numerous books on his experience growing up with undiagnosed Asperger's syndrome. He says that "Neurodiversity is the idea that humanity is by nature neurologically diverse – we have different ways of thinking that are founded in structural brain differences – and that diversity is essential to our success as a species."

As an advocate for Neurodiversity, Robison has helped shape policy on autism by working with the National Institutes of Health, Centers for Disease Control, Autism Speaks, World Health Organization, U.S. Department of Health and Human Services and the Institute for Autism Research. Even though his list of credits is long, Robison



John Robison and Kiss lead guitarist Ace Frehley

didn't learn of his Asperger's syndrome until he was 40. At age 62, he shows no sign of slowing down—his writings have been translated into 18 languages and sold in over 70 countries. The ABILITY team sat down with Robison in Baltimore to discuss everything from advocacy to guitars to cars.

John Elder Robison: I just was observing that you're a full-spectrum disability magazine and group, and most of what I have worked in is advocacy for neurological differences that contain components of disability. So the neurological things in my family are autism, ADHD, anxiety, depression, epilepsy. I have lifelong personal familiarity with that but like a lot of families with neurological differences, we also have physical disabilities and challenges, things like—well, epileptic seizures are a leading cause of death for autistic people. We can die in our sleep from undiagnosed seizures. Many of us live with chronic intestinal pain. Many of us, like me, have joint problems and mobility problems. Actually, I didn't even know that those things would rightly be called disabilities until I learned about my own autism and learned that medical complications like that accompany autism, because when you hear about autism, you hear that a person with an autism diagnosis has a communication dis-

ability. But you don't really think that such a person might live with chronic gut pain. How would you think that? I guess I'm continuing to see that.

Chet Cooper: How did you get involved with NIH?

Robison: Well, I started speaking in public after I began writing about life with autism. A scientist from NIH asked if I would like to serve on a community advisory board to advise NIH on the direction of autism research. That was back during President Obama's tenure. He had pushed NIH to involve more members of the affected communities in guiding research for those communities. In other words, to have folks who lived with a stroke to advise on stroke research, folks who lived with autism to advise autism research, folks who live with anything else that we're researching to help advise researchers not on which piece of science seemed better, but which proposed pieces of research were potentially meaningful to the community. And also about whether the research was constructed in such a way as to be accessible and respectful and so forth with the community. Those concepts were just evolving.

Cooper: So, a little bit of a nothing-about-us-without-

us concept?

Robison: Well, no, it wasn't that at first. At first, the idea was for affected people to guide doctors and scientists who would figure out how to help us. And from that, I was asked to join other committees and eventually we got to a point of myself and other autistic people writing our recommendations for what we believed the government should be researching into a strategic plan for autism for our country which in turn guides our public health agencies and other researchers. So at that point it became nothing-about-us-without-us, with autistic people not saying, "I agree with this proposed thing that you want to do for us," but autistic people saying, "This is what I think our country should be doing to support autistic people." That's nothing-about-us-without-us.

Cooper: Because it's such a spectrum, how do you engage those people on one part of that spectrum who have a very difficult time communicating and difficult times with their own bodies and how autism is affecting their person?

Robison: Well, over the last 20 years, I've gotten involved with a number of groups, autism schools, programs, workplaces. I've spoken at many, many schools, universities, and other organizations, and I meet autistic people of all stripes wherever I go. So sometimes I'll see an autistic person who might not speak in words, but that person might raise their hand or smile at me in solidarity with the words I say. Sometimes a person who doesn't speak in words might type a message to me on an iPad and the iPad will say it to me, or they will type it on a screen and I will read it. And then of course people say, "Well, I'm here with my brother, and both of us have autism, and my brother doesn't talk so much, but I do." And then of course I talk to parents and I talk to teachers, clinicians, all kinds of people. The autism community is all sorts of folks, and I do my best to discern the general concerns in the community from what I hear and what I see.

I feel that as a representative of the autism community before the government, I was appointed by the Secretary of Health and Human Services to represent autistic people. I wasn't appointed to represent people like me or people with certain values. It's not like an election where the public choose you based on your views. I was chosen because I am autistic to represent autistic people, so I take that seriously and I do my very best to allow all voices and points of view to be heard before the government, whether I agree with them or not.

Cooper: It's always a challenge in my mind to try to truly give a voice to such a broad spectrum of stripes, as you say.

Robison: The thing that's challenging about autism is that you have a very broad spectrum which extends from difference in eccentricity to profound, total disability, and you have a range of accompanying effects where some people with autism diagnoses do not seem to have other medical complications. Then there are people like me who have an autism diagnosis and are not aware that something like chronic intestinal trouble is a common co-occurrence of autism. And finally, there are people who are profoundly physically disabled by conditions that accompany autism. So it stands to reason that those folks, with such a great range, are going to have very different wants and needs. They might all say, "I want support and acceptance," but "support and acceptance" might mean something very different. "Support" for one person might be counseling about relationships or executive function, where "support" for another person is protection against life-threatening seizures.

And of course, the first person might not be affected by seizures at all. If you said, "What do you need?" to one or the other, they could say something totally different. And yet they all need support. That means that our obligation as a society is very, very broad.

Cooper: Prior to your starting to speak and write about autism, what were you doing? What's your trajectory? Where have you been?

Robison: I grew up with autism before it was recognized in folks like me, who were articulate and verbal. In school, I was put in language lab to repeat phrases endlessly. to improve my speech. I was put in counseling for emotionally disturbed kids because "emotionally disturbed" was the word for autism, OCD, and such back in the '60s. But I attended the same social studies or math or English or whatever classes as everyone else in my school. Now, instead of putting kids in programs like I was in, people are put into this whole "special ed" track. Special ed can mean that you are with a bunch of kids for whom collectively the teachers have very low expectations, and you're ridiculed by the other kids who aren't in special ed. And the last thing you want is to be in special ed, you don't want anything to do with it. That's an example of how we are singled out and treated worse than in my day in school. And that's, I believe, a mistake that we make in the conduct of special ed in America. I don't think we should have special ed. I think we should have accommodations as people need them. But I think that to the extent possible, everyone should be together.

I ultimately couldn't complete school, so I left and went out on my own. First, I worked in music and engineering, and I worked a bit in industry, and then I started a business repairing and restoring cars. It was at the business where I learned the social skills such that a person who came in once, I could talk to them



and be pleasant enough that they would come back twice.

Robison: I got to know some of the clients who came to our business, and one of them was a therapist who, after talking with me over a number of years, said, “I wonder if I should even say anything to you because you’re a successful guy, but you’ve told me so many times how you feel like you’re outside, in the dark, in the rain, looking in at all the people in society and you don’t know how to be inside. There’s a name for that. They’re just starting to talk about it.” This was in the 1990s. He said, “It’s called Asperger syndrome, it’s a kind of autism.” And I was frankly stunned at that. I had no idea. But then I read the descriptions in a book on Asperger syndrome, I realized that it absolutely fit me. Not looking at people when I talk to them, not understanding body language, standing too close, standing too far, walking away when someone was talking. Even my fixations with trains and boats and machines, all those things turn out to be characteristic of people like me. And people like me, I read, are a large group. There are a lot of us.

So, for the first time I had a non-judgmental explanation of why I was different, and that made me start to think that there must be thousands of young people growing up just like me. I never knew why I was different, and it would be valuable, I thought, if somebody who was my age could speak out and say, “Hey, you might feel like you’re a failure in school, as I did when I was 16, but you can grow up and you can be

OK. You can build a business, and maybe you won’t feel like you fit in a regular workplace, but I built my own workplace, and I fit in fine.” And I think that was a valuable thing, and that’s what started me on the road to advocacy. I felt that with me, the stuff I was doing, fixing cars in a small city in America, anyone can fix a car. You might think, “Well, I’m not going to grow up and go to school and do this fancy thing,” but no matter where you live in America, you can fix a car. So, I thought that that was a relatable thing.

Cooper: What about the Amish country?

Robison: What about it?

Cooper: They don’t have cars.

Robison: Well—

Cooper: (laughs) You’d be fixing buggies, probably! You’d tinker with something.

Robison: I guess if you ask in seriousness what about an area where they don’t have cars, I was always interested in machines. Cars are of course a really visible machine. Everyone in most parts of America is around those machines. If I was in an Amish community as a boy, I expect the machines that would have fascinated me would have been the wooden and metal workings of wagons, the mechanisms of water wheels, the mechanisms of plows and harrows. My great-grandfather was the county agent in Gwinnett County,

Georgia in the Depression. Before he taught me about cars, he taught me about farm machinery.

Cooper: Nice!

Robison: And the Amish absolutely know farm machinery. I would say that my early gifts were understanding machines. So yes, I said “cars,” because every city has cars. But it’s also true that every city has machines, and a person who has an affinity for machines can find a place anywhere.

Cooper: Right, right. Have you heard of the institute Exceptional Minds in LA?

Robison: No.

Cooper: All of the students who come in to train are on the spectrum. They train animation and video production—

Robison: Oh, yes, I’ve read about that, yeah.

Cooper: They’ve found that there’s an affinity to a large group of people with autism and Asperger’s who like that kind of thing. You’re saying your affinity is mechanical machines. These folks—and I’ve seen some of their work, and it’s—

Robison: Yeah, there are folks who do computer graphics and design and stuff. That’s another area where a lot of us can excel. That’s definitely true.

Cooper: Was the auto business you created a one-man shop? Did you have a place where there were multiple mechanics under you?

Robison: It was a one-man operation in the garage next to my house 35 years ago. Today it’s five buildings on two and a half acres, and there’s a bunch of people doing all kinds of different things. I’m here talking to you in Maryland, and the car company is back home running.

Cooper: What do you look at right now in your future? What do you see yourself doing from now through the next five years?

Robison: I hope that I can retain good health and continue to be able to go and speak, because I think that the message of neurodiversity and inclusion, as you said, the idea of nothing-about-us-without-us, is really important, and I think it’s important that older people stand up and speak for that as well as young people. I’ll do my best to continue doing that.

Cooper: Did you look at our emoji quiz?

Robison: I did, yeah.

Cooper: Did you try it?

Robison: Yes, and I saw somebody wrote “Burger King” and I thought “cheeseburger,” and I wondered how “burger” related to the crown, but I do see how that would be. What’s this emoji?

Cooper: That one turns out to be “popcorn.”

Robison: Oh, What’s this? Sun ___?

Cooper: Close. “Solar power.”

Robison: And—

Cooper: “Coffee break.”

Robison: Oh, yeah. I guess I look at these things and people send messages with these emojis on phones, and my own phone has a screen with a hundred of them, and you know, I kind of don’t use them. It’s one of those things I think being autistic that I think of this kind of stuff literally—

Cooper: Exactly.

Robison: So I look at what this is and it was not clear to me what that is intended to depict, and therefore I don’t know that I’d have thought “popcorn,” but I imagine if I learned the meaning of the emojis and I started to learn the pattern, I would be able to solve a problem like that. But right out of the box, since I don’t use them, I think I interpret what I see literally in the context of my own life, and I guess I don’t do it right.

Cooper: The emoji phenomenon, it’s kind of a form of language. They’re using emojis for people who are non-communicative, who have dementia. They’re realizing that they’re able to create these emoji sequences to communicate with people who have become nonverbal.

Robison: You have to hope that what you read as the communication is the same thing that they intended.

Chet Cooper: This one is “No time for bullshit.” What about this? “Drink, drink, drink, eat”?

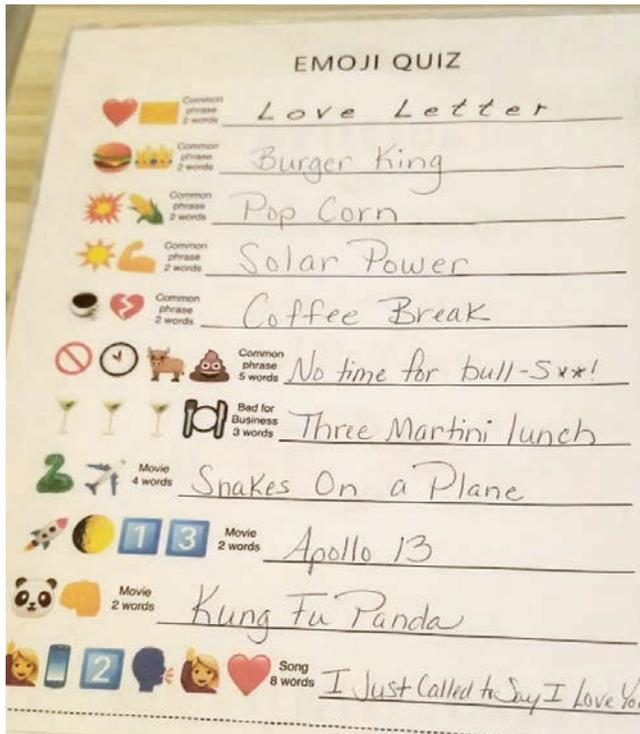
John Robison: This is three-martini lunch.

Cooper: Perfect! Do you know how many people do not get that? And this one, you know what that is?

Robison: Is that a panda bear?

Cooper: Yeah. So the movie is “Kung Fu Panda.” Do you remember that movie?

Robison: No, I never heard of that.



Cooper: It was a cartoon. This is a Stevie Wonder song.

Robison: Uh— (pause) I don't know.

Cooper: "I just called to say I love you." Which is tough. Myself, I wouldn't know that that meant "I." They say it's universal, but it's also female, so that word throws me. I don't get that. I get the phone would be "call," and then "to," and then that would be "speak" or "say," and then back to "I" and then "love."

Robison: My wife says that I don't have much of a sense of popular culture. I guess I don't know that I associate things with any movie names, I don't really watch movies.

Shelly Rohe: Is there a difference for songs since you were involved with music?

Robison: Music and movies. Music is a thing that if I was working, putting equipment together, running sound equipment for a show, I had a job I focused on to deliver clear sound for the audience. I wasn't out there, I wasn't trying to meet people or dancing or things like that. I had a job to do. I was very focused, and that's what I did.

Rohe: In your talk, you said you engineered equipment like guitars based on how an artist wanted it to sound. You could visualize the sound?

Robison: Yes, like when people told me about wanting a certain kind of sound effect, I imagined what would

be an electrical circuit that would make the effect that they wanted, and I would build those things, and then I would have people try the prototypes out and see how it sounded, and we would modify them until we had what we wanted. And that might have been a sound effect in a box or something that was built into an instrument. It might have also been an attribute of a big concert sound system. But when I was at a show when something like that was being tested, I would be really concentrating and listening to the thing at hand and seeing if it did what I expected it would do. And also, of course, that it didn't just blow up in the middle of a show.

Rohe: Did that ever happen?

Robison: Yeah, sometimes it happened, yeah.

Cooper: But it was a good sound, though?

Robison: Sometimes the equipment would break. With our main sound systems, we would have enough amplifiers, enough speakers, that you could lose one or two or even 10 or 20 in a big system and the audience would never know. And yeah, that would happen. We would blow equipment during shows. You would always have to either be prepared to run without it or change it out at an instant's notice, and that's why you were always—even if you seemed to be just standing at the side of the stage, you were ready to jump up there in a second if it stops working. And you never know when that will be. It's like a guitar, if you break a string, you've got to jump up and hand the guitarist another guitar.

Cooper: When you were doing prototypes, did you use equipment you knew and modify it, or did you literally write the mathematical formulas of sound waves?

Robison: At first, I modified equipment that existed, but then I began building things from scratch. Later stuff I did was equipment I just made out of parts, out of nothing.

Cooper: How did you know what was going to come out? Was it a mathematical formula? Parts you knew had certain sound connections to them?

Robison: I knew that various components had certain attributes, and I imagined that if I strung them together in a particular way, they would do the thing that I wanted. And I would build them and see if that was true.

Cooper: Did you build guitars, too?

Robison: I didn't craft the structure of the guitar to play, but I built electronics that went in the guitar that shaped its sound. In other words, I was an electrical engineer and not a luthier. A luthier would be a person

abilityJOBS.com

The leading website dedicated to employment of people with disabilities. It also has the largest resume bank with tens of thousands of job seekers with disabilities, from entry level candidates to PhD's. Join today.

JOB SEEKER

EMPLOYER

who would make a guitar or ukulele or whatever. I didn't do that. I put electronic guts in them.

Cooper: So you had existing guitars, whether Fenders or whatever.

Robison: Or Les Pauls or Stratocasters or Telecasters or Gibson EB-3s or Fender Precision Basses or whatever it might be.

Cooper: Did you ever go to any of the factories, like the Fender location?

Robison: No, I never went to Fender or Gibson, no.

Cooper: We did an article on Fender's life, which is in Fullerton, California.

Robison: Yup, I remember that. Fender Electric Instrument Company, Fullerton, California, yup. It was Leo Fender, right?

Cooper: Right. He had a disability.

Robison: He did? When I was doing that I didn't know anything about disability. I was just making my way the best I could. My awareness of disability is relatively new. I always just did the best I could. I always assumed that other people could do stuff better than me. And I believed that I was like a second-rate person, because other people could do stuff better than me. I understand today that that's an unhealthy way to see yourself, but that's how I and probably a lot of people saw ourselves if we grew up and weren't able

to do what other people could do and we didn't have friends and we didn't have academic success. That's how I imagined myself. But if you had called it a disability understanding, I don't know that I'd have known what you were talking about. I didn't make that association until much later in my life.

Cooper: Where do you live?

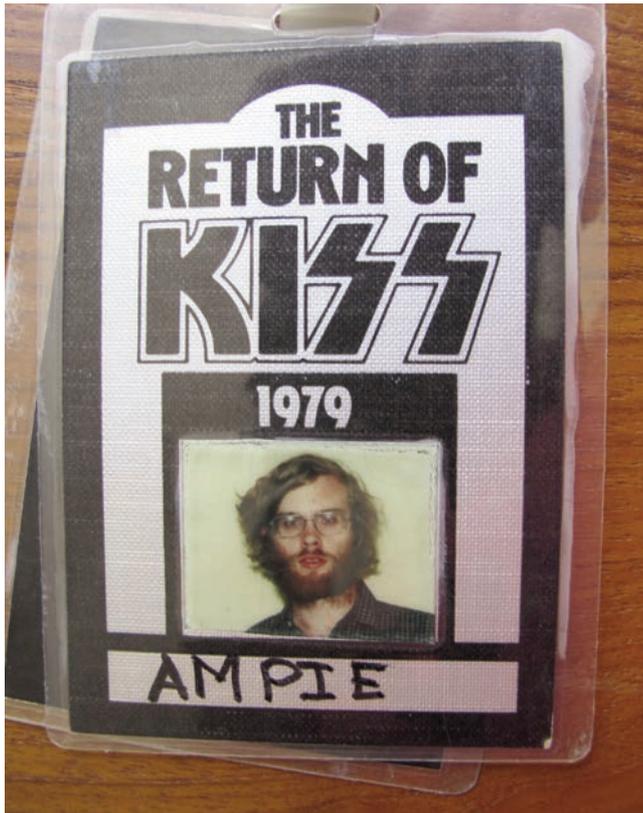
Robison: Amherst, Massachusetts.

Cooper: So you have to deal with the seasons changing?

Robison: Yes.

Cooper: You said you have five buildings now? Each building has separate bays?

Robison: Well, the buildings do different things. We have general service and repair for Mercedes, BMW, Jaguar, Land Rover. We service Mercedes Sprinter commercial vehicles and Ford Transit commercial vehicles. Then we have another business with us that does state inspections, another business that does front-end alignments. We also have part of the backup 911 ambulance response capability for our city. We have our room in our complex for—at this moment it doesn't, but we have held up to about 20 ambulances, so we respond to emergency calls out of there. With all those things, because we're an emergency response center for our city, we never close. So if we have blizzards and the roads are closed for snow, we are not closed, because you always have to be able to get the ambulances out. We have plows and snow removal



and folks who take care of the buildings. We do a much wider variety of things than just the fixing of cars that I started with. But it's all related to motor vehicles.

Cooper: Have you thought of hiring people with disabilities when you look for new employees?

Robison: We do. For five years we had a state-supported program to teach the automotive skills to folks with developmental disabilities. We've employed people with cognitive disabilities and autism and ADHD pretty consistently over the years. Not because we have gone, say, to the state and said, "We want help bringing people like that in," but because I'm a neurodivergent person, my son, who's worked there some, is. It's just how we think. We gravitate towards people like us, I suppose.

I think that if you identify in a certain way, you're going to probably have more of those folks. If Judaism's a big thing in your life, perhaps you employ Jewish people because you think, "I'm going to give them opportunity in my community." For myself, as a fellow with autism, ADHD, dyslexia, and such in the family, I'm comfortable with people who are like me. For somebody else, we may be different, but for us, we are us, you know? And so that's how I see employment like that.

And I think that it's important to note that other people who come to work there who either don't have disabilities or don't have the same disabilities, ulti-

mately everyone has disabilities at various points in their lives. And I think for them to come there and see somebody like me who runs it and is not just a—is not working there with somebody accommodating me, if you want to be there, it's my establishment, and it's my rules. And that's very different from asking employers for accommodation. And I guess I feel like many people who are different, whether you call it disability or they're different for some other reason, we do well in the trades. Because frankly, you do not care about a person's conversational skills or how they look or how they walk if your toilet is clogged up and that person can unclog it and that is the job you want done. If your car is broken by the roadside, you want your car to drive again. And if you want cabinets made for your kitchen, and guy you might describe as weird or strange or whatever, if that fellow can make beautiful cabinetry, beautiful cabinetry is the thing you'll remember for the next 20 years. When we make our own place, we're not asking for accommodation. We're just being like everyone else. And to me, that's what inclusion's all about. It's about, like, in marriage, right? If you marry somebody and you're in good health and you have a stroke or an injury and all of a sudden you're disabled, you don't expect your wife will leave you.

I feel like it ought to be like that in the workplace. If someone has a disability in a workplace, there shouldn't be any question that they still have a home in that workplace. And of course, that's not true in a lot of America, but if you're a person who lives that yourself, if you're the owner of the business, you probably would understand that with people who work for you. I guess I just wish, recognizing that everyone is disabled at some point, that that was a broader thing. I look at companies that measure employees by how many steps you take an hour. You might think all these people can do this when they're 20 years old, but what are they going to do when they're 60? Will you just toss them out? Because everybody ultimately won't do those kinds of things. And I feel like that is an area of social policy where we have a long way to go.

But small businesses speak to that. A guy who runs a hardware store is not going to change somebody out because the guy's been with him 20 years, and when he came in, he was young and spry and now he's old and slow. A company that doesn't have a person who's—it's just like a big faceless corporation, you do see people pushed out for that, and I think that's wrong. So I guess I just try to speak about all these ideas, but my understanding of these things as disability advocacy as opposed to just doing what I thought is the right thing, that is new to me.

Cooper: You were saying that you were first board member of INSAR to have autism. Can you talk about that?

Robison: Today I'm involved in autism science, both in my roles advising government organizations on autism and neurodiversity and policy and directions of constructive research. I'm also a member of the board of INSAR, the International Society for Autism Research, which is the professional society for autism researchers.

Cooper: What does it do?

Robison: INSAR publishes a journal, Autism Research, a professional, scientific journal. We put on a conference where scientists present research and discuss it and we disseminate scientific knowledge about autism. We promote scientific standards and best practices in the conduct of research. We try to create an organization that people will want to join. We hope that grad students will see the promise or reward of a career in autism research and they'll join as student members, and then they'll become early career members, and then they can become older members and ultimately fellows of INSAR. We try to be an advocacy organization for people who are committed to autism science.

Cooper: I'm sure you're asked this often, that it comes up in some form, about what your thoughts are or what science is saying on vaccination.

Robison: We haven't really found a connection between autism and vaccines in the ways that people have alleged. However, it's my experience in public advocacy that you can't change a person's belief. You can't take it away from them, but you can give them something they think is better to believe. Maybe they think it's better because they think it's more accurate, maybe it fits their understanding better. When a person who says to me, "I believe my child was injured by vaccine," I've learned that for me to say, "Well, science says you're wrong," isn't particularly constructive. It doesn't change their mind. It leads to an argument. It doesn't accomplish much. If I say that, they say, "OK, why is my child autistic? Why did this happen?" And while I could say, "Your child's autistic because some of us are born this way, and there's good evidence for that," that's true. But we also have scientific papers talking about how the incidence of autism is greater if you live within one mile of a California freeway, if the father is over 40 at the time of conception, if the mother contracts certain strains of flu during pregnancy. Autistic behaviors can be mimicked by lead poisoning, by mercury poisoning.

A parent hears all these things, and you can't blame them for saying, "That doesn't sound like inheritance to me." Unless we have answers, it is very hard to combat supposition or belief. We need facts to do that. Frankly, we're not there in understanding the tremendous complexity of how neurological

divergence emerges. There's no question that some of us are born different, but there's also no question that some of us are different through injury, through trauma, through all sorts of factors. And I guess what I say to somebody who says, "I believe my child was injured by vaccine," if I say, "I don't believe that I am injured by vaccine. I'm an autistic person. I don't think it's my place to tell you what you said believe about your child, but what I do hope is that you will join me in agreeing that we want to work together for the best quality of life for all autistic people, for your child, for me, for my autistic child. We should absolutely be together and in solidarity that we want the best services and supports and the best opportunities for all autistic people to live their best lives." How we came to be how we are should not matter. That's not part of the discussion about a best life.

Cooper: That's a nice response. My only issues with vaccine is that it does affect others. Measles is an example. If people are not vaccinated—

Robison: You know, that's true, but many things that we do affect other people, and I feel that for a lot of people, belief in vaccine as an agent of injury is like an article of religious faith. Unless you can give a concrete, acceptable answer for why a person should believe different, I don't think you can change that person's belief.

Cooper: There are consequences for those beliefs.

Robison: I do understand that, but I feel that I have to look at—as a public advocate, where can I build consensus and achieve the best result?

Cooper: I think you're right on.

Robison: And I believe that I'm on a good track, that working together for the best outcome is a thing we can be a team on. We don't have to agree on where we believe it came from, on where it's going except insofar as we want it to go to a better place for those of us today. ■ ABILITY



MARILEE

talkington

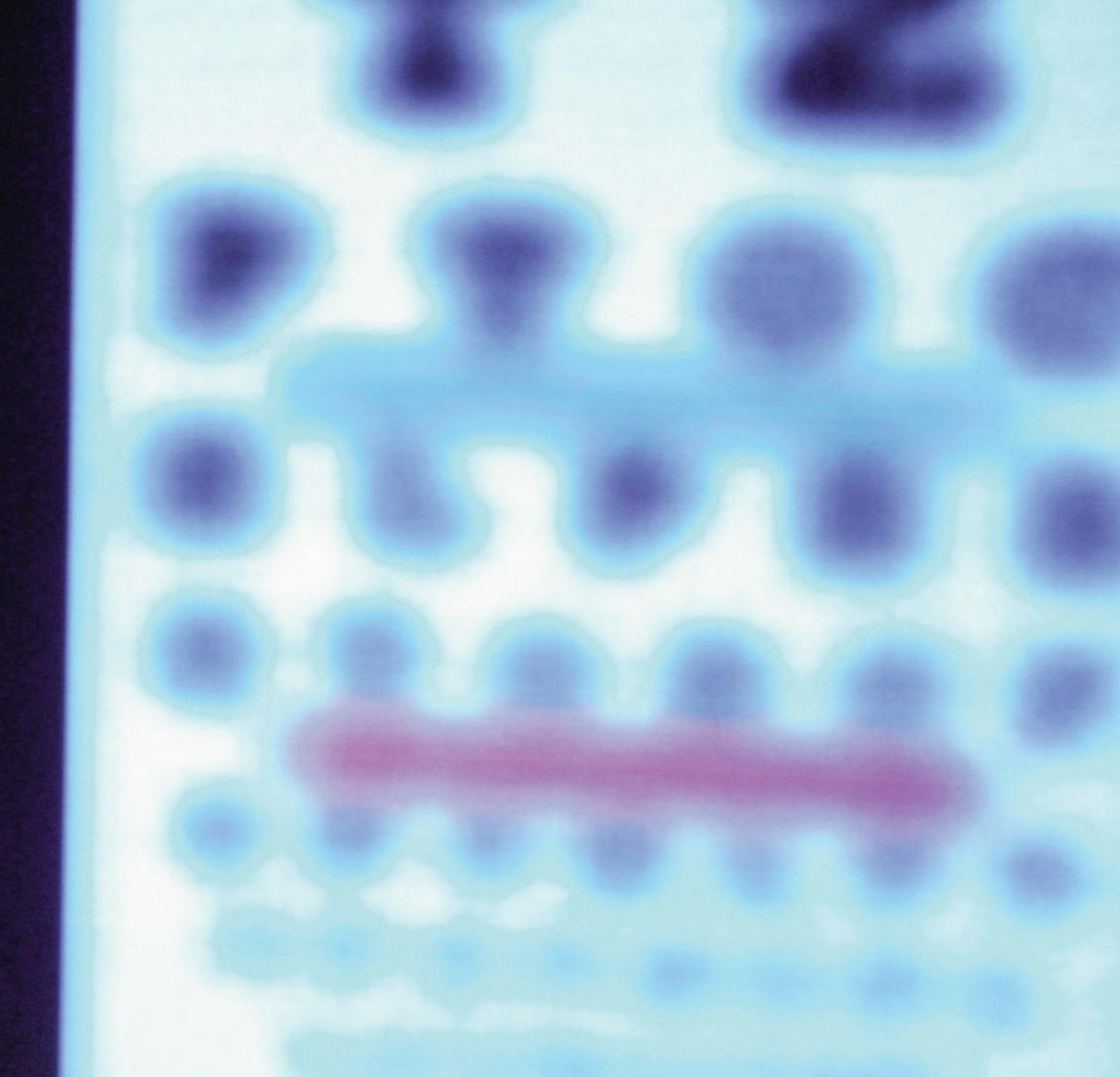
a clear vision to advocate



Marilee Talkington is one of just a very few legally blind actors in the country to earn an M.F.A. in acting. She earned her M.F.A at the prestigious American Conservatory Theater (A.C.T.). She has worked professionally in the theater for over 2 decades. Her break out TV role was Annie Barth, a blind woman, on “NCIS”. You can now find Marilee on Apple Tv+’s futuristic post-apocalyptic drama, “See”, where she stars alongside Jason Momoa from “Game of Thrones”. In addition to acting, Marilee is also a writer, director, teacher and designer. She is also known for her protest art and installation art. Marilee has become a strong voice for actors who are blind and low vision. She is one powerhouse of a busy talented woman.

ABILITY Magazine attended the 2019 Media Access Awards in Beverly Hills. The annual MAA in partnership with Easterseals honors the TV, film, and new media professionals who have helped to create and promote opportunities for those with disabilities in the industry. The awards include writing, producing, casting, performance and directing. The night was full of Hollywood glamour including a red carpet, evening gowns, celebrities and fancy hors d’oeuvres. At the end of the evening Melinda Chilton and Shelly Rohe sat down to chat with actress, Marilee Talkington. Meeting her was both empowering and enlightening.

Melinda Chilton: You live in New York right now?



Marilee Talkington: I do live in New York right now.

Chilton: So you've come to where it's a little bit warmer?

Talkington: Oh, my gosh! Yes! It actually started to dust. It was snow-dusting right when we left. It was cold. And it's so great, because we've got a fireplace on our television. We put on the YouTube Yule log, and it's so perfect. (laughter) It's crackling and you can check the one that's 15 hours long and you can leave the house and leave the fire going until you come back.

Shelly Rohe: How long have you lived in New York?

Talkington: This time, three and a half years. I was there

right after grad school. I got my MFA in acting from ACT, I graduated in 2004. I believe, I'm still one of only two legally blind actors in the country with an MFA in acting. I was really proud about that in 2004, but it's 2019 and that should have changed.

Chilton: How would you have liked to see it change?

Talkington: There should be so many more of us, just quite simply. There should be many, many, many more.

Chilton: And why do you think there isn't?

Talkington: Oh, fear, deep fear, and the stigma, especially



Talkington on stage

blind and low-vision actors in particular. We're the least represented of the disabilities. And even when you have a group of actors with disabilities in a room who are doing training, often the blind and low-vision actors are still excluded even from those exercises, because everything is steeped with visual bias. I think that the reason I got in and this other woman got in is, we can pass. I can pass as sighted. You wouldn't know. If I didn't have this (her cane), you wouldn't know.

I was born with rod cone dystrophy, so I was born totally blind centrally. I have no central vision. I only have peripheral vision, and I've been losing that over time. I'm light-blind, so if there's too much light I'm total. Folks with my vision will usually talk to you like this. But, what I'm doing is looking to the left of you, just so I can catch you in my peripheral vision. But I'm looking at you. So this is what confuses people. I make eye contact, to the best of my ability. But, that's because my mom is blind and I have the same thing that she has. I have a very vivid memory of fifth grade. What is that, like, 10 years old?

Chilton: It's about 10 or 11.

Talkington: She gave me—you know, when you have a disability, you get the talk. When you're "other," you get the talk. This was one of the first talks she gave me. She said, "You have a choice. You can either look at people the way you need to look at them to grab information, or you can look them in the eye. Teach yourself how to do that. If you look at people the way you need to look at them, they will treat you differently. That's how the world works." And it's true. And she said, "I'm

not telling you what to do, but just know that the world will treat you differently if you do what you need to do." As a child, I wanted to fit in, so I taught myself to orient, just keep oriented to people's eyes. It's part of my—well, I have a hard time not doing it now, except when I'm with my husband. It makes me a little emotional to say that. He's the only person I don't do it with. I think there's something, a part in my head, that literally all veils disappear when I'm with my husband. And it's not even like—I've tried. All of a sudden, literally one day I realized that I was talking to him like this. Do you know what I mean? I caught myself and all of a sudden I got really self-conscious and I said, "Baby, does it bother you that I'm not looking at you?" And this was his response. He was shocked. He said, "You mean does it bother me that I just got Mona Lisa with the Hope diamond around it?"

Chilton: Oooh!

Rohe: Aw!

Chilton: Oh, I love that! Your husband is making me cry, and I haven't even met him. How beautiful. How did you meet this gem of a husband?

Talkington: In the back seat of Frank's car. [all: Ooooooh!] Frank was my husband's best friend, and Frank was dating—they've broken up since—one of my very good friends, Cita. A family member of mine had died and I was very depressed. Cita walked into the house, and I was like, "Fine! I'm getting out of the house." She said, "Frank's buddy Andrew is going. We're all going to go see a solo show." So, I literally

walk out of the gates of the house, I open the car door, I slide in, and I say, “Hi, I’m Marilee.” He’s like, “Hi, I’m Andrew.” And then literally in a matter of less than a minute we started talking about physics and God. I don’t know how it started. And we’ve been talking about that for 10 years.

Chilton: Wow!

Talkington: His passion is—theoretical physics, and I’m more of the spiritual side.

Chilton: Oh, interesting! I always find Albert Einstein talks a lot about science and how it supports spirituality. I find it fascinating.

Talkington: Yes. I do too. It is fascinating.

Chilton: But back to you. You are beautiful. You are absolutely gorgeous. You look so 1940s.

Talkington: Thanks!

Chilton: And you do fashion. Did you do this lovely outfit of yours?

Talkington: I do fashion now. Yeah, I put this whole thing together.

Rohe: It’s beautiful.

Talkington: Thank you. I made it.

Chilton: Wow! Your cane is very ornate.

Talkington: Thank you. I don’t have to use a cane. I can. Sometimes I need it, sometimes I don’t. But—and this is where I start to get emotional—I have no role models. I’ve never seen anybody like me, ever, on-screen or in print or anybody who is in my business. The agreement that I made with myself is that if I get into a position where I get to have any sort of level of visibility that I need to represent, then I want to represent in a way that is in full power, full ownership of my value, my worth and my beauty, and to marry both disability and not just fashion, but ferocity.

Rohe: I like that!

Talkington: I really want to put out images that break the stereotype of ‘blind people aren’t sexy’ or ‘they’re not attract’. Because that language is so strong. They say, “Those people are ugly.” And they’re not. And we see it on-screen, too.

Rohe: Or don’t.

Talkington: Exactly, or don’t. We see the asexual or we just don’t see it at all.

Rohe: Speaking about on-screen, what is this we heard

about your new class?

Talkington: Oh, this training program. It’s a five-week, full-time, six-day-a-week professional actor training program for blind and low-vision actors. I’ve been thinking about it for a very, very, very long time, pretty much since I started acting. What’s different about this is, it’s not just like, “Oh, come act. If you’re blind or low-vision, we’ll have some acting classes.” I basically have created a new pedagogy, a new thought around the training, which is, when you enter the class—

Actually, let me back up. We have to think about who designs these acting techniques to begin with. Those are people with a full sense of sight, a full sense of hearing, and all mobilities. So all acting techniques, dance, voice, is taught through those lenses for people like that. This idea kept whittling at me. Having had the experience myself over so many years of having to adapt, to lie, to prove, to fake it, having to be left out, I wanted to create a program where the foundational belief system is, “You are whole.” Period. “Your lived experience is valid.” Period. “You are not missing anything needed to be a visionary artist, a contributing artist, to be an artist, to be creative in any way, shape, or form. You are not missing anything. What is missing is the access and the vision of the training that exists now.” With that foundational belief system, go into the actual techniques and go, “OK, basic acting techniques. Let’s do an eye contact exercise.” We don’t do those. Reinvent the exercises so that we can still get to the core of how do you become a great storyteller? How do you unfold what is inside of you so that you can share it with the world? We’re just doing it in different ways.

And on top of that, I’ve found that when you have blind students with sighted students- this is very, very, interesting- if you just have blind students in a room, that’s it, and you start working, their own level of perception, the sophistication of their perception, and what they can hear and what they begin to believe goes from zero to a hundred. It can happen so fast.

Chilton: Wow!

Talkington: I had a sighted person in my class that I was teaching this summer. We were about an hour and a half into class. We were working on scenes and everybody is deep in the scene and giving feedback. “I heard this, I heard this, she did this,” and you’re going, “Oh, my gosh, it’s so amazing how everybody’s really perceiving this.” We had one sighted person go, “Oh, gosh, Rachel was just so amazing. I wish you could see what was on her face!” Literally everybody, every single person in the class went phoomp!

Chilton: Oh, wow!

Talkington: The energy collapsed immediately. Their confidence went straight down. That sophistication and



Talkington in *Lily's Revenge*

perception disappeared. It was one of those moments where literally everything in my body -my friend told me what I did- my hand flew out to her and I said, “We don’t need that! We don’t need it!” She ended up crying and it was a whole big thing. I needed to spend the next 10 to 15 minutes talking to the class, because all of a sudden all these doubts started coming up.

Chilton: Oh, all the old tapes came back.

Talkington: Immediately. And I was like, “Let’s talk through this. What did you just experience before that happened? Let’s go back to that.” That’s what this training program is doing. It’s five weeks, full-time, six days a week, their perception is right and valid and whole.

Rohe: What will happen, though, when they get back to that voice again and they’re in casting?

Talkington: It’s going to happen.

Rohe: Will you—as they go up to 100% increase in self-esteem or whatever the language might be, are you looking at trying to build some resistance at the end of that training to say, “This is probably what will occur. I’ve seen you grow”?

Talkington: Yes. It’s a great question. I wouldn’t use the word “resistance,” but “integration” and “advocacy.” I’m building into the program how to self-advocate. And also talking about, because I’ve been doing this for so long, “This is what you might be faced with.” And offer it back to them. “How would you want to talk yourself through this? This is how I talk myself through this. It’s not foolproof. But how would you work through it?” And give them that in the program so they know. Because it will happen. You’re totally right.

Rohe: When you open that up to the class that’s 100%,

do you allow the students to all share the ways they will perceive that central reality? Are they all saying, “This is the way I would handle it”? You’re at a different level, probably, than the students in the class, you’re the teacher. So you open up that sharing?

Talkington: Absolutely, because they’ll learn from each other. And they actually know more than they think.

Rohe: One of the things Chet has taught me, and others on our ABILITY team, is, well, he throws us in the deep end and makes us teach. That’s the way to learn, to teach. You could take a student who might not be there yet and say, “Tell the person next to you how you would . . .” It’s amazing. I’ve seen people open up so many times. You can take a person who doesn’t think they have anything to teach and make them a teacher.

Talkington: I love it. I love it. Fantastic.

Chilton: And too, it kind of puts you in your power. You can think, “What can I share? What kind of knowledge do I have to I share?”

Talkington: Yeah.

Chilton: I love what you said—I think—just being an actor is tough. I’m an actor. It’s a tough business, period. For everyone who has the cojones to get out there and go for it, especially in LA or New York. As a teacher, you teach them about their talent and then you also include the tools to help them psychologically and emotionally maneuver through life, because life throws you curve balls. And it sounds like, they’ll be able to handle those curve balls better after they’ve been through your class.

Talkington: I hope so. And I feel like hopefully I’ll be

able to handle it better too, on many levels. I think, as Shelly said, they're going to teach me a lot. I've been on this road by myself. I need them almost as much as they need me. It's not just about saying, "How would you handle this?" but also about saying, "OK, now we're together. Let's move together. Let's go together." Of course, it doesn't mean that it's not going to be challenging even if we move together. I read something interesting in a book. I read, it's the people who break the ceiling that will get cut with the glass. You've got all these scars, from the cuts of the glass. When you have a group that crushes through something together, all of a sudden those pieces of glass are much, much smaller. I think there will be a beautiful symbiotic relationship that will happen in exchange.

Rohe: Have you done many of these classes? Is it new?

Talkington: This project is totally new. It's never been done before. This kind of stuff has never been offered before. What I've done is workshops and private coaching where I'll teach teachers who teach other people. What I'm hoping—actually, I'm not hoping, this is going to happen. I'll write a case study after this so that I can take this to universities, conservatories. Hopefully I can get a documentary crew coming in. I'm working on that right now, to find out if people want to come and start filming.

Chilton: When do you start?

Talkington: It starts January 6th to February 7th.

Rohe: You're so articulate and thoughtful in your approach.

Chilton: So much passion!

Rohe: Yeah, and I love the fact that it's local and we can see it all happen.

All: Yes!

Talkington: Come. Come visit.

Rohe: Do you have a website?

Talkington: www.accessacting.com. It's called Access Acting Academy. I used "access" very specifically, because it's not just accessing the work, but it's also accessing your creative authentic voice. That's what we're about.

Rohe: I have a question. How old were you when you knew you wanted to act?

Talkington: Then I'm dating myself.

Chilton: You don't have to tell us when you were that age, just what age?

Rohe: You talked about not having role models. It's tough to think you have something when you don't see anyone else out there.

Talkington: I think it wasn't until I was about 23.

Chilton: That was yesterday.

Talkington: Exactly, just a few years ago.

Chilton: I love the idea of your class. I studied acting for a long time. I grew up with a speech impediment. I stuttered. I stuttered like King George.

Rohe: Not now.

Chilton: Now I'm making up for lost time. I couldn't speak. So, I did musical theater, because I could sing and I could dance to express myself. The actors I'm riveted by and the ones I love to watch are the ones that are so honest and truthful. That's good acting, being as honest and truthful as you can possibly be, and you don't need your voice, your eyes, your ears, your sense of taste or touch to do that. It's just finding your way to be honest. That comes from your heart, and that's what we all have.

Talkington: I love that you're saying this. I'm on the board of directors for a program at Queens Theatre called *Theatre for All*. They work with all disabilities. It's two weeks. It's a few classes. There's a woman who participated in it, and I can't remember her name, with a severe disability. You can't understand what she says. But you know what she's saying.

Chilton: Beautiful. I love that.

Rohe: Did you notice the good looking guy tonight who is an actor, model, and deaf activist? Nyle DiMarco.

Talkington: [whispers] I got to take a photo with him. [speaks] I got to take a photo with him, on the red carpet. Oh, my gosh!

Rohe: You're married!

Talkington: I know, I know! (laughter)

Chilton: She can look!

Talkington: I can look, and I'm going to tell my husband too, that I got to—

Chilton: It's like going to an art museum and looking at the beautiful pictures on the wall. You can look at them as long as you want, you just can't take them off the wall and take them home.

Talkington: Thank you! I just didn't know I was going to have an opportunity for a photo. And he's a model.



Marilee Talkington

Rohe: Did you know about him?

Talkington: I'd heard about him. I think I saw a photo of him once.

Chilton: I didn't see him. Is he still here?

Rohe: You went to the restroom and missed him.

Chilton: Oh! It just happens. You go to the restroom and handsome men go onstage.

Talkington: He won "Americas Top Model" and "Dancing with the Stars." He won both. And he's, like, a star in his own TV show.

Chilton: I'm sure he's all over YouTube. You're an activist for disability and what else?

Talkington: Oh, Women! I speak up, speak out when I can.

Chilton: What's your advice to young women? Everyone feels different sometimes. There's something that makes everyone feel different and left out, like they don't fit in. What would be your advice to young women feeling like that right now?

Talkington: (pause) I think there is power in owning that part of yourself that feels vulnerable. I think when we start rejecting it, that's when suffering comes.

Chilton: Right.

Talkington: I think that otherness—if there is a way to say yes to it in some way, because I don't want to add

all those other words, like "I'm special for it," but just say "Yes," just even try saying "Yes" for a moment and see what that feels like. Just think there's power in that.

Chilton: Accepting.

Talkington: Yeah, which is hard. "Well, you should just accept yourself." It's a hard thing to do. And I will also say that I think that most young women are more powerful than they think they are.

Chilton: Absolutely.

Talkington: And the belief systems around them are telling them they're not. So speaking up, even when it's scary, can be quite an amazing thing. I had an experience as an adult woman. There was a—did you at all hear about the World Science Festival that happened a couple years ago with the male physicist and the female physicist and the moderator was talking over the female physicist over and over and over and over?

Chilton: No!

Talkington: I happened to be in the audience. Because it's physics, I like to go to these things. It was a big auditorium. The man speaking and the moderator just keeps talking over the female physicist and explaining everything and going on and on. You can feel the tension in the auditorium, people were going, "Oh, let her speak, let her speak, stop, stop, stop." And my body is literally starting to shake, and I finally found myself saying, [loudly] "Let her speak, please!" And you don't really hear it, because they were the only ones with microphones, but the whole room erupted. Erupted! And it went viral. That moment—I posted about it. I didn't realize, I was just Facebooking. The moment went viral, and I ended up in all these magazines and I ended up on the BBC with this famous physicist and we were talking about what this moment was and what it means to speak up when it's terrifying. Because we're constantly being silenced in rooms, being talked over. It was one of those moments. What I was thinking about literally, what was going through my head, "If you don't say something, you're complicit. Let her speak." It was that thing. I couldn't be complicit any more. But I was so terrified. Circling back around, I feel like there are moments to be deeply courageous. It'll be scary as heck. But if you do them, you're going to expand and own that much more of your power, because now it'll be—

Chilton: You were scared?

Talkington: I was terrified. But now when it's happening, no. "Stop!" It's so much easier now. It gets easier every time you do it.

Chilton: These belief systems laid upon young women or those with a disability, who do you think the biggest culprit is of those negative beliefs being put upon us?

Talkington: That's a tough question, because I was speaking to a scholar, a friend of mine, yesterday about these belief systems. She can track them back. Disability, folks with disabilities are the most marginalized groups throughout history. She can track it back to Mesopotamia. We're saturated with them. There's no way—it's in everything. But I believe that it's the media. It's television and film, what we see on the screen that perpetuates our invisibility as human beings, it perpetuates the negative—

Rohe: Have you ever heard the term “symbolic annihilation”?

Talkington: No.

Rohe: It's been used for gender and race more than for disability, but I liken it to disability, too. It means that when a group isn't represented on film or television, the media, they feel unnecessary, unused, not useful. They become symbolically annihilated. That's where that term comes from.

Talkington: That's it. I think that's right. It's so interesting to watch. I'm part of a show right now where the entire world is blind. I filmed this last year. It just came out on a new network, on Apple TV+. Big deal, lots of celebrities in it, and hundreds and hundreds of characters. They literally only cast a few actual blind and low-vision actors. I think next season they'll do more.

Chilton: Good.

Talkington: The award show tonight opened my eyes even more to how much the media, TV and film, play a big part in our belief system and how we see the world. They tell us how we're going to see the world.

Chilton: Absolutely. I think it's time for filmmakers, TV makers, those lovely networks, our new streaming platforms, to really step up and use disabled actors. Who was it? One of the presenters tonight. He said, “If you can't find it in your heart to do it, then do it for your pocketbook.” Of course, that's not a word for word quote.

Rohe: Yes!

Chilton: Because there is money to be made. They always say to follow the money trail. So, let's talk money. There's money to be made. You have to look at your audience. There's disability people who want to watch these programs to see people they relate to. I say the same thing about the baby boomers. You're crazy if you're not making content with actors over the age of 65.

Rohe: Mm-hmm!

Chilton: Because the baby boomers are retiring, they're

in their sixties and seventies, and they're watching TV. My mom's like, “I'm 73. I don't care about the love life of a 20-year-old. I want to see people my age.” There's a movie on Netflix I just watched. What's her name? She named her baby Apple.

Rohe: Gwyneth Paltrow.

Chilton: Her mother, what's her name?

Rohe: Blythe Danner.

Chilton: Yes. Blythe Danner and Sam Elliot. Ooh-la-la! They're in a movie together on Netflix. I just watched it. And they have sex. Yeh, they do! And who told me to watch it? My mother! (laughter)

Talkington: Go Mom!

Chilton: Because she found it. It's a really funny, heartfelt movie about these swingin' single people. It has a lot of heart. All people in their 60's and 70's. My mom found it on Netflix, because she's learning how to use Netflix.

Rohe: Good for her!

Chilton: And she called me one day, she goes, “What have you done to me? I just watched all the seasons of “Longmire”

Rohe: She's binge-watching!

Chilton: I go, “Mom, you just binge-watched.” She goes, “What?” So now she calls me, “I just binge-watched a Kiefer Sutherland show”. (laughter) And then she calls me and goes, “There's this Sam Elliot movie on Netflix, did you watch it? I couldn't sleep last night. I watched it. I even had a rum and Coke while I watched it.” (laughter) She lives on a farm in Illinois, so I'm just like—ok. Seriously, I think it's so silly not to cater to your audience. Know who they are and make content, especially for the audiences that don't have as much content as there should be for them. There is money out there.

Rohe: About your class - How does that work with - there's a cost to the class?

Talkington: No.

Chilton: There's no cost to the class? God bless you. No cost?

Talkington: No. It's totally free. That was one of the number one things. It has to be free for this population. Blind and low-vision people have the highest unemployment rate of any group in the U.S. The access—it has to be complete access.

Rohe: How are you choosing people?



Talkington: Well, we'll see what—there's an application, so it'll be a video audition. They can do a monologue or a two- to three-minute scene. They send their head shot and résumé. If they don't have any experience, they can still apply. I encourage that because so many blind and low-vision folks have never even thought that this could be possible. So yes, if it's a beginner, apply. Do the work, really do your best work in your audition and answer the questions. The application form is very simple.

Rohe: Is it accessible?

Talkington: Absolutely. It's completely accessible. Everything's online. It's a Google form, which is totally accessible. I beta-tested everything. The mobile site, completely accessible.

Rohe: So they have to pay their way to get here?

Talkington: That's right. We don't pay travel and housing. I couldn't get funding for that. But tuition is totally free. Any other questions about the class?

Chilton: How many are you taking?

Talkington: We thought about this a lot. We could have accepted more, but 12 seemed to be a really great, solid number. You still have enough for a true ensemble and everybody will get individual attention.

Chilton: That's very important.

Rohe: Where will it be held?

Talkington: We looked at the Odyssey Theatre tonight.

Chilton: That's a nice space. I saw a play there. Exciting!

Talkington: We would like to get access to the whole thing. Chilton: And they'll be working on a professional stage, too.

Talkington: Yes, which is so key, because one of the classes that I'll specifically be teaching is navigation stage movement.

Chilton: Oh, good, that's a good stage to do that on.

Talkington: Because it's a big deal in the blind community. "Where do I go? How do I enter?" It's always an issue, always a fear. So they'll be on a stage from the get-go.

Chilton: Yeh. Enter stage left, come down stage right! Yes!

Talkington: Exactly. Feel where the audience is.

Chilton: Find your light.

Talkington: And that's—

Rohe: Wait a minute, find your light?

Talkington: We have to learn that, too. The thing about lights—

Chilton: Can you feel it?

Talkington: It depends on what kind of lights they use. If they use LEDs, no.

Chilton: Oh.

Talkington: If it's old stage lighting, yes. This is where we get to create with them, because every single blind person will have something different. "What do you need? What do you need? What do you need? Great, let's innovate that. Great, let's innovate that. Did you learn something from that?" Then we start doing this cross-fertilization that'll be extremely exciting.

Rohe: I know you could learn the steps on a certain stage. You know the stage, distance, you measure it out in your mind, where to center yourself during scenes. Would that be the case for all? Would you have to study that particular stage you'll be on?

Talkington: There are a bunch of different ideas. We could do half-rounds on the ground.

Rohe: What is that?

Talkington: Dowels, wooden dowels, those round sticks of wood. When you slice them in half, they're called half-rounds. They're raised on the top and flat on the bottom.

Rohe: Like speed bumps?

Talkington: Speed bumps. You could put half-rounds down, gaffe it, so that there's markers.

Rohe: A trail, if you will.

Talkington: We could do raised—you could layer tape and have raised bumps. There are all kinds of physical things you can put on the ground that they can feel. For me personally, one of the things—when it's full light and I can't—it's not part of the stage aesthetic to put a half-round down. That's when I have to do the same thing 15 times in a row and then do it as part of my dance call before every single show. That'll be part of them learning what they specifically need to do to orient themselves to the space. But there are ways that we can service—make it easier, start things off and then go, “What works for you? What doesn't? Can you think of something else? Does this spark another idea in you that'll work for you?” and get it immediately. There's quite a bit—not a big budget, but I have a budget for anything accessible that somebody may pop up with in a class. We go get it and bring it the next day.

Chilton: You are so amazing. You mentioned that you didn't have a role model. I think you'll be a role model for a lot of people. You probably already are.

Rohe: I think so too. How do you vet the person who says, “I have low vision”?

Talkington: I think if we have a ton of applicants, I'll have a conversation with them and say, “Tell me about your vision. How do you experience it?” I don't know what the legality is. I'm legally blind, but there can be people who are low vision who come in. I started taking acting classes when I wasn't—I mean, I've always been totally blind centrally, but there are low vision actors out there that we'll accept.

Chilton: Low vision is not legally blind?

Talkington: No. Legally blind is like 20/200 and beyond. Visually impaired could be, like—it depends, because it's not just acuity that we're talking about. And what I mean by acuity is 20/20, 20/30, 20/40, 20/50. It could be that you only have a certain degree, field of vision. It could be some days your vision is covered in snow and some days it's not. There are so many different visual—

Rohe: A person with one eye, would that be—

Talkington: Yes. If they identify. Some people don't publicly identify, because there's so much stigma around it. They medically identify as blind or low-vision. They'll know.

Rohe: Stigma.

Talkington: I was talking to Tim Cook about this, the CEO of Apple. Media teaches us what to think about ourselves and what to think about other people. The words, the stories, who's up there, who's not, who's representing us, how are they representing us.

Rohe: Are they representing us?

Talkington: And the thing is. I don't want to be represented by somebody else. I have no interest in that, thank you very much.

Rohe: How'd you talk to Tim Cook?

Talkington: It was through the show that I was on, Apple TV+.

Chilton: I'm so happy you're doing this. I think too, we work with actors. I've taught acting. I am an actor. You have to have acting chops. I know people who are specialty actors or character actors. Say they're looking for a six-foot redhead. So, every six-foot redhead shows up, and because they're a six-foot redhead, they think they can have the part. Probably the six-foot redhead who's studied acting and honed her craft will get it. You maybe the type they are looking for, but you still have to study and get good. This is an industry, a profession.

Talkington: Yes.

Chilton: There's no free rides for anybody. You've got to get out there. So I'm happy you're teaching. That little boy in the “Peanut Butter Falcon” film, the one Shelly interviewed, he's a good actor. It's not just that they were looking for someone with Down syndrome. This is a Down syndrome young man who has acting chops.

Talkington: Absolutely. And I think in a perfect world, everybody would have the opportunity. This is a beginning to giving them the opportunity, but that doesn't mean all blind and low-vision actors will be able to get into acting classes elsewhere. And the creator of “Pose”, do you know that show about the trans and LGBTQ community in New York in the '80s? It's fantastic. Their five lead characters are all trans actors. None of them had camera experience. And he said, “I wasn't looking to cast stars, I was looking to make them.”

Chilton: Wow!

Talkington: And I was like, “Word.” And you could tell which ones have had it and which ones have not, but the level of authenticity is so high that you just lean in. You melt into the story. So there's both. ■ ABILITY

TOBY forrest

In 2010, *ABILITY Magazine* interviewed Tobias Forrest. The article started: “I was twenty-two, and I was diving off of a waterfall in the Grand Canyon,” Forrest said. “The water was too shallow where I had jumped, I shattered my fifth vertebrae—and I realized I was going under. I thanked God for my life, and then I died.

I just got extremely lucky, in all respects. A lot of strangers came together and got involved in saving my life that day. I wasn't quite ready to give up.”

*He shares a house with friends, seeks out work as a Hollywood actor (his credits include *Weeds* and *Six Feet Under*), paints, writes poetry, hosts an online radio show, and navigates the usual uncertainties of a creative life with infectious optimism and with a natural, breezy charm. And is the vocalist in the band, *Cityzen*.*

Over the years we think of Toby as part of the *ABILITY Family*. In this interview we chatted on the phone.

Chet Cooper: Hello!

Toby Forrest: I'm looking for Mr. Copper?

Cooper: (laughs) Let me see if he's around.

Forrest: Is this Chet Copper?

Cooper: (laughs) There are so many times that I've heard that or people asking for Chad or “Can I talk to that idiot?”

Forrest: (laughs) The thing about “Chet” is, you wonder what it's short for. Chedda? Chester?

Cooper: I was attending the Connie Stevenson Extravaganza in Jackson Hole, and standing next to this person. He turns to me and puts his hand out and I shake his hand. He says, “Chad.” And I say, “Chet.” And he says, “Chad.” And I said, “Chet.” He was getting frustrating as we were still shaking hands his grip was getting tighter. It was Chad Everett.

Forrest: He sounds familiar.

Cooper: He's was a lead actor, before your time. He kept thinking that I didn't know what he was saying. But he didn't know what I was saying.

Forrest: That's one for the movies right there. Did you guys finally figure it out?

Cooper: Yeah. I figured it out. I'm Copper.

Forrest: And I'm sure he was gracious at that point. Or he was completely fed up and he was just like, “Whatever. Chet. I'm gone.” Anyway, thanks for jumping onboard the *Daruma* train and helping us get a little steam.

Cooper: Tell me, Mr. Toby, how did you get involved in this indie film?

Forrest: Well, have you talked to John Lawson yet?

Cooper: Yes, but his interview will be in the next issue.





Toby and Jim Belushi

Forrest: Nice. John is a good friend of mine. We're almost neighbors in real life. We help each other with auditions. He had an audition so he came over. I helped him film his audition and he said, "You know, you should do this other part." I said, "No, it's your audition." He said, "But the other part is for someone who's a paraplegic." And I said, "But I'm a quadriplegic." And he said, "You should audition anyway." He had to talk me into it. I was doing a play at the time, so I was like, "No way! I'm doing five shows a week, getting naked onstage, taking showers." I auditioned and then we both got callbacks and we both got the thing. We filmed it at my house, so it was almost a little bit of life imitating art in that sense. Although we get along a little better than the two guys. (laughs)

Cooper: Tell me about the play.

Forrest: The play was called *Cost of Living*. I was doing five shows a week. I was taking showers on stage and an actress, who plays my caregiver onstage, had to transfer me, dress me and do all this stuff. I was busy doing those shows, and then this came along, "All right, this must be a test as an actor." I've never done a trailer in two-and-a-half days, and also had a film doing this trailer in the morning and then do the play in the evening. I thought, "All this will be a challenge as an actor, which I may not have again, so let me do it for that reason." And I liked the story, the relationship between the characters. It was an opportunity to work with John Lawson, and once I met Kelli McNeil, who wrote the screenplay and Alex Yellen, the director, I was thinking, "You guys are adorable. I can totally see this happening." And seeing how Alex works and his talent with making things happen and the quality of it.

Cooper: Shelly, who's on our team interviewed Alex

and Keli. She did talk about her brother, being part of the story. And the fact that while writing the screenplay, she had some idea of what was going on as she wrote it.

Forrest: The disability wasn't hers directly, but she was affected by it directly, so she has an experience that a lot of other writers would never have had. She's the authentic voice that a lot of other writers would not have had without that experience. So that being the seed for her creation is more important than anything. That's how I felt about it. I was like, this is not a story about your family, about your family member, not even about you. This is a story about an aspect of life that happens to be a detail of a story that you could add real richness to. Those two guys might not be disabled, and it would still be a good story.

And that's the point. The story should be good enough without disability, and when you add disability all it does is lend authenticity.

Cooper: I'm going to quote you on that.

Forrest: OK. Good luck trying to get me to say it again.

As an artist, you want to be able to get to a point where you can say, "Oh, my gosh, I'm getting things that are not surface-level characters. They're not one-dimensional characters. They're not wheelchair characters.

Cooper: If I understand correctly, you were just in a fashion show?

Forrest: I just did a bunch of stuff. Fashion show?

Cooper: But I've seen the way you dress. It doesn't make any sense.

Forrest: (laughs) I know. I've been wearing a lot of three-piece suits lately.

Cooper: The last time I saw you, was that when we were playing around with the sitcom?

Forrest: Yeah. I guess since then I've done the play. It was a beautiful Pulitzer Prize-winning play. Then I had a small part on a TV show where I played a lawyer, so I had to be dressed up for that too. I played a lawyer on a show called *Good Trouble*. Then I have been doing a lot of audio description for people who are blind through Audio Eyes.

Cooper: You're doing the narrative?

Forrest: The voice that describes what happens in between the dialogue. That's really cool.

Cooper: How did you get that gig?

Forrest: The owner is a friend of mine. They brought me in once as a test run, and it was pretty fast and pretty good. And they gave me a bunch of episodes to do. I did them all and then I went away to do a play and some other stuff. When I come back to town, they'll give me some stuff— a show or a movie— when they get overflow. I go into their studio with their engineer and jump in there and audio-describe for people who are visually-impaired. It's amazing. It's cool for me to go. I have a spinal cord injury, but I have a lot of friends who are visually impaired. I have every kind of disabled friend you can imagine. It's cool to be able to say, "I get to be a part of that community to some degree."

Cooper: That's cool.

Forrest: And then after that I went to Serbia.

Cooper: Wait, freeze on Serbia. For our readers who don't know what audio description is, give us an example.

Forrest: It is the action that's happening that is being described between the dialogue. It's almost like a narrator describing all of the action.

Cooper: Give us an example.

Forrest: OK. So if, for instance, there was a TV show and a character comes in and yells at another character who does a bunch of stuff, I would describe all the stuff. For example, I would say, "She opens the door. She runs in. She throws the keys at him." And then you hear her, "Blah-blah-blah!" Then I would say, "He puts his hands on his head. She turns around and runs into the kitchen." That would be a description.

Cooper: I actually ducked when you were saying that. I felt the keys coming. You did some travel abroad?

Forrest: Yeah. I did a movie in Belgrade. That was a lot of fun.

Cooper: How did that come about? What was it all about?

Forrest: It was amazing. I was flown there and put up in a hotel for a movie. I'm not going to tell you what it's about. I'll tell you that it's about a competition where the main character will not compromise her values in order to win. I play the head judge, who is one of her nemeses in the film, who does not appreciate her. I basically have a lot of conflict with the main character. The ultimate decision comes down to me. And I got to play a British character who was very sort of posh, which was nice.

Cooper: I didn't know you did a British accent.

Forrest: Me neither.

Cooper: This will be good for copy. Go ahead and give me your British accent and we'll put it in.

Forrest: (laughs) First, I'll tell you how I studied the British accent. There are two main ways. There's the real proper one. I would do it by doing the tongue-twister. I'll do it in the proper one first. [with British accent] "Betty Botter bought a bit of butter, but she said, 'This butter's bitter. If I put it in my batter, it will make my batter bitter.' Betty Botter bought a bit of better butter and it made her batter better."

Or you could do it Cockney, which would be like...

Cooper: (laughs) Why after all these years I've not heard somebody do that, I didn't know.

Forrest: You had to wait until that moment. That's how I would practice. I had no idea how to do the British accent. They asked, "Do you do a British accent?" I said, "No, I just have to phonetically say the words that my character has to say." And all the British people said I was pretty spot-on.

Cooper: Is that project done now?

Forrest: It's being edited and then it will be shopped around. Hopefully, it'll be out in the next year for sure in 2020.

Cooper: Is there a working title yet?

Forrest: I don't know yet, because it's being shop around. I have to wait and see what it becomes. But it's got some great actors in it. I don't know if you watch *Glow*?

Cooper: No.

Forrest: It stars one of the girls from that show, Kate



Toby in Belgrade, Serbia

Nash, who's great. So I got to work over there for almost two weeks. Then I came back to a bunch of auditions and I booked one of them right away, which was a big guest role in *How to Get Away with Murder*. Last week, I was filming that show, and I got to work with Viola Davis. Just her and I, facing off, an emotional scene with Viola Davis, a Tony-award-winning actress, and in my top ten of people I'd want to work with.

Cooper: Now you only have nine more to go.

Forrest: Yeah. I took notes. That was with ABC. It was really cool to see how much of an effort ABC made to make things comfortable and accessible and how much they wanted to include me in everything. The director was amazing, getting to connect with him and make choices as an actor. A lot of times you don't get to do that.

Cooper: What's on your plate now? What do you see in the future?

Forrest: I'm working on a bunch of my own stuff right now. I just had a little read-through yesterday of a short film that I wrote. I'll film that for sure. The director I just worked with in Serbia has another project that we are hoping to get started on and do, where I would have a leading role in a movie.

Cooper: You're talking about in the States, or in Serbia?

Forrest: We might film in Serbia. We might do both. It depends. You can get a really big studio over there, which is great money-wise. When you're making a small movie, you can do more, unfortunately, in other places. So I'm working on some of my own things. And then there is another movie, *Daruma*, which we're

obviously trying to move forward and get funding for. That would be amazing because that's a leading role. There's another movie I auditioned for that I'm meeting with them about. It's a biopic, which would be cool, because then I would play an actual person who has lived, not just a character. That's pretty exciting. We'll see where that goes. I won't know until end of next month.

Cooper: What about singing? Do you still perform?

Forrest: No, although my bandmates and I have talked. The 10-year anniversary of our album will be happening at some point next year. We might get together and perform. But I'm always open to it; it's just unfortunately, with music, it gets to a point where you have to hit sustainability with a disability, and if I get to a certain point where I'm going to lose any and all coverage and take the leap as an actor, I need to make sure that I have the time and focus to be able to do that. With music, unfortunately, no one got past the wheelchair. There were a couple of meetings and people who might have been interested, but they couldn't figure out how to market a guy in a wheelchair running a band.

It's a young person's game, in a sense. Had I started 10 years earlier, I might have had more of a chance at music. Right now, I've been very fortunate because I did a TV show with a recurring role last year on CBS. They brought me in a couple times. They used my car and one of my songs in the episode. In one episode I got paid for my acting, my car, and my music. I was able to place my music into the TV show that I was doing and checkmark the bucket list. So, OK, I checked the bucket list last year by getting my music and my car and my myself into a TV show. I was able to do it this year by going out of country to do a movie and work with an

amazing, Oscar-winning actor. It was unbelievable. So fortunately, it looks like the acting career is heading in the right direction, and I might be able to pull music back into the fabric as it unfolds. I don't know. I've been able to put my music in, I would say, half of the projects I've done recently.

Cooper: Oh, nice.

Forrest: I've got them in a couple of movies. I did a movie with Christopher Titus that's out right now called Special Unit. I don't know if you saw that one yet.

Cooper: No.

Forrest: It's a great comedy. It's got more people with disabilities, more actors with disabilities, than I can't think of than any other movie. It's got at least 12 of us. Three of us are main cast members.

Cooper: It puts the Farrelly brothers to shame. Too inside of a joke?

Forrest: No, I get it. (laughs) But the Farrelly brothers helped a little bit. They paved the way with Danny Murphy. I wouldn't be where I am without Danny Murphy. I feel like he's a little bit of my guiding light.

Cooper: The Farrelly brothers opened the door for Danny?

Forrest: Danny opened the door for the Farrelly brothers.

Cooper: Somebody was opening the door somewhere. I don't know why they keep closing it.

Forrest: I'm saying in the sense that when he watched one of their movies, they asked him, "How was the movie?" He said, "It was great, but you didn't have any people with disabilities in it." And that turned the light on for Peter Farrelly. From that moment on was when they started including Dan and then other people with disabilities.

Cooper: Do you know how they knew each other?

Forrest: When they were teenagers, they were at Martha's Vineyard, I think, and they were diving off of a dock. Peter was going to dive, but Danny dove first and broke his neck. The water was too shallow. That's the story I know. They were friends from childhood, maintained their friendship, and then years later these guys are up-and-coming directors. They asked him to watch their movie, and he said that, so they ended up putting him in the very next movie, which was Kingpin, I think. But then I met Danny the day I got home from the hospital. He was at a party at my house. He was the very first guy I met and helped guide me through my disability. I had no intentions of acting, but when that came along, he helped guide me there as well.

Cooper: Was it random that he came to your house? Or did he come to mentor?

Forrest: He was there in a sense to mentor because my father had met him through his girlfriend at the time, who was his dentist. You know how it's, like, three degrees? Danny was the only person they knew who had a spinal cord injury, and he came over. That was a great first person to meet.

Cooper: That's cool.

Forrest: So that's it, man, long story short. Just focusing on a lot of different areas, doing a little bit of writing on my own. I've been writing a lot. So, we'll see. That's on the bucket list, to eventually do something that I wrote.

I have a feature film that I wrote that eventually I would love to do. It's got all the stuff I would want to see in a movie—or some of the stuff I would want to see in a movie. That's my eventual goal, to do that movie. But we'll see what happens.

Cooper: Have you thought about trying to write something about your own life?

Forrest: No, no. I've got to work on the ending.

Cooper: (laughs) I could tell you how it ends: no one gets out alive.

Forrest: (laughs)

Forrest: Well, you know the number one cause of death.

Cooper: Being born?

Forrest: Right. Life. But that's it. I don't know. Do you have any other questions?

Cooper: No — You're the man.

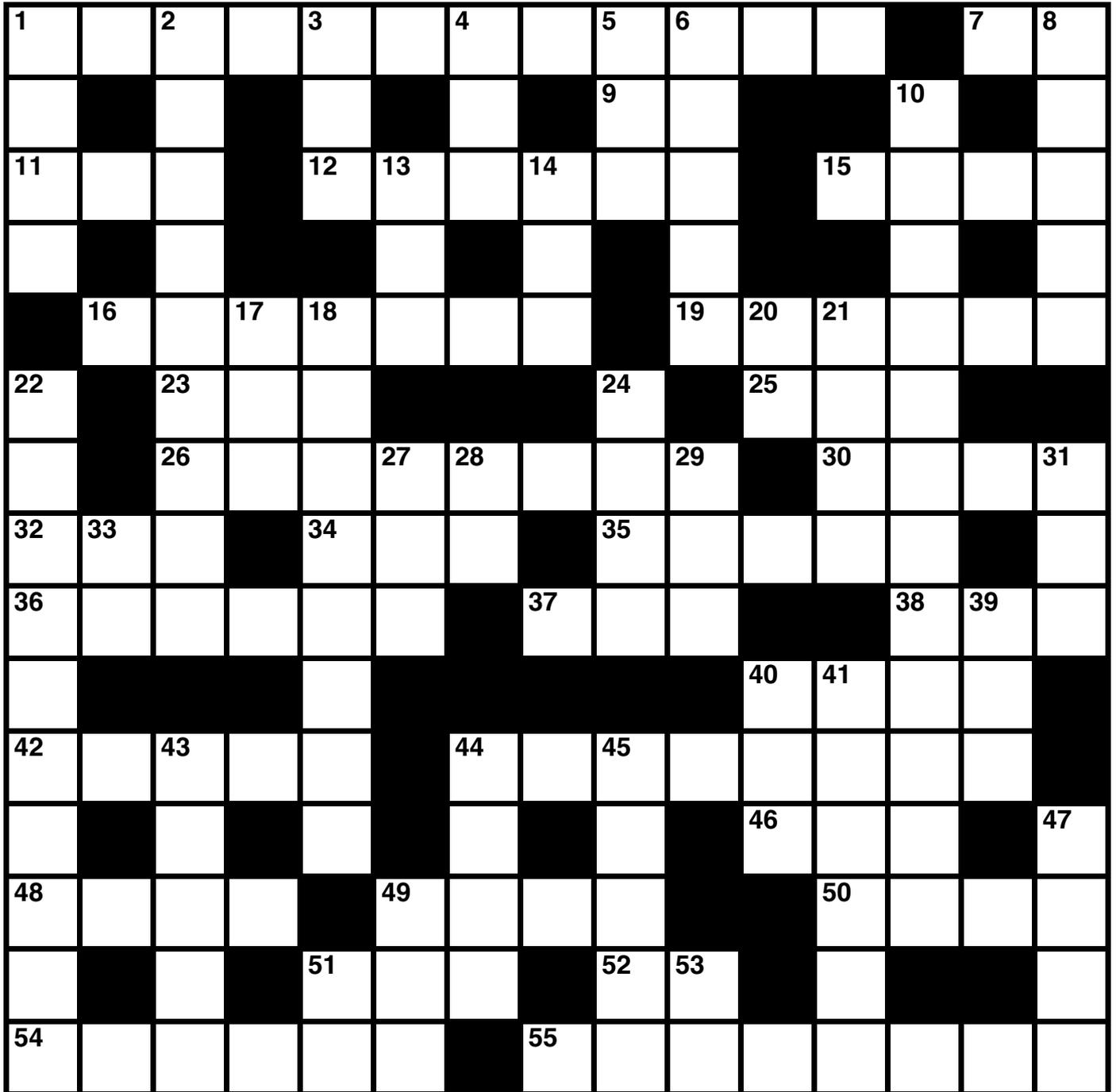
Forrest: You're the man, man. Thank you, buddy.

■ ABILITY

@tobyforrest



ABILITY'S



Crossword Puzzle

Find Jobs at Smart Places

Find your ideal job within our national network of 700+ colleges, universities, hospitals, and labs working together to promote *equity* and *excellence* in the higher education workforce.

Visit www.hercjobs.org to access free resources and manage your career:

- Search 30,000+ faculty, staff, and executive-level jobs
- Create a free account to save searches, upload your resume and get job alerts
- Get career advice from higher ed professionals including advice for professionals with disabilities

To browse jobs or become a member institution visit www.hercjobs.org



ACROSS

1. Founder of R.O.C.K.S. helping young people with serious illnesses and disabilities, 2 words
7. Raise
9. Power in a person according to the Tao
11. "The ___ is the limit"
12. Organization that helps hotels create accessible environments for people with disabilities
15. Goals
16. First comedian with a visible disability to appear David Letterman's "The Late Show" - Chris ____
19. Imprints, as in memory
23. ___-jongg game
25. Porridge ingredient
26. Host of the Special Olympics World Games 2019, 2 words
30. Take some exercise in the pool
32. Tin
34. Voice, as a grievance, say
35. Clear soup
36. They throw pies at each other
37. ___ West of Hollywood
38. Plane arrival time guess, abbr.
40. Cry from a bad golfer!
42. Chill out
44. See 10 down
46. 12 on a sundial
48. Rights org. works for freedom of discrimination for PWDs, abbr.
49. See 10 down and 44 across- 2 words
50. "Small screen" award
51. Animal companion
52. British politician
54. Chinese fruit tree
55. Supported
49. Greeting

DOWN

1. Last word of APDA, abbr. (org. for Parkinsons' sufferers)
2. Comedian who has participated in many golf charity events, 2 words
3. Founder of the organization in 18 down- last name
4. Wall hanging
5. Brit TV network
6. They fly in V shaped formations
8. Puts up on Facebook
10. Special Olympics anthem title, goes with 44 & 49 across- 3 words
13. It's illegal to discriminate on the basis of this
14. Russell Crowe's middle name
17. Arrest
18. Home of the International Art Education Center for the Disabled (it's in China)
20. From head ___ toe
21. Actors in a film
22. Vital equipment in team sport at the Special Olympics, 2 words
24. Swedish band in the Rock and Roll Hall of Fame
27. Insult, in slang
28. 60 min., abbr.
29. Anger
31. Business degree
33. Pacino or Yankovic
39. Danson on the screen
40. Canadian hero who ran across the country to raise money for cancer research, Terry
41. Types of willows
43. Purple flowering shrub
44. Attempt at a basket
45. Jabberwocky, The Raven, etc.
47. Changed hair color
49. Golf starting point
51. Exercise, for short
53. Letter addiiton

answers on page 70

SEE BETTER

AT ANY AGE

AUTHOR

- The Miracle of Pi in Eye
 - LASIK in the 21st Century
 - Cure for Keratoconus

VOTED BEST

- Newsweek Showcase Top Doctor
- LA Daily News Readers VC Star Readers
- Consumer Research Council

DOCTOR'S

DOCTOR

- Surgeons & Physicians
 - Chiropractors & Dentists

SURGEON

TO STARS

- Actors & Celebrities
- Olympic Athletes

FOR PATIENTS

18-45

- Thin Flap Lasik
- ICL

FOR PATIENTS

45-65

- Superlasik
- Pi in Eye

FOR PATIENTS

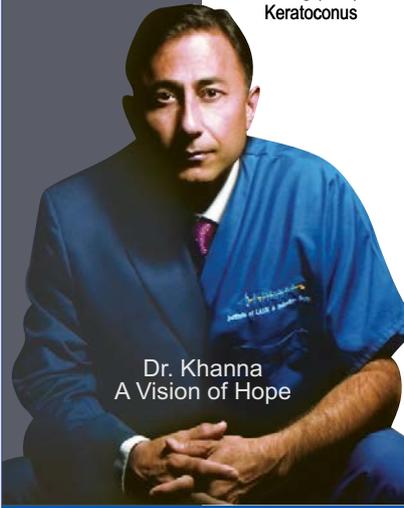
ABOVE 65

- Pi in Eye
- Laser Cataract Surgery

OTHER THAN

LASIK

- Pterygium
- Intacs & Cross-linking (CXL) for Keratoconus



Dr. Khanna
A Vision of Hope

Khanna Vision Institute

1 - 877 - 2

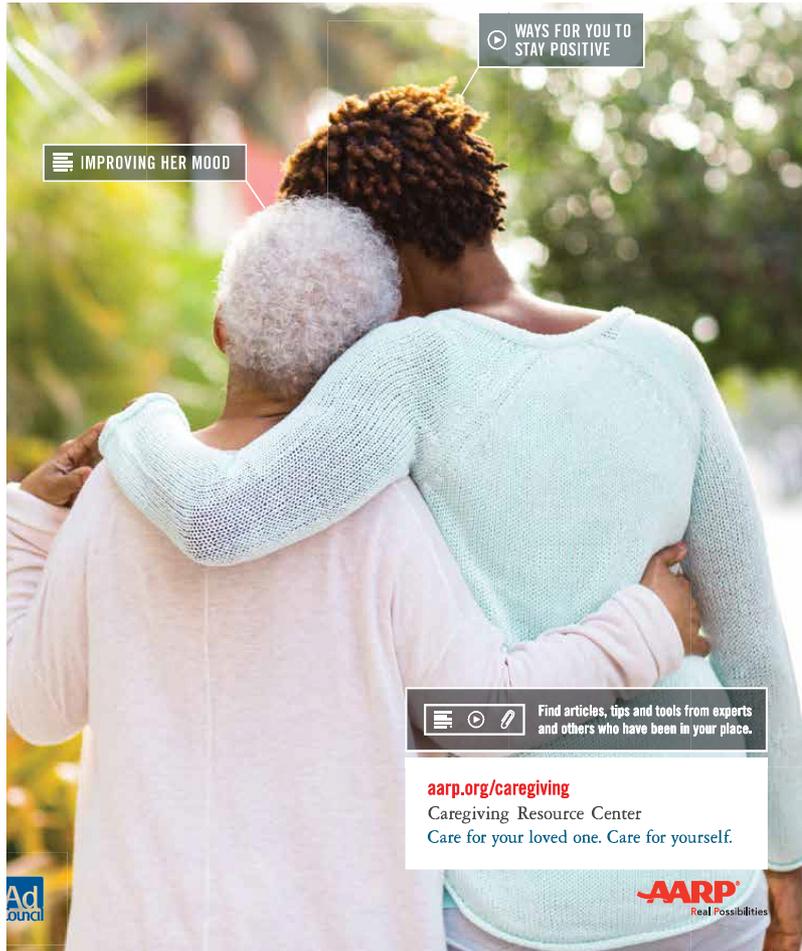
www.khannainstitute.com

Beverly Hills

240 S. La Cienega Blvd. #250
Beverly Hills, CA 90211
Phone: (310) 482-1240

Westlake Village

179 Auburn Court #1
Westlake Village, CA 91362
Phone: (805)230-2126



D	E	T	S	I	S	S	A	E	E	H	C	L	L
E			R		P	M		T	P	E	A		L
Y	M	M	E			E	B	O	T	U	C	L	A
D			I	L	X	O		H	I				B
	D	E	S	E	P	O	S	U	P	X	L	A	R
	E		R	E	F					G			E
A			E			A	E	M		S	N	W	O
B		H	T	O	R	B		R	A	I	R	A	N
M		I	W	S		B	A	H	D	U	A	B	A
			T	A	O	A			H	A	M	A	S
S	E	S	H	C	T	E	A	C	E	S	O	N	F
T			G		S		R		G		R	R	N
S	M	S	A	I	V	E	I	A	T	N	A	K	S
O			R		T	E	R		I		A		S
P			U		E	N	G	I	A	V	L	L	A

A V R I L L A V I G N E S
Crossword Puzzle

24 HOURS A DAY, 7 DAYS A WEEK, WE ARE HERE.



The American Cancer Society is there for you to help answer your questions, connect you to the resources you need, and just listen.



We're here to help you through every step of your cancer experience. Visit www.cancer.org or call 1-800-227-2345 anytime, day or night.



Information

We can answer your questions about cancer, including prevention, diagnosis, treatment options, and clinical trials.



Day-to-day Help

We can help you with everyday needs like transportation and lodging during treatment.



Emotional Support

We can connect you to local and online support groups for both patients and caregivers.

Imagine The Difference You Can Make

DONATE YOUR CAR

1-800-394-0136



**FREE TOWING
TAX DEDUCTIBLE**



**Heritage
for the Blind**

**Ask About A FREE 3 Day
Vacation Voucher To Over
20 Destinations!!!**

Help Prevent Blindness

Get A Vision Screening Annually



With a ton of ways to increase your independence at Abilities Expo, your glass really is half full!



**FREE
ADMISSION**



- Cutting-edge products and services
- Get answers from the experts
- Adaptive sports for better health
- Informative workshops
- Service animals open doors
- Inclusive dance empowers
- Daily living aids
- Therapeutic cannabis: Real facts
- Life-changing activities for all ages

**Abilities
EXPO**
Serving the Community
Since 1979



Follow Us!
#AbilitiesExpo

www.AbilitiesExpo.com
Register online today. It's free!

Boston
September 13-15, 2019

San Mateo
October 25-27, 2019

Dallas
December 13-15, 2019

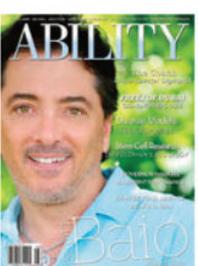
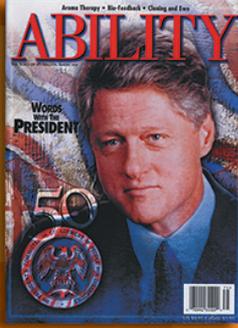
Los Angeles
February 21-23, 2020

New York Metro
May 1-3, 2020

Toronto
May 29-31, 2020

Chicago
June 12-14, 2020

Houston
July 31-August 2, 2020



Annual Digital Subscription - Includes ABILITY Magazine Premium Membership

\$29.70

On-line: e-book format with flipping pages and multi-media

Quantity

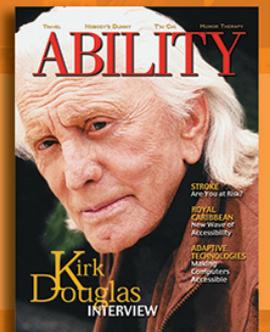
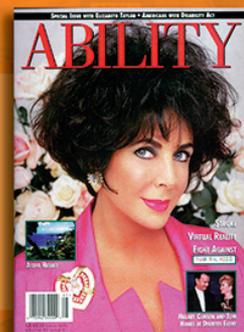
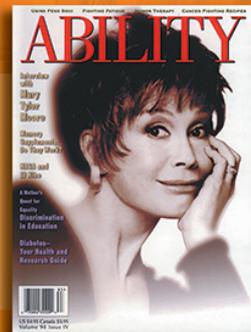
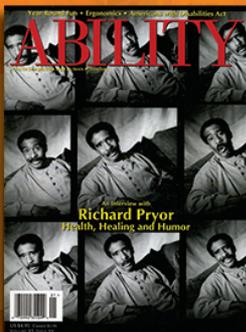
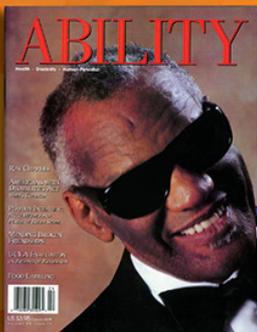
[ADD TO CART](#)

SKU: DigiAnnual

[Add to wishlist](#)



ABILITY MAGAZINE



www.captivoice.com



**Listen to everything
you want to read**

cap*ti*



**Try ABILITY
Magazine
with Capti**

**The screen is small
and time is short**

by Charmtech Labs LLC



Apple® and the Apple logo® are trademarks of Apple Inc., registered in the U.S. and other countries. App Store™ is a service mark of Apple Inc.

ABILITYJOBFAIR

ABILITY SOLVES ACCESSIBILITY
with Live Video Career Fairs



join the **ACCESSIBLE** revolution
with a **COMPLIANCE** evolution

With the support of abilityJOBS and *ABILITY Magazine*, ABILITY Job Fair presents an interactive face-to-face video career fair technology to corporations, governments and non-profits so that they may actively recruit candidates in the most efficient way. This is the first platform to emulate the live career fair experience accessible for tens of thousands job seekers with disabilities.

Live Video • Screen Reader • Speech to Text • Sign Language Interpreters • Text Based Messaging

abilityjobfair.org