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ABILITY

ALL WHEELS UP
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CHINA'S WANG
YUZHONG

RANDY
TRAVIS
PART 1

+ Blind, Autism and Deaf Advocates:

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Elizabeth Sammons
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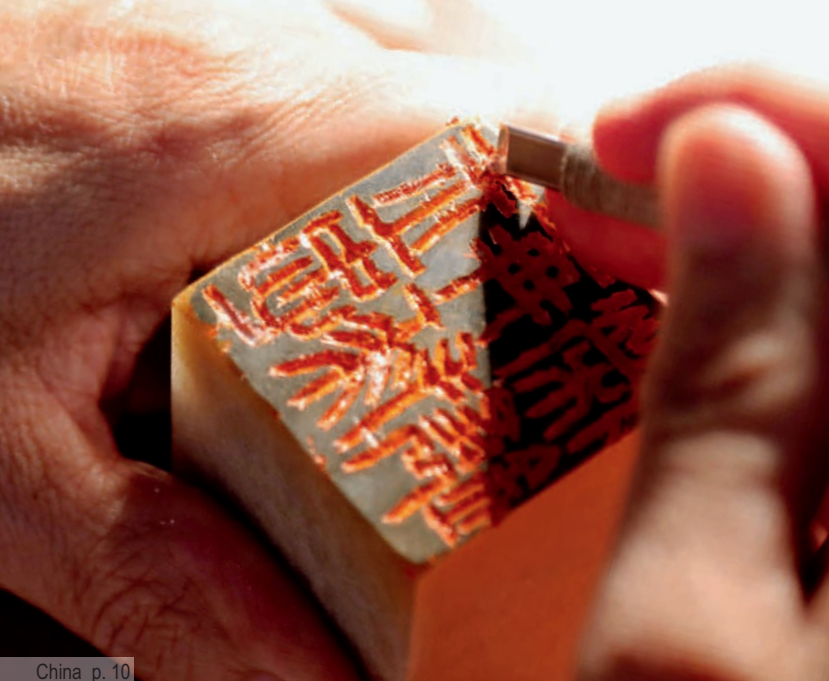
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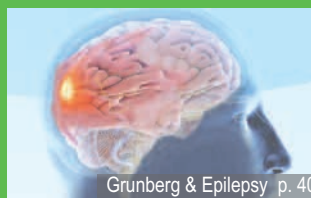




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Utah has been pretty cold, much like every where else! We haven't been going out too much just hanging in the house or with friends. The good thing about the cold weather is you don't feel bad to stay inside and watch TV. I have been soaking up football playoffs, the SX (super cross) races that just started and Winter X games, it's been some great coverage and everything has been very exciting. At least it gives me lots to do.



At Christmas we flew to Florida to hang with my family. It was also my brother's 18th birthday so we stayed at Disney's Fort wilderness campground for his birthday and for Christmas. The day after Christmas we came back home and hung out in Saint Augustine before we had to head back.

We just kind of chilled at the campground, drove around in the golf cart and looked at Christmas decorations. We

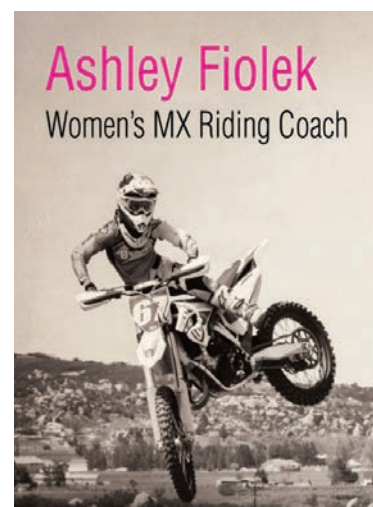
put lights on our golf cart and my mom brought her Christmas tree from home to help decorate our site, we also stung up a bunch of lights and we brought our fire pit so it was a lot of fun.

My mom and dad bought this new portable pizza oven from Ooni, it has a brick stone and gets up to 925 degrees! We all made a bunch of pizzas and my brother made a smores dessert pizza we had so much fun flour was flying everywhere! My brothers girlfriend came for a couple of days to hang out for his birthday, that was nice because we all sat around the fire and we played some games. My parents brought their 3 dogs plus my brother and his girlfriend so me and Lindsey slept outside in our tent, it was actually lovely the weather was perfect at night.

When we came back to Saint Augustine we got together with all of our friends one night and went downtown, that was a fun time we miss everyone. One of the nights my family invited some of our family friends over that we have known forever and we did an oyster roast out in our backyard. I miss doing that so I'm glad we had the chance to do that while we were home!

I'm going to pick up a new bike on Saturday and I'm excited I will be able to start riding again I will just have to bundle up! I'm planning on riding the Day in the Dirt races that will be held at Dade city in March. My dad is going to ride too and we are going to be part of the iron man competition. If you guys are in the Tampa/Brooksville area in March come on by and say Hi!

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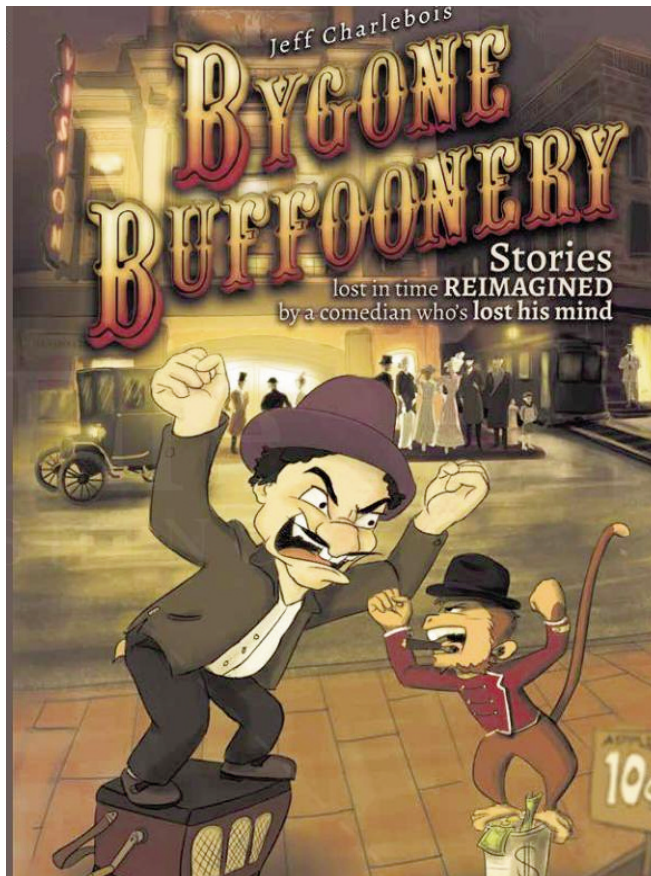
Don't You Dare Laugh!

So, these two Jews walk in a bar and... Oops let me try this. A Pollack and Catholic priest are in a plane and... Never mind. A drunk Irish man runs into a Mexican and says... I'll leave that be. A black guy, a Chinese fellow and a gay Swede were driving down the road... No, I shouldn't. What do you call a guy with no arms and...? I can't go there. Two blondes were driving, and one thought her blinker wasn't working... Forgive me for not finishing any of the jokes, but I just couldn't take the chance of being canceled. I can take being booed, humiliated, spit on, but not canceled. I have too many meaningless things to say. This is where we've now come as a society. We must all tiptoe on our words for fear the someone or some group will be offended.

If, by chance, you have the guts to tell a joke these days to someone, you must first look all around you to make sure no one else can hear you because they may have a stroke if it offends them in any way. Then you must preface each joke with a disclaimer that protects you from being labeled something terrible like a racist or misogynist. "I love the Mexican people. Some of my best gardeners were Mexican. And I must eat tacos three

times a week. Anyway, how many Mexicans does it take to screw in a lightbulb? Juan." You see, you've covered yourself. You let the person know that you've had interactions with the Mexican population and consider them good people. So, if you're accused of being a racist or xenophobe, you can remind them of your initial addendum. Your protection clause. "No, no, no, remember I stated I've hired them before and even eaten their food, so I'm good."

Another trick that is often used before telling a joke is to state that someone just told you this joke and you're not sure what you think of it. They ask you what it was, you tell them then await their response. If they say, "That's terrible" you back track, agree with them then say something like, "I know. I didn't even want to tell you it, it disgusted me, so bad." But if they laugh, you can now take full credit without any reservations. "It's a killer one, huh? I've been laughing about it all day." This also opens the door to roll into some other jokes that you have in your back pocket. You can fire them off until you hit that one where they say, "Oh my God, that's really offensive." Then you just backtrack and say, "I



know, isn't it? When Frankie told me that, I was pissed. I said I didn't appreciate it and told him to just keep those jokes to himself. Racist bastard."

In the olden days, when I grew up, life was not like this. Believe it or not, people enjoyed laughing. They didn't analyze a joke wondering if or how it could be offensive. They just took it at face value and if it was funny, they laughed and, here's the kicker, they moved on with their day, even with a smile. I believe there's only about ten percent of the population that gets offended by jokes. These are people who have no sense of humor, no life and lack purpose that they feel they must right the wrongs of society. Most of them have PHD's so they think they know what's best for everyone. They get shows canceled, comedians ostracized, employees fired, etc. They demand apologies then never accept them. I would like to go through their history and search letters, emails, Tweets to pull out things that they said that was inappropriate. Then, cancel their asses.

Sadly, it's become a thin-skin society and we're all paying the price. Our freedom of speech becomes more eroded everyday. The offended are destroying the culture of fun for all of us because they lack fun in their lives so why not tear it all down. Ban the laughs is their motto. As a comedian, when I write a joke, I find myself mumbling, "Nope, can't use that one. It could offend poodle owners." We used to look to comedians to say the things we were thinking, but didn't have the guts to say. But even the comedians must tip-toe with material knowing one trans joke could end their career. We miss

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 vaudevillian 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.



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you, George Carlin. Tell me he wouldn't have field day with the easily affronted woke crowd.

I used to love it when I ran into a friend and he would say those six beautiful words, "Did you hear the one about..." I never considered it a mortal sin to laugh at stereotypes of groups of people. The Irish drinking too much. The Italians in the mafia. The dumb Pollock. The ditsy blonde. Can't we just laugh, people? Keep in mind that almost every joke has an element of truth given the listener a connection that makes them laugh. Using "rocket scientist" instead of "blonde" probably wouldn't work in your typical blonde joke. As a rule of thumb regarding jokes, don't analyze, just laugh.

Every year the bar gets raised higher to tell jokes that won't be construed as offensive. At this rate they'll be no jokes to tell. We need jokes! We love jokes! What else is there in this stinking world. For all those who get insulted and upset, keep it to yourself. Maybe consider getting an emotional support animal. Don't ruin it for those who have a life. Here's a news flash. If you find a joke offensive, don't worry, nobody dies. Just to finish... So, the blonde asks her to stick her head out the window to see if the blinker is working. Her friend sticks her head out the window and says, "Yes, no, yes, no..." There, was that so bad. Now, just laugh and move on with your day. ■ **ABILITY**



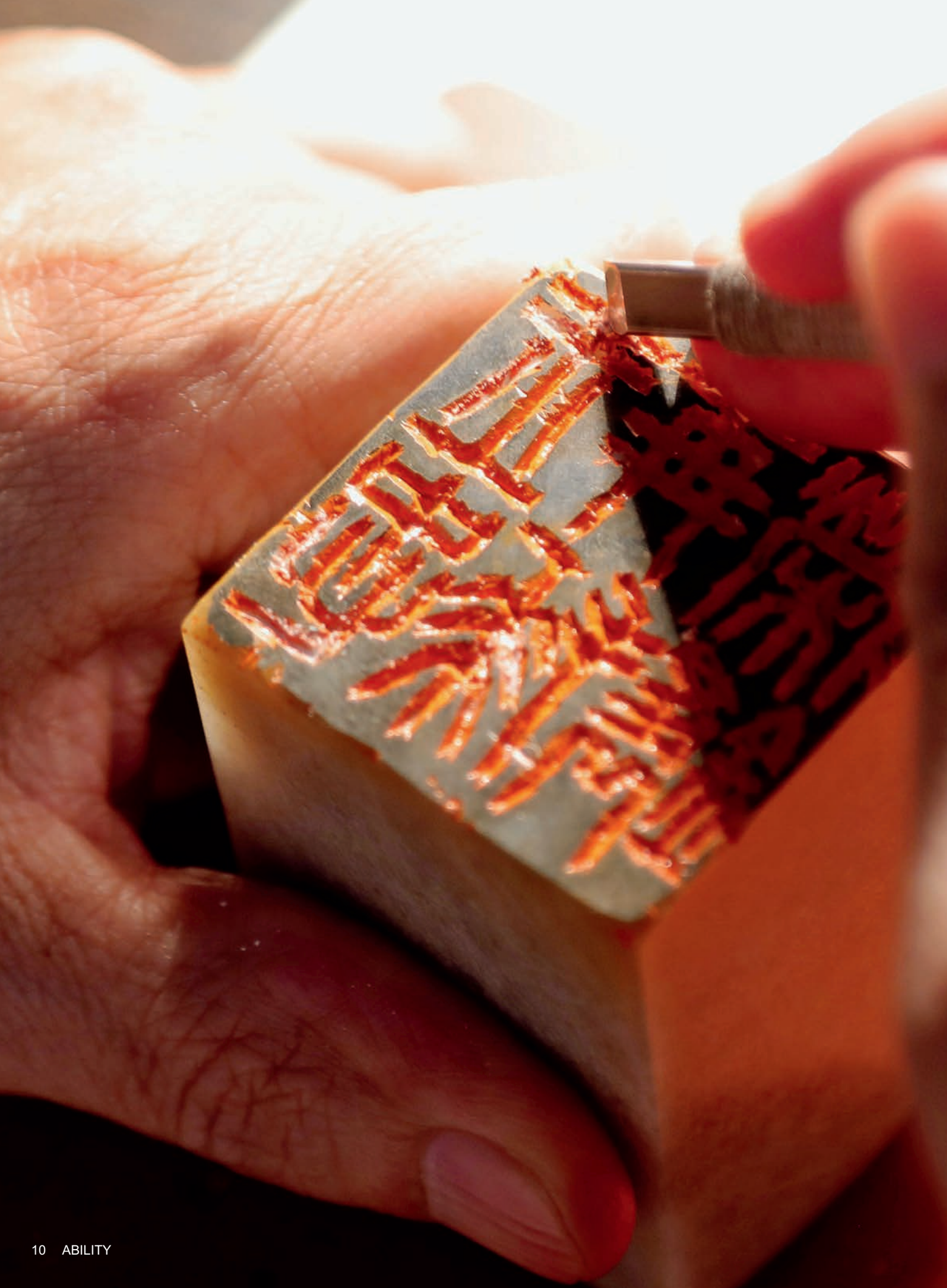
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BYGONE BUFFOONERY

Stories lost in time Reimagined
by a comedian who's lost his mind

Jeff Charlebois



王玉忠 石头放不下 传统丢不了

Wang Yuzhong: Preserving Chinese Seal Cutting Tradition

Wang Yuzhong was born in Beijing in 1958 and survived polio, Wang has persevered in the art of Chinese seal cutting for more than 40 years. In his young adulthood, his studies with Chinese seal cutting master Mr. Liang Yanyu gave him a foothold in traditional Chinese seal art. His further mentorship with Chinese calligraphy virtuoso Mr. Kang Yin led to the development of his own style. More recently, Wang's move to the guidance of traditional Chinese artist Fan Zeng elevated his calligraphy-based seal cutting skills to an even greater height.

In the Analytical Dictionary of Characters, one of China's earliest reference books on the philology of the Chinese language, the character “勒” (pronounced “le” in Chinese, as in “clutch”) is defined as a pattern of lines that the constant forces of water may leave on rocks. It carries a cultural connotation that even the slightest trickle of persistent effort can make a difference, attaching greater significance to a process-driven mindset than to a result-driven approach, as the Chinese four-character idiom “constant dripping wears away a stone” implies. Nowadays, people seem more captivated by the allure of instant gratification. They rush hither and thither, trying to be everywhere, all for the sake of achieving some result in the shortest span of time possible. Few would want to stay put and watch one slowly drill through “stone.” But there are always individuals who, with loyalty, tenacity and even ecstasy, save the “stone” and keep it for as long as possible.

Deep in the China Bookstore on Glass Street in Beijing, one can find a small room branded with the name “Le Hut.” Wang Yuzhong, the owner of this property, refers to himself as the “Seal Creator of Le Hut.” He's been practicing the art of Chinese seal cutting for over 40 years, during which time he's refused all offers of financial support to open a seal boutique store in the capital or to practice the art in Japan. He wouldn't leave his studio, his city or his country. “There would be no art creation in its truest sense if I went to Japan, just a money

grab,” he said. “Things will not feel right if they are separated from their own culture.”

Wang's 10-sqm studio is often glorified when noteworthy people come to seek a piece of his handiwork. It is a life well portrayed through a line from a famous Chinese poem, “No one illiterate I surround myself with.” But this is not what really matters to him. What does matter is when his stone, by some terrible accident, is dropped to the ground.

“I can hardly move when I see stones.”

When Wang Yuzhong was seven months old, he was infected with the polio virus (poliomyelitis). Fortunately, this turn of fate didn't afflict him with a sense of inferiority. “Don't take pity on me,” he insisted. “Although my legs and feet don't work well, we are equal.” Native Beijingers are known to have much rolling off their tongues once they start talking, but Wang is calm, reserved, but nevertheless sincere in all he has to say.

Wang Yuzhong studied alongside able-bodied children until he finished high school in 1975. His family started to plan early for his future, hoping that he could support himself as soon as possible. Chinese universities were off-limits to students with disabilities at the time. Wang's uncle worked in the Capital Stenciling Factory. A craftsman of the older generation, skilled in making traditional Chinese hairpins of gold, silver and copper, he offered Wang guidance and inspiration and brought him into the seal cutting business. To secure for him a job that could be performed entirely by hand, Wang's uncle took him to Liang Yanyu, a renowned seal artist who also worked in the factory, after Wang graduated from high school. There, he began to learn the art of seal cutting and calligraphy. The seal cutting maestro became a great positive influence, teaching Wang Yuzhong not only how make good seals, but also how to be a good man.



Wang Yuzhong with Mr. Liang

Wang's first job after graduation was in a mimeograph factory set up by the Fengsheng Sub-District Office of Xicheng District, Beijing, where most of the employees were elderly or had disabilities. At first, he was assigned to the printing work group. Later, he moved to the stenciled lettering group. Over 40 years have passed, and the factory has long ceased to exist, whereas Wang is still in business today. This far exceeds his original expectations. He had often entertained the idea of quitting. "The reason I really couldn't stay was the bad environment," he explained. "People around me either were elderly or had disabilities, and many of them simply killed time at work, expecting government support. The thing is, if you've lost your legs, you still have your hands, and even if you've lost your hands, you still have your brain. You've got to do something."

Mr. Liang Yanyu once owned a famous stone seal cutting franchise store—Engraving House—on East Glass Street, until the People's Republic of China was founded in 1949. In the mid-1950s, the Engraving House was merged into the Capital Stenciling Factory. About a decade later, the brand name was restored to its original status. Later, the Xuanwu District Government further revived it at the Glass Street location.

In 1978, Wang Yuzhong left the mimeograph factory to work in the Engraving House. He'd been one of the earliest students there by the time China began to implement its reform and opening-up strategy. A ride on this high tide would still require hard work. It seemed at first like just another job, but as time went on, Wang found himself increasingly drawn to it. He discovered that whatever there is to be done, one must immerse oneself in it completely. "Once you delve in, it will be amazing."

Stenciling is also a step-by-step process, and handwriting

a standard script was all Wang did in the Engraving House, as it is usually the step that follows engraving. At that time, the rules were very strict, and "script work" should be nothing other than "script work". "If we did something different, that would be thought of as wicked and out of line. At that time, when we occasionally spilled some creative juice, we would be criticized for goofing around." Several years later, a dissatisfied Wang Yuzhong resolved to take a shot at being his own boss.

One morning, Wang ran into a friend who was working in the Industrial and Commercial Bureau, and their exchange unfolded as follows:

"What keeps you busy these days?"

"Trying to start my own business. What would you say about stenciling?" The question rolled off Wang's tongue.

"I see nothing wrong with that."

Wang Yuzhong thus followed his friend directly into the bureau, filled out the forms and then went back to work. Surprisingly, he got his business license within a week. Beijing's first self-employer was licensed in 1982, and Wang Yuzhong joined this new group in 1984.

Following the implementation of China's reform and opening-up policies, the number of foreign tourists in Beijing began to rise. The Glass Street became a popular attraction, and with that emerged a group of gallery and painting shop owners, including many of Wang's old acquaintances, whom he'd known ever since beginning his apprenticeship. "At that time, most visitors were Japanese. They were interested in painting and calligraphy, and had a big appetite for seals. One customer bought as many as seven or eight seals in one purchase." Back then, it was common practice to attract business at the airport and other destinations. It was not easy for Wang to do that. The gallery owners would send interested customers to his small studio.

He kicked off his business from home, starting with seal cutting. Back then, he charged 30 cents for every character he was asked to engrave. "An apprentice and I would have to cut as many as 120 seals in one night," he recalled. "Sometimes the order would arrive at 11 o'clock at night, and we would have to deliver it by 7 o'clock the next morning." Staying up all night was a new normal. On average, at least 40 or 50 seals were carved every day, and the prices rose from the initial 30 cents to a staggering 5 yuan per character.

From his days in a home-based workshop to the current era of the Glass Street studio, Wang Yuzhong has continued to occupy the same 10-sqm hut through more than 40 years of changes. "In the 1970s and 1980s, one could get rich by trading in calligraphy and painting



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antiques. If you put your mind to it, it may still be quite good. But I have a one-track mind, and nothing else can attract my attention. I can hardly move when I see stones."

When you lead a horse to water

Seal cutting has a long history that dates at least to the use of imperial seals and signets, the progenitors of modern Chinese seals, in the pre-Qin period (2100 B.C. – 221 B.C.). Considering only their practical properties will yield no understanding of how they ushered into being an entire genre of art. Aesthetic value's played an equally important role.

From a stenciling worker to a respected expert in calligraphy and seal cutting, Wang Yuzhong is glad he's always had a teacher leading the way so that he didn't go astray. In his studio hang photos he took with three masters of art: Liang Yanyu, Kang Yin and Fan Zeng, all of whom were famous in China's painting and calligraphy circles.

Liang Jin, a grandson of Mr. Liang Yanyu, has been close to Wang for a long time, for they came up together as fellow disciples. "My grandfather had many apprentices," Liang recalled, "and most of them gave up halfway, as they were not really into this art and craft, or simply saw it as a way to earn money to pursue fame and fortune. Yuzhong was the only apprentice my grandfather took to heart after China's reform and opening-up in the 1980s."

"From the moment he took me in to the day he passed

away, he never once raised his voice at me. Back then, most teacher-pupil relationships would've involved at least a few harsh scolds," Wang Yuzhong said of his teacher, expressing deep gratitude. Mr. Liang had warned him, "Don't take yourself too seriously, and be modest." To this day, Wang has kept this piece of advice in mind, regardless of the skill he's acquired. "There will always be somebody better than you, so you'd better be modest." China Central TV once contacted him about doing a show, but he refused. "Seal cutting itself is an apex of art," he maintained, "and anyone interested will naturally want to learn about it. I don't have any stories to tell, just works to deliver."

Mr. Liang died in 1998, leaving Wang Yuzhong feeling empty. "My teacher was gone, and I lost my anchor and had no idea where to go." During that time, he put his mind to making money, but the more contact he had with the outside world, the less confident he became.

Wang's second mentor was Mr. Kang Yin, who helped him transcend the status of skillful technician and become an artist and a master. In 1985, Wang began to study inscription and calligraphy with Mr. Kang, a philologist and epigraphist who believed that the application of both calligraphy and seal cutting should be based on a rigorous study of ancient Chinese characters and knowledge of some pictographic rules. Mr. Kang greatly inspired Wang in terms of bronze script, official script and regular script. During his studies with Mr. Kang, a dive into ancient Chinese characters broadened his vision. "You can't presume to study calligraphy just because it's a fad all around, or you'll make yourself a fool," Mr. Kang would often warn his students.



Wang Yuzhong

The project that has brought Wang the greatest satisfaction so far is titled *Lisao*, the name of a classic Chinese poem. It has 96 paragraphs, 477 sentences and 2,472 characters. This text took him more than five years to inscribe on 217 stone seals. The idea originated from Mr. Fan Zeng, a teacher whom Wang Yuzhong met through a friend in 2002, and on whom he left a good impression. “Known to me is a man of humble, loyal and benevolent character, and his works are of unyielding strength and integrity,” Mr. Fan said of Wang after seeing a few of the seals that he’d brought to their first meeting. “Come often when you have the time,” he added upon parting. In 2008, Mr. Fan took in seven craftsmen as his closed-door disciples and presented each with a piece of his calligraphy work as encouragement. To Wang Yuzhong, he gave the inscription, “Extremely skilled and well off on a middle way.”

Mr. Fan Zeng told Wang to learn more about traditional Chinese culture. When Wang was preparing to work on *Lisao*, the sheer size of this project was intimidating. “Take it slowly, it will take years of focused work,” advised Mr. Fan. In 2019, *Lisao* was finally completed. For Wang, this also marked a milestone of his professional growth over the years. Works of art invariably reflect the course of social evolution. There were times when fashion also intrigued Wang, but over time, he found that his artwork was not meant to be fashionable, and that he still needed to uphold tradition. “Working on *Lisao* was like pumping the brakes,” he reflected, “when I was headed in the wrong direction.”

“‘Hate’ or ‘love’ the stone?”

Randomly turning a page of the text version of *Lisao*, Wang Yuzhong points to the characters inscribed in the style of Yuan Zhuwen, one of the earliest seal cutting artists in the Yuan Dynasty. “These lines are all alive, and they run full and mellow, but now many people don’t really care if they inscribe in Tiexian or Yuan

Zhuwen Style.” The topic of seal cutting seemed to raise his spirits. “Chinese seals follow strict rules,” he explained, “yet with the right mix of both dense and loose lines inscribed in a steady and natural manner. Run wild as a horse, or close up tight in places where you should. Qin seals are diverse in style and mostly have dense patterns. What makes it a good seal is that you can trace it back to something traditional. It’s not just for fun.” He speaks of preserving tradition as if there are engravings on his very veins.

When working on a new idea, Wang usually conceives of it in his mind first instead of sketching it on paper. “Once it’s there in my mind, I’ll write directly on the stone and keep going as far as my mind takes me. Nothing can hold me down. My thoughts are always changing, and I just go along until I can’t change anymore.” Traditional Chinese culture has been passed down through a continuous lineage and is vividly reflected in seal cutting. Every character that Wang cuts out fits into that tradition, though imbued with innovative elements as well. New styles and patterns should always honor morphological traditions.

Mr. Fan once joked, “You’ve been expressing enmity for stones for decades, carving, cutting and grinding them. Why don’t you simply call your studio ‘Stone-Hating Cottage’?” After that, he thought about it for a bit and then wrote a banner for the property: “Stone-Loving Cottage.” But what does “love” mean here? “It’s just that you have to love it to make something good with it, just like loving your wife.” According to Wang’s wife, however, he loves stone even more than he loves her. “He doesn’t like to go out or travel,” she said. “He feels right only when he settles himself in this room.” The employees of China Bookstore arrive at work at 8:30 in the morning, but Wang usually arrives at 8:00 am, even on cold winter days, earlier than the security staff. Sometimes, when it rains in the morning, making his commute difficult, he waits with agitation. The minute the rain stops, he dons his coat and hurries off to his studio. Only then does he feel at peace.

“The insider knows the ropes,” as the saying goes. People in the seal cutting circle take pride in owning a seal created by Wang, but the himself artist doesn’t much care what others think of his works. “Anyone who knows will naturally know,” he maintains. “Even me. When I finish my work today—wow! But when I look at it tomorrow, ouch! Art knows no end.” ■ ABILITY

by Wang Yumeng



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

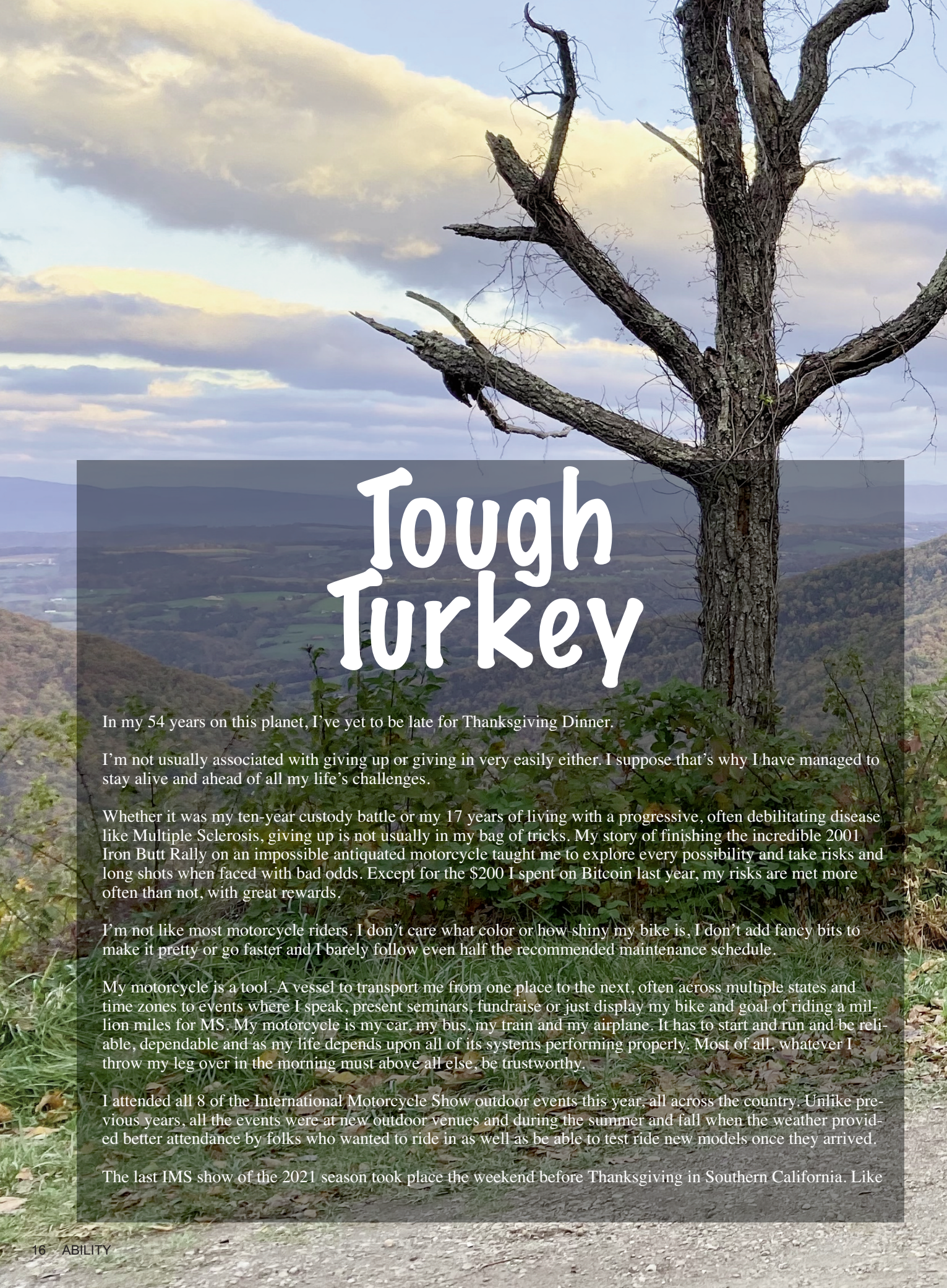


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Tough Turkey

In my 54 years on this planet, I've yet to be late for Thanksgiving Dinner.

I'm not usually associated with giving up or giving in very easily either. I suppose that's why I have managed to stay alive and ahead of all my life's challenges.

Whether it was my ten-year custody battle or my 17 years of living with a progressive, often debilitating disease like Multiple Sclerosis, giving up is not usually in my bag of tricks. My story of finishing the incredible 2001 Iron Butt Rally on an impossible antiquated motorcycle taught me to explore every possibility and take risks and long shots when faced with bad odds. Except for the \$200 I spent on Bitcoin last year, my risks are met more often than not, with great rewards.

I'm not like most motorcycle riders. I don't care what color or how shiny my bike is, I don't add fancy bits to make it pretty or go faster and I barely follow even half the recommended maintenance schedule.

My motorcycle is a tool. A vessel to transport me from one place to the next, often across multiple states and time zones to events where I speak, present seminars, fundraise or just display my bike and goal of riding a million miles for MS. My motorcycle is my car, my bus, my train and my airplane. It has to start and run and be reliable, dependable and as my life depends upon all of its systems performing properly. Most of all, whatever I throw my leg over in the morning must above all else, be trustworthy.

I attended all 8 of the International Motorcycle Show outdoor events this year, all across the country. Unlike previous years, all the events were at new outdoor venues and during the summer and fall when the weather provided better attendance by folks who wanted to ride in as well as be able to test ride new models once they arrived.

The last IMS show of the 2021 season took place the weekend before Thanksgiving in Southern California. Like





every cross-country trip I take, I loaded up the bike with my clothes and gear, changed the oil and the rear tire and headed out for a three day, 3300 mile ride from New Hampshire to California.

The bike was rolling along great and I was making good time until somewhere in Virginia. It was my third stop of the day for gas and a quick restroom break. Getting back on the freeway, I was soon met with stopped traffic from an accident a mile ahead. As I was slowing to a stop, the bike started to cough and the engine died. I rolled over to the edge of the lane and tried to restart it, but it would not catch. I tried a few more times as the traffic was limping forward and finally it started, but would not stay running. I found by revving the motor constantly, I was able to move ahead with the traffic. A few minutes of this and the traffic cleared the wreck and we were running at full speed again. But the engine wasn't right, I was finding I had to keep it revving very high to stay running. Once I reached a reasonable speed, it seemed to do ok.

My first thought was I had picked up some bad gas at the last stop and it was clogging the pump or fuel system. My bike had 74,000 miles on it and fuel filters getting plugged were common at about this mileage. I seemed to be doing ok if I kept riding at high speed, so I did just that. My thought process was that running through the bad gas in about 4 hours would be easier than having to find a dealer or a place where I could remove and drain my tanks without losing a day or hours that would make me late for California. My plan

was to push through the bad gas as fast as I could at high speed and refuel with cleaner gas as soon as possible. I hoped and believed this would clear it up.

Well, by the next day I had refilled 5 or 6 times, and the engine did not get any better. It would not idle at all, it would sometimes struggle to go 65 mph and other times still pull hard at 80 mph. I was pouring in fuel additives and snake oil at every gas stop hoping to unclog whatever was damaged by running the fuel through the engine. One thing for certain was I was getting half the efficiency I was used to, and barely 25 mpg!

I called my friends at Yamaha to discuss and asked that they ship a new fuel pump and filter assembly to California, where I would have a couple hours to swap it out as well as the help of the factory technician attending the trade show.

I made it to California, not without worry and fear, as Los Angeles traffic is bad enough not having to navigate it with a bike that stalls every time we slowed down! I arrived exhausted, beaten from the uncertainty and dread of breaking down each of the three days and 45 hours I spent attempting to reach the other side of the country, but received that we would fix it and I would be able to have less stress on the ride back home.

The show was busy, but I managed to get the new fuel pump installed between delivering seminars and greeting fans. My bike was hidden from display as tools and parts were sprayed all across the ground waiting for me



to complete the repairs. The tech brought me a set of spark plugs and an air filter and we also changed the past due oil and filter, hoping the bike would run like new again. Unfortunately, after a day of repairs, it still ran terribly. The computer did not show any electrical issues and all fingers were now pointing to the fact that I had just ridden it 3000 miles in very poor condition and probably messed up the injectors or damaged the valves.

By Sunday, I had removed, cleaned, tested just about everything I could manage to get to in a parking lot with limited tools. My engine had real damage and needed to be brought to a dealership for diagnosis and repair. I was faced with a grave decision.

I saw only two options. I could leave the bike and all my gear at a California Dealer, try to find a flight Thanksgiving week to New Hampshire and then a return flight after the bike was fixed, possibly months later. Or, I could take a big chance and try to limp the barely running bike 3300 miles home, crossing the entire country yet again. Of course, it was the week of Thanksgiving, and if riding through holiday traffic on a bike that wouldn't idle or go over mountainous hills was bad enough, I also had to be home the day before Thanksgiving if I wanted to stay happily married!

The Technician in California wasn't very pleased with my choice to risk breaking down and further damage to the motor, and bet me \$50 the barely running bike

would not make it all the way to New Hampshire.

I choose to ride Yamahas because they are dependable, reliable and have never left me stranded. Any and all issues I have had over the last 500,000 miles were self-induced, and if I did break down heading for home it certainly would not be the bike's fault. After getting me to California I felt I could trust my bike to do it's best and I was not about to give up either.

Despite learning afterwards that my engine had suffered a burnt valve and I was riding with zero compression in one of the two cylinders, my T7 and I rode across the entire country in three days, arriving home just in time for turkey, hot potatoes and the best gravy ever! ■ **ABILITY**

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STEPHANIE ORTOLEVA

With a resume spanning decades, Stephanie Ortoleva, Esq. has founded, headed or sat on the boards of more groups and organizations than one could hope to shake the proverbial stick at. A civil rights attorney and scholar by training, she served in the US Department of State from 2004 to 2009 as a Human Rights Officer and as the Disability Coordinator. During that time, she represented the US government at the negotiations of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), worked in partnership with the UN and the Organization of American States, and advanced the participation of women and persons with disabilities in areas including peace-building and post-conflict resolution, economic development, violence prevention, environmental preservation and fighting infectious disease. In 2009, she received the prestigious Franklin Award for her work on human rights and was the State Department's featured employee for Women's History Month. And yet, as far as Stephanie was concerned, she was only getting started. Frustrated by the absence of intersectional initiatives for women with disabilities, she founded her own organization. Women Enabled International (WEI), incorporated in 2011, partners with grassroots organizations around the world to provide support and resources to women with disabilities and arm them with international expertise and legal tools. After serving for 10 years as WEI's executive director and heading up projects around the globe, in 2021 Stephanie decided the time had come to pass the torch to the next generation. ABILITY Magazine's Mekiya Walters spoke with her about making the world a little bit better for women with disabilities than it was the day before.





Ortoleva & US Congresswoman Shela Jackson Lee at IFES Congressional Briefing on Women with Disabilities, Peace & Security — 2016

Mekiya Walters: What motivated you, as a young person, to pursue this particular constellation of interests: law, activism, scholarship and civil rights issues?

Stephanie Ortoleva: Well, I was born with low vision and gradually became blind, so a lot of it was lived experience. I have a degenerative condition called congenital glaucoma. Basically, there's too much pressure in my eyes, and that caused damage to the retinas and the optic nerve. Nowadays, they have surgical techniques for it, but back then, there was nothing the doctors could do.

I grew up in a suburb of New York City, and I was one of the first blind people in the community to go to a "regular" school, as opposed to a segregated program for people with disabilities. That made a big difference for me. It gave me a sense of empowerment and made me feel that I was part of the mainstream community. I've retained that feeling all my life.

My parents were very supportive. Very loving. My extended family was another story, but they didn't have much say in raising me. In my early years, I didn't experience much discrimination. When I got to high school, there was one teacher who told me, quite bluntly, "You really shouldn't go to college, you know.

You're just a blind woman." That upset me! Of course, I went to college. No one tells me what I can't do. I met some very supportive professors, I worked hard, I did well, and years later, here I am.

Mekiya: Here you are! That would've been — what? The '70s? There wouldn't have been much assistive technology available then. How did you navigate the education system? Were you mainly using Braille?

Stephanie: I never actually learned Braille. Earlier in life, I wasn't totally blind, and I'd always find myself cheating by looking at the dots whenever I tried to learn. Turns out that wasn't very productive! I just read large print until I couldn't anymore.

Mekiya: And then?

Stephanie: I taught myself to use screen readers once they came along. That made a big difference for me, personally and professionally. It was very, very liberating. I got pretty good with technology, to the point where my husband was the one asking me for help with the computer, and he has no visual disability at all. I'm not quite on the cutting edge like I once was, though; I'm one of the few people still using the old Window-Eyes program. At some point, I know I'll have to teach

myself JAWS because it's the dominant program now, and Window-Eyes has mostly been discontinued. But the thought of tackling a new software right now, in the middle of starting a business, is a bit daunting.

Mekiya: Understandable. I want to talk about the business, but first, going back to your college years--

Stephanie: Yes. I graduated and worked a couple jobs, but at a certain point, I began to feel that the law was calling to me. There were people who discouraged me from leaving my established job and running off to law school, and I think they had good intentions, but again, no one tells me what to do. I went to law school.

Mekiya: To study international law?

Stephanie: Back then, most American law schools, including my own, focused only on domestic law. I studied constitutional law and civil rights law. International law came later, when I was working for the State Department.

Mekiya: Did they hire you straight out of law school?

Stephanie: No, I started with the US Department of Education, in an office specializing in civil rights--where I met my husband, actually. You know, office romance: that taboo thing that was strongly discouraged!

Mekiya: Wait, I want to hear more about that. Do tell!

Stephanie: Well, it's funny, isn't it? Once you reach a certain age, you're either going to meet your partner through your friends or through your office. Work is such a dominant part of one's life, there's no point in trying to keep romances from occurring. My husband and I were very discreet, of course. Some of our colleagues didn't even know we were living together. That went on for a couple of years!

Mekiya: So, you were in stealth mode, I guess?

Stephanie: Exactly!

Mekiya: Right. Okay, back to the State Department--

Stephanie: The State Department. I was getting more and more interested in international issues while I was working at the Department of Education, so eventually I found my way over to State.

Mekiya: What was your purview there? Were you working on women's rights issues? Disability issues?

Stephanie: Human rights. Which is a pretty broad umbrella. One day, I'd be working on women's issues, and the next I'd find myself working on disability issues. After a while, I began to notice how the work on

women's issues rarely included women with disabilities, and the work on disability issues rarely included women. At a certain point, I decided to leave that job so I could drill down on the intersection of gender and disability.

Mekiya: Was that when you founded Women Enabled International (WEI)?

Stephanie: Exactly.

Mekiya: I'm curious, since we're an international magazine, about the international trajectory your career has taken. How does your international perspective inform your work?

Stephanie: I think it's essential to approach any kind of international collaboration as a cooperative effort, not as something dictated by me or anyone else here in the Global North. The concerns that I have, as a blind woman in the US, are going to be very different than those of, say, a blind woman in Guatemala. We were always committed to approaching our partners as the experts on the situations in their countries because, if you're in Uganda, you'll know a lot more than I do about what's going on in Uganda. Obviously. We weren't there to tell them what to do. We were there to provide them with resources.

Mekiya: What kind of resources?

Stephanie: A lot of it was legal guidance. We'd help them identify whatever leverage they had and how to apply it. Basically, we'd teach them how to work the international system. We'd also mediate conflicts sometimes. For example, in one country, there was a conflict because the disabled women felt they weren't being included in what the disability rights movement was doing at the international level. We supported the women and made sure they had a seat at the table.

Mekiya: Did you collaborate with third parties?

Stephanie: We'd often work in partnership with the United Nations. Whenever a government ratifies a treaty--not something we're all that familiar with here in the States; we still haven't ratified *several* important human rights treaties!--that government comes up for review every few years by the body that supports the treaty. Sometimes, we would work with our colleagues in other countries to help them prepare and submit shadow reports to the treaty body.

Mekiya: What's a shadow report?

Stephanie: The government has to submit a report, but the public can send the treaty body one of its own, which is called a "shadow report" because it sort of shadows the government's report. International collaboration is especially important here because it makes it



Ortoleva and UN Special Rapporteur on Violence Against Women Rashida Manjoo — 2011

harder for hostile governments to intimidate their critics or suppress information that might cast a negative light on them.

Mekiya: I think you were alluding just now to how the US still hasn't ratified the CRPD. What impact has that had, if any, on your work with WEI?

Stephanie: Not much because our focus is global. We'd occasionally prepare reports on things going on in the US, but that's really not the focus of our work. That said, it's disappointing, infuriating, *mind-boggling* that the US hasn't ratified that treaty! Especially since we were so active in drafting it.

Mekiya: You were one of the delegates, weren't you?

Stephanie: Yes. When I worked at the State Department, I was part of the US governmental delegation that negotiated the CRPD.

Mekiya: What was that experience like for you?

Stephanie: It felt a bit strange, to be honest, because I was officially representing the US government, but in my heart of hearts, I was more on the side of the

activists. I met a lot of activists there because it was one of the first major treaties where a lot of non-governmental organizations were actively involved in the negotiations. I also got to meet with leaders from some other governments, which, frankly, were far more supportive of disability rights than our own.

Mekiya: How did the negotiations work? How were compromises reached and decisions made?

Stephanie: As with most negotiations, there was the formal part, where nothing much really happened. Representatives from different governments would get up and give prewritten speeches. And then there were the informal negotiations--the backroom conversations, if you will--where the real work got done. That's where we'd make each other promises, haggle over compromises, trade power, if you will.

Mekiya: Since then, have you witnessed significant changes in the international disability rights movements, especially with regard to women with disabilities?

Stephanie: Nowadays, there are many more organizations focused on disability issues than there used to be. That's happening all over the world. And more of those

organizations are run by women and focus on women's issues. It seems to me that women with disabilities are really beginning to claim their share of power in the world. In more and more countries, we're making our voices heard.

Mekiya: That encouraging. How do you think it's manifesting in day-to-day life, at the grassroots level?

Stephanie: Hard to say because it's different everywhere you go. In my personal experience, when I went to law school, and even when I first started teaching, none of the law students had ever met anyone with any sort of disability. At least not that they knew of. As time's gone on, especially in the last several years or so, it seems like that trend has almost reversed. Pretty much every legal intern who's worked with me recently has had some kind of prior experience. Most say they've had classmates with disabilities. Maybe it's just selection bias--after all, they're the ones who chose to work with *me*--but still, it's encouraging.

Mekiya: Does that change the dynamic in the classroom?

Stephanie: It changes the comfort level. Nowadays, the non-disabled students and interns seem a lot more comfortable working with me. They're not so timid. They're not walking on eggshells all the time. That's good because we don't have to spend so much time figuring out boundaries. We can just dive right in and get more work done.

Mekiya: Do you think there's been a corresponding shift in media representations of persons with disabilities? Or is the media still behind the curve?

Stephanie: Definitely still behind the curve. There's very little attention paid by the media, in the US or internationally, to disability issues. Especially where they intersect with women's issues. At WEI, we made some efforts to reach out to mainstream media outlets to get these issues covered, and we found that it's extremely difficult to penetrate the mainstream media sphere. Maybe they'll do some cute little story on International Disability Day, but even then, they'll end up applying some outdated framework, like the medical model. They don't seem to think there's any appetite whatsoever for--well, for what we're doing now. A deep, probing interview.

Mekiya: Speaking of the medical model and problematic frameworks, how do you feel about the terms we use to talk about these issues? Words like "disabled" and "non-disabled"?

Stephanie: I'm troubled, frankly, by the language we use. "Disability." "Handicap." They're not very positive words. They've been imposed on us by the outside world, so that's problematic, but even when we choose

our own language, there aren't really any easy answers. For example, with person-first language, you're supposed to say "person with a disability" instead of "disabled person." But for disabled women, it gets a bit trickier. Whichever one you put first, that's the identity you're emphasizing. So, are you a "woman with a disability," or are you a "disabled woman"? There's a lot of disagreement around that.

Mekiya: Where do you come down on that? Which do you put first?

Stephanie: It depends. In some circumstances, my gender has a greater impact on the interaction. In others, it's my disability. I thought about that a lot when I was founding WEI. I knew I didn't want to call it "International Disabled Women" or something like that. I went with "Women Enabled" to put the emphasis on what we can do.

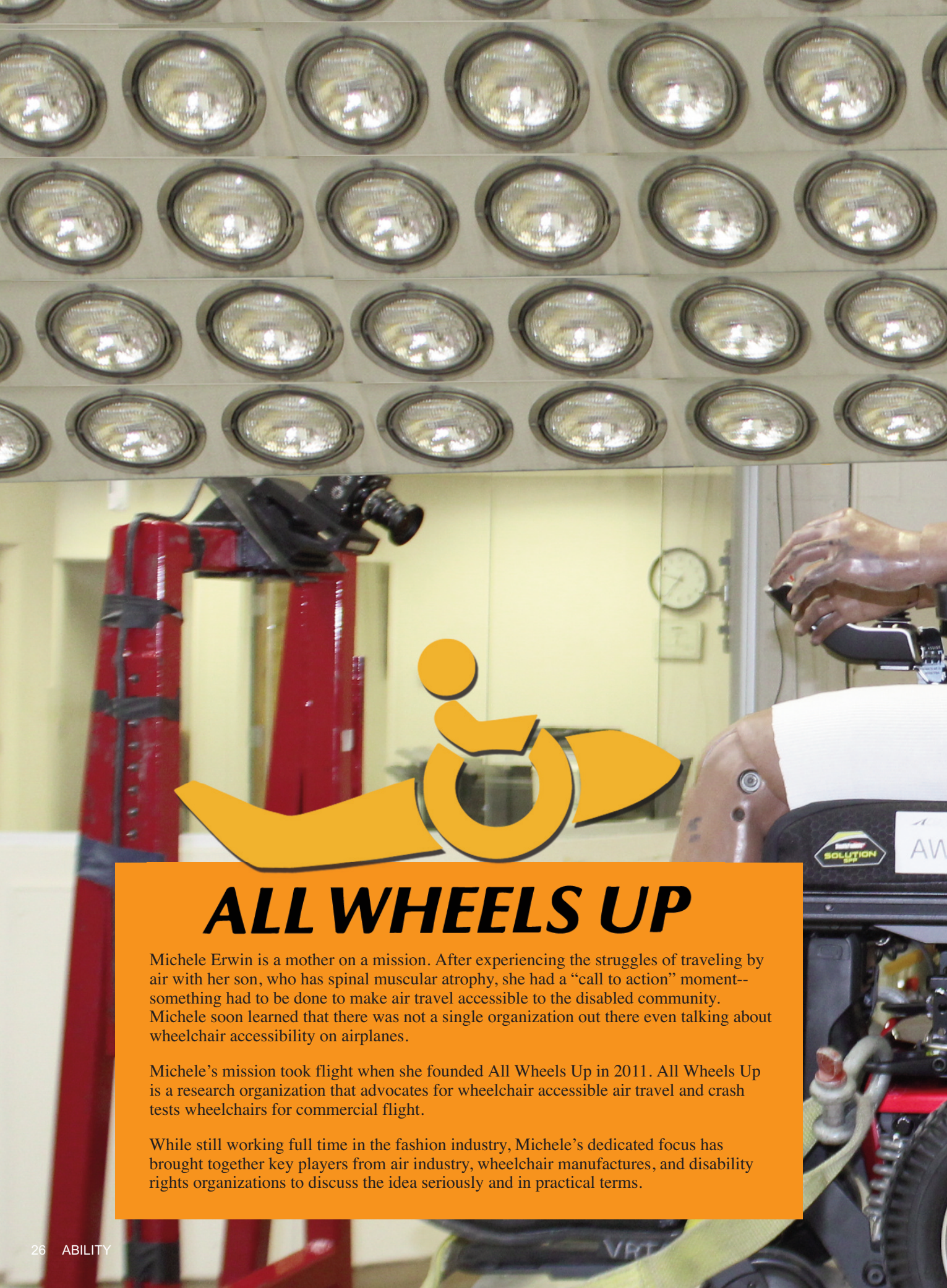
Mekiya: I guess you're probably going through that process all over again, now that you're starting a consulting business.

Stephanie: Yes. By the way, I want to say something about why I left WEI. My mother used to have this theory that, every year, on her birthday, she ought to find one new friend who was one year younger than the youngest friend she already had. That was how she kept up with the younger women. She taught me how important it is to connect with young people and draw from the strengths of the upcoming generations. That's why I left WEI. As the founder, I was always going to have a lot of influence and power in that organization, and I didn't want my objectives and ideas to overshadow those of the younger leaders. I think it's vitally important that they're not just involved with this work, but also empowered. Without young leaders, the movement will die.

Mekiya: You don't hear that very often. I really appreciate it, actually. From where I'm standing, as a Millennial, it does seem like we're more often shut out of power. But at the same time, you've got a lot of experience and institutional memory that younger people don't have, and you need that to accomplish anything of substance in the world. Are you also finding ways to pass that on?

Stephanie: That's why I'm starting the consulting business, so I can keep working on the issues I care about and passing on knowledge to anyone who wants it or needs it. I'm still figuring out exactly how it's going to work, but I know the primary goal is to help individuals and organizations understand what disabled women and girls have to offer and how to include disabled women in their work. ■ **ABILITY**

stephanieortoleva.com



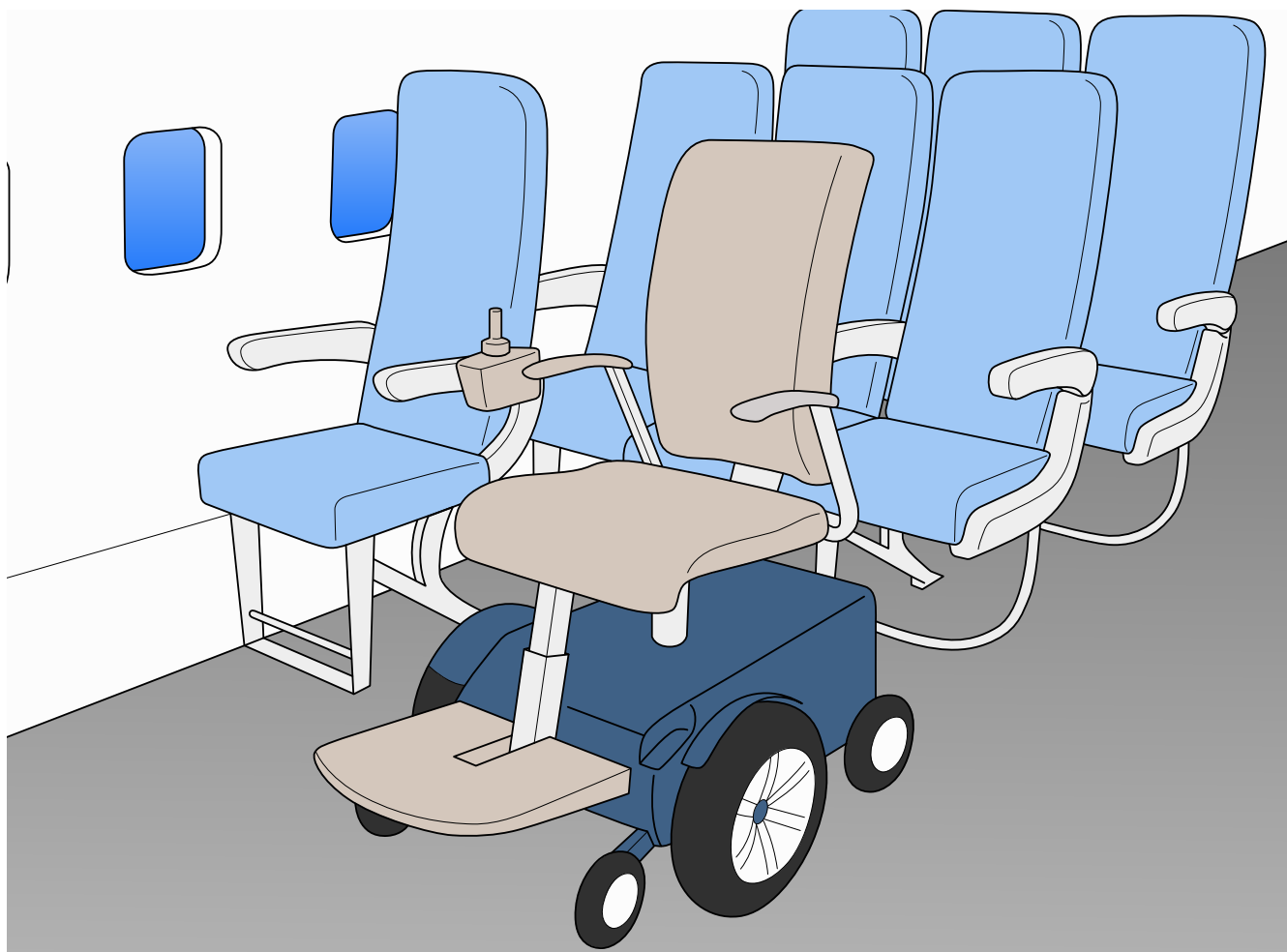
ALL WHEELS UP

Michele Erwin is a mother on a mission. After experiencing the struggles of traveling by air with her son, who has spinal muscular atrophy, she had a “call to action” moment--something had to be done to make air travel accessible to the disabled community. Michele soon learned that there was not a single organization out there even talking about wheelchair accessibility on airplanes.

Michele’s mission took flight when she founded All Wheels Up in 2011. All Wheels Up is a research organization that advocates for wheelchair accessible air travel and crash tests wheelchairs for commercial flight.

While still working full time in the fashion industry, Michele’s dedicated focus has brought together key players from air industry, wheelchair manufactures, and disability rights organizations to discuss the idea seriously and in practical terms.





Denise Miller: How did you get involved going from fashion design into airplane wheelchair accessibility design?

Michele Erwin: I have a son who has spinal muscular atrophy or SMA. It's a neuromuscular illness very similar to ALS, but it affects children. It's a muscle-wasting illness. He uses a wheelchair.

I was traveling with him when he was young and learned very quickly how difficult it was to travel with a wheelchair. On a very frustrating flight, I was thinking, how is he going to do this when he goes off to college or has a career and needs to travel for work? It dawned on me--how *do* people travel by air with wheelchairs?

When I got off that flight, I started doing research and learned that there was not a single organization out there even talking about wheelchair accessibility on airplanes. There was no one to call, no group to join, no one to share frustrations.

It hit me then that something's got to change. To be honest with you, I wasn't really looking to create a company; I wasn't looking to invest my life to trying to move this enormous air travel elephant! (laughs)

Miller: (laughs) What did you decide to do? Where did

you start?

Erwin: I decided that I was going to stick my flag in this issue and say, "OK, this is what I want to work on." I decided to move accessible air travel forward--more than the small box that the airlines regulated it in. The airlines general perspectives were "we've made it as accessible as we can," and expected the disabled community just be happy and accept that they tried to accommodate us.

Looking around me, I saw many modes of transportation offered disability travelers accessibility, like, lifts on buses, trains, wheelchair accessible cars, and more. I knew it was time make air travel as accessible as any other mode of transportation to the disability community. So in 2011, I started All Wheels Up.

Miller: So what is All Wheels Up? Is it a business or a non-profit organization?

Erwin: All Wheels Up is a non-profit. We don't make anything. We don't sell anything. We do not design anything. We are set up like a cure-based nonprofit. We advocate for wheelchair spots on airplanes. We advocate for funding in Congress and for things to happen.

We learned in 2011 that wheelchairs and wheelchair

securement systems that are currently on the market today pass a 20g crash test. The airplane seats that you and I sit in today are tested at 16gs. Just putting these numbers out there, it begged the question of why couldn't there be a wheelchair spot on airplanes if wheelchairs and tie-downs already go through the rigorous testing that they do.

Miller: Tell me about the wheelchairs spots and locking systems. How does it work?

Erwin: Our proposal is for those who use electric wheelchairs, as well as properly modified manual wheelchairs, to independently maneuver themselves onto the plane into the designated wheelchair spot. The wheelchair passenger could enter by either the front or rear entry of the plane. The passenger can fly comfortably and safely in their own chairs.

We have researched the crash test worthiness of wheelchair restraint systems and wheelchairs for commercial and private flight. All Wheels Up conducted the first ever crash test for wheelchair spots. We funded two crash tests one in 2016 and one in 2019—both proved to the FAA that the wheelchair spots were able to withstand 16 G-forces.

We don't think that there will be one type of wheelchair spot that will work for all airlines or all airplanes. I believe that there are multiple configuration ideas. We live in a world where every organization is full of ideas, and I think all of them should come to the table and all of them should be funded for research.

As for the locking systems, there isn't a device today that exists that the FAA has said is suitable for air travel. There are multiple companies working on that. But the goal is that there would be a universal locking system, just like in your minivan or on the bus that would be able to tie down any wheelchair. That is the ultimate goal. The goal is for the wheelchair user to use their favorite chair brand per se and not have to use a different brand. We are working with all of the wheelchair manufacturers.

Miller: Can you explain the cure-based non-profit approach?

Erwin: When I was saying we're set up like a nonprofit cure-based organization, they pay for all the tasks in the pipeline to a cure. There are maybe five tasks to that cure. We're paying for all of those tasks to be investigated and researched. We don't necessarily believe that, just like in drugs, that there's necessarily one solution.

Sorry that my dogs are barking!

Miller: (laughs) That's OK! They're excited!

Erwin: They're as excited as I am, darn it! "Where's

that wheelchair spot?"

Currently, we're funding university projects for support data, such as, budget impact models, regarding adding a wheelchair spot. Airlines may consider this a cost detriment, but we want to demonstrate that by adding a wheelchair spot you can save money and increase revenues.

We're all about information-sharing. We have been speaking for over ten years with the regulatory agencies, FAA, the FDA, DOT, RESNA, and other organizations that create these standards. We want and encourage all of these manufacturers to talk to each other. Our goal is to get everybody collectively working on accessible air travel; working toward the same goal.

Miller: Were you aware of the PVA's fight for the airline industry to keep tracking damaged wheelchairs?

Erwin: All Wheels Up works very closely with PVA and we are a part of the PVA informal coalition that works towards accessible air travel. We have a very good working relationship.

Miller: Do you know of Dr. Haseltine's work on protecting wheelchairs during travel?

Erwin: I am not familiar with Dr. Florence Haseltine personally, but I am aware of the cases. All Wheels Up applauds all work being done to improve accessible air travel. We are working on the long-term goal which is a wheelchair spot that will translate to safer travel for the wheelchair user (both physically and physiologically), as well as reduce the risk of damage of the wheelchair because it will be used as its intended use a transport seat vs luggage.

Miller: Where are you today?

Erwin: We're funding a strategic roadmap uncovering what actions need to be considered—like, financial impact, safe evacuation plans, and standards for wheelchairs that can be used in the designated spots. We are asking the hard question: how do we get from today, with no wheelchair spot on airplanes, to implementation and certification?

Every organization is considered a stakeholder—whether a plane manufacturer, an original equipment manufacturer who creates the inside of the airplane, to the wheelchair manufacturers and the wheelchair tie-down manufacturers—what is their role? When do they step in? When do they step out? When do they have to all work together? We're creating that road map because now we have multiple organizations that haven't necessarily ever worked together before, but are focused on the same goal. We want to create a successful collaboration.

Miller: You're like a hub.



Erwin: Yes. I definitely would think that we are the project manager of this in large scale, absolutely.

As funders and project managers, we make sure that the ball doesn't get dropped. We constantly beat that drum to make sure that the work is being done. If we have to fund it ourselves, we will, because we wouldn't be having this conversation today about a wheelchair spot on airplanes if it wasn't for the fact that All Wheels Up paid for the first round of testing back in 2016 and then subsequently funded the next round of testing in 2018. Airlines asked a lot of questions and we answered those questions. So basically, that's what we do. The airlines said, "Great, you've proved it's possible. What will it cost me?" That's now what we're coming to the table with.

Miller: How is a wheelchair stored during the flight?

Erwin: Power chairs, and any other heavy wheelchair, are stowed in the cargo part of the aircraft. The DOT requires airlines to return your assistive device in the same condition as it was received. However, that does not always happen. The working number that we're using, because it's good data before COVID, is 28 wheelchairs are damaged per day. That's over 10,000 annually.

Miller: That's a lot of damaged chairs.

Erwin: At the end of 2018, the government started requiring airlines to report the number of damaged devices. We are funding a paper right now to get what those numbers were prior to 2018.

We're also going to do a forward trajectory of what these numbers could look like in the future if nothing is done. I'm a part of the ACAA informal working group coalition of large organizations like Paralyzed Veterans of American, which leads that coalition, and others, but something I learned just recently is that while there's a mandate from the FAA Reauthorization Act for fines, no fines are actually implemented for damages of wheelchairs.

Wheelchairs are frequently damaged; there are cases where chairs have been dropped on the tarmac, and even lost. Disability activist Engracia Figueroa died in October 2021 due to the damage done to her custom chair by the airline. Engracia used a loaner chair that airlines gave her in July while her chair was being repaired. She ended up with sores because of an ill-fitted chair. She died due to the complications from the sores. We already know that there will be a public hearing with the DOT to discuss the damages of wheelchairs.

Miller: That is terrible. People's chairs are their lifelines; it's their connection to the world.

Erwin: I think for damaging someone's wheelchair is basically breaking their legs and their hearts. For the sake of argument, let's say the airlines are fined \$700 per damaged chair. I think it should be more, but let's use it. That's over \$7 million on 10,000 wheelchairs. What we should also be asking is why aren't the airlines fined? I understand that they're paying damages to wheelchairs, but why aren't they being fined? I think we should definitely be asking our Congress people why

this hasn't been implemented.

Miller: How has the pandemic impacted your activities?

Erwin: Back in 2020, when the world shut down, we were told that there was no appetite for accessible air travel. While there wasn't necessarily "work to be done," we didn't stop. We worked internally, figured out what we're going to do.

We launched our Fly Safe Today program. In our initial pilot program, we gave away special needs harnesses for those with reduced upper trunk strength to support them in the seat during air travel. We also gave away ADAPTS evacuation slings that can assist crews transfer special needs passengers in emergency situations. We ran out within 48 hours. We are now funding another hundred sets. We don't feel that people with disabilities need to fund their own safety, and if the airlines or airplanes or airports aren't going to provide this, we're going to try to do that. We're now providing these for free, all contingent on funding.

We have a deeper waiting list than the hundred, because there is such a need in white space for this program. It would appear that, again, we were the only organization looking to fund research for a wheelchair spot and the only organization looking to fund safe, accessible air travel within the parameters that is it today.

Also we are advocating in Congress for very specific ADAPTS evacuation slings to be added to every emergency kit, of which there are three on any single-aisle airplane, to be added to every plane.

Miller: How are the slings designed to work to help evacuate a disabled person?

Erwin: The slings can be brought on in the passenger's bag. If there is any emergency, the sling can slide under the passenger. The sling is from the head to below the knees. I think they're over six foot long. And they have multiple handles on each side. Several people can get that person down in the aisle and onto the sling. The sling can then be lifted by flight attendants or good Samaritans, and the passenger can be carried out safely.

This sling has already been used in an emergency situation. We sent this information on this particular evacuation to the FAA, the DOT, and the Senate Transportation Committee. This particular device was used in an emergency landing at Dulles Airport in 2018 with a young man who had cerebral palsy, and he was safely evacuated down the deployed slide. There was smoke in the cabin, and other people with disabilities and elderly were left on board because the crew didn't know how to get them off of the airplane. The ADAPTS evacuation sling was borrowed from this family because the flight attendants were unprepared. They borrowed this ADAPTS sling from this family to rescue the other people from that airplane.

If this is not an example of the airlines being ill-prepared for an emergency when it comes to people with disabilities, I don't know what is.

Miller: What is Congress doing? What's the next thing that's slated for you to talk to Congress about?

Erwin: We have a lot of different projects that we're working on. The first one is the ACAA, the Air Carriers Amendment Access Act. That is an updated version of the ACAA, which is the Air Carriers Access Act. Different wording is being added that specifically to make airplanes more accessible. We tried to get an expanding wording in there than just the very broad stroke of makes planes "accessible." We wanted to specifically have a wheelchair spot added to that. We were unsuccessful. However, we think maybe in the 2023 FAA Reauthorization Act, we push a little harder and maybe see where we can get there and ask for maybe funding for the OEM to invest specifically into that.

Erwin: There are so many things that we need to investigate. I'd like to see the reporting of how many disabled people are injured whether it is from the transfers from the wheelchair to the airplane seat or sustained injuries because of not having their wheelchair. I'd like to see some of these numbers. Just like we're really surprised with the number of damages of wheelchairs, I think we'd be really surprised. I have been told that Engracia Figueroa's death is not the first one; it's just the first one that's been reported.

We need to make sure injuries, meaning pressure sores or anything like that, are also documented. If this is happening, we should see if we can get the airlines to pay for medical services in addition to wheelchair repair damages.

Miller: So this kind of comes full circle--back to the wheelchair itself. Don't airlines have guidelines on how to stow wheelchairs?

Erwin: There is work being done by a lot of organizations, the airlines, the wheelchair manufacturers trying to figure out what the best way is to handle wheelchairs and have them be stowed. At the end of the day there is no best way.

For example, we can say, the best way for a 400-pound wheelchair is to have a lift and the lift from the ground up into the conveyer belt and in. Even if one airport has one lift, it's not getting to the gates that are in need of it. If there are over 40 gates at an airport, you need more than one lift.

Miller: Would this fall under a safety violation by damaging the wheelchair?

Erwin: I don't know if this is necessarily a safety issue in respect to the damage to the wheelchair. But I would



Michele Erwin

say that probably a safety violation is that airlines are the only organizations that get to sidestep OSHA. If you read OSHA regulations, employees can't lift over 50 pounds, and especially not in a twisting motion. You are required to use special devices. Airline crews are lifting disabled people into an airplane seat, and on top of that, they're doing that lift into twisting motion in a very small, very restricted area. And then you have four people lifting a 400-pound wheelchair, that's still 100 pounds, 50 pounds over OSHA's regulations.

Again, the airlines and the airports are the only organizations that are not fined by OSHA in regards to not meeting these safety regulations. To me, it's always the why. Why? Everybody keeps saying that the airlines are so big, things like that. To me, that's an interesting—when I learned that, that's interesting to me, that there are no fines there, either.

In our budget impact model, we're also showing how many airline staff are out on disability whether it's the lifts of the wheelchair or the lifts of the people getting into the airplane seat and how many people are out on medical disability. However, why aren't there fines also being incurred by these organizations for putting these people at risk?

Miller: Really, it's a very complex problem!

Erwin: Quite, quite, yes. The airline industry that says they're all about standards and the rules, but they don't seem to follow the rules when it suits them. That is what amazes me is, they're all about the red tape, but they

can easily skirt any of the rules when it benefits them.

Miller: Are the airlines losing potential customers from disabled community?

Erwin: One hundred percent. We know about 40% or more of disabled people do not travel. If you think of one person who uses a wheelchair who won't travel, they typically don't travel alone. If you say 40% or more people aren't traveling, think of that one ticket and times it by four because that one person is traveling with a significant other or an aide or their entire family. If they could have the opportunity to fly, instead of driving to that destination, they would fly to that destination.

Miller: Right. And definitely it's not all for pleasure. I'm sure it's for medical care and medical assistance, research, test trials, things like that.

Erwin: Absolutely. We are communicating and trying to work with the pharmaceutical companies and talk about our work and say, "We're here for you. You'll get access to clinical trials, access to your medicine, access to care." We're definitely beating that drum as well. It's a multifaceted problem, and when you start unraveling this very large onion, and it has so many layers, it's not even access to care, what about fair and equitable employment. We know people who have to take their own vacation time to drive to conferences, to business trips because air travel is not accessible. Why are they expected to take their own private vacation time to drive because they need to be at peer-related events?

If large employers, say the Fortune 1000 companies are saying that they want equitable employment for people with disabilities, and then this should also be on their platform, making sure that accessible travel is there for their employees.

We're working on a new bill to create special funding specifically for accessible air travel, so OEM can get that special money. Whatever we're working on, you can keep informed if you follow us on social media.

Miller: What does your son say about you and all your energy for him and his future?

Erwin: He's 14 now. I started this 10 years ago. He loves it. I don't think he knows a life without it. He's used to Mom traveling for this all the time. He knows I go to Washington DC a lot or other places around the country and the world to talk about accessible air travel. I think he's proud of me. ■ **ABILITY**

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LU RANDALL

Born and raised in Rochester, New York, Lu Randall earned a BS in art therapy and art education from Buffalo State College and a master's in rehabilitation counseling from Wright State University in Dayton, Ohio. From there, she relocated to Philadelphia, where she ran a day program for adults with chronic neurological damage. In the early 1990s, she moved to Pittsburgh, where she started working with the parents of children with autism while raising three sons with her husband, Bill. She now leads an organization that helps people with autism and their families access support, information and resources. ABILITY's Itto Outini chatted with Lu about her on going work.

Itto Outini: Can you start by sharing a bit about your organization?

Lu Randall: My pleasure. The organization's called Autism Connection of Pennsylvania, and we're an affiliate of a large Pittsburgh disability nonprofit called Achieva. We have about 20,000 subscribers to our email newsletter, and maybe six or seven thousand followers on social media, and we focus on support, referrals and education. So, someone might call us up and say, "I have a daughter who's autistic, she's got this or that problem," and I'll refer them to someone who specializes in whatever she needs. Therapy, education, vocational training, all kinds of things. My staff and I take about 270 help requests every month—through texts, email, Facebook, websites, phone calls, etc.—however you want to connect with us, we'll make it work. That's what we're here for.







Itto: What initially sparked your interest in advocating for people with autism?

Lu: My dad almost certainly had autism, although it was a self-diagnosis. He was a brilliant satellite radio engineer, but he needed a lot of structure in his life and always struggled during social interactions. I used to help him with anything involving other people: calling places to see if they had the parts he needed, going out to pick things up for him, those sorts of things. So, I got used to that from an early age.

Itto: And how has your understanding of autism evolved over time?

Lu: I'd say it's broadened and deepened as I've met more people with autism and gotten more education. I've witnessed a lot of diverse experiences and come to understand how that diversity's grounded in neurological differences. I don't have autism, but I do have PTSD, so I'm not neurotypical, either.

Itto: How does that affect you?

Lu: It makes me kind of hyper-vigilant, but at the same time I can be really bold as an advocate because when we survive life-threatening events, we can sometimes become braver about other things. I've done therapy and had a lot of support over the years, and that's enabled me to move on from being a victim to being a survivor,

and then to being a thriver. I think it helps me connect with others who are different, too, even if it's not the same difference. And I think it's helped me raise my sons to be more aware of those differences. For example, one of the kids in the neighborhood where they grew up is autistic, and when they were younger, they would play with him, and he didn't have any spoken language, so they learned to read his body language and behavior. Once, I remember, at dinner, my older son asked his brother, "Did Adam speak any autism today?" And his brother said, "Oh, yeah!" which showed me they'd heard me when I said he just has another language and accepted that.

Itto: You also do public speaking, right? And training sessions?

Lu: I'm not speaking in the public schools right now because of the pandemic, but I'm still working with a friend of mine, City of Pittsburgh Police Lieutenant Eric Kroll, leading trainings for law enforcement in the city and surrounding counties. One of the board members at Autism Connection, attorney Bill Ward, used to be a judge, so we offer justice system training and legal education, too.

Itto: What are you focused on now?

Lu: Currently, breaking down the cradle-to-prison pipeline. We want kids with intellectual disabilities and

autism to get accurate diagnoses when they're young so they can get the help they need instead of having misunderstandings at school and getting punished, suspended, expelled, which might lead to even worse outcomes, homelessness, encounters with the police, etc. I think American society is still very much in denial about how much time and money we spend punishing people with disabilities for their disabilities.

Itto: What do you do to address that? How do you challenge people who are in denial?

Lu: Oh, I'm a terrible dinner guest! I'll show up with a casserole and a lecture, like, "People with disabilities don't just go to jail because they feel like it, you know! That's what happens when you don't have access to food and housing!" I talk about these issues all the time. I make people listen.

Itto: Can you elaborate on the part about going to jail, please?

Lu: In the US, people with developmental disabilities like autism are incarcerated at a much higher rate than most people would ever imagine. I've been working in my community for a long time, and I started with children, so I've gotten to watch a lot of them grow up and deal with different situations, and I've witnessed how, whenever anyone acts a little bit differently, there's always someone who calls 911. From there, things can easily spiral out of control.

Itto: What's the relationship like between the incarceration rate and the crime rate for persons with developmental disabilities?

Lu: Totally divergent. People with developmental disabilities are much more likely to go to jail, but they're also much more likely to be the victims of crime than the perpetrators. Even when they do get involved in criminal activities, it's usually because someone else manipulated them. People with autism, for example, tend to be very honest, trusting people, and they expect the same from others, and nefarious people take advantage of that sometimes.

Itto: And that's why they're more likely to go to jail?

Lu: That's part of it, but there are other factors, too. Sometimes, people with autism make social errors, and people who don't know about autism, especially when they're police officers and trained to identify threats, read those errors as suspicious behavior. People with autism also struggle with communication, and our criminal justice system has, let's say, narrow standards for what they deem credible. Someone with autism might be trying to give testimony, for example, by saying something like, "He hit me. Last Tuesday. It was Sean. He did this to me," and the detective comes along and shoots it down: "That's not going to hold up in court."

I've got tons and tons of victims who've come forward and communicated, which is already very, very hard, and then someone tells them they're not credible. It's destructive, and it's sad.

Itto: What can be done to change that?

Lu: These problems are rooted in silence and stigma. The only cure I know of is more education. I've seen powerful people—judges, for example—decline to ask if someone has a developmental disability because they don't want to hurt their feelings. I understand it's motivated by compassion, but it only reinforces the stigma. It implies that having autism or whatever is shameful or bad. The more we talk about disabilities, especially the invisible ones, the more we break that stigma down.

Itto: What do you think can be done to combat stigma for people with invisible disabilities?

Lu: I'm a strong believer in science. I love teaching people about neurological differences and how they lead to different types of thinking. Sometimes those differences are even advantages. People with autism have extra nerve cells in their brains, which can boost their memory and creativity and let them do amazing things, like memorize the entire periodic table, but sometimes it also causes brain "traffic jams." If you don't know what that traffic jam looks like, you might think that person's not intelligent, or maybe they have bad intentions, but really it's just a different kind of processing. We need to give people time and space to process things in different ways.

Itto: Is that just for people with invisible disabilities?

Lu: No, it's for everyone! Something people need to understand is that no two brains are the same, and with every difference, there are advantages and disadvantages. When people have autism, their brains get stuck with social interactions. But that's normal. Brains get stuck all the time. Someone could choke on a carrot when they're two years old, and then they might never eat carrots again. It might be something you're born with, or maybe something that happened to you, or a combination. It doesn't matter. The problem only comes in when someone's different in a way that's poorly understood by their community. That's why education's so important. I like to show people brain scans so they can see for themselves.

Itto: Do you have any ideas for how to better educate people about invisible disabilities?

Lu: Kids are very receptive, so that makes me optimistic, actually. When I was speaking at public schools, I would always start by saying, "I have glasses, and my eyes are connected to my brain, so I have a brain difference, too!" I might mention people who are hyperactive since that's such a common diagnosis in the US, and



pretty soon, kids will be raising their hands and shouting out, “I have this! I have that! I go to a therapist!” We’re taught to be ashamed of these things, but once you start talking about them, people start to feel proud.

Itto: You said you’re optimistic. In your opinion, are things already changing?

Lu: Yes. Slowly but surely. Since 1973, people with disabilities in the US have had the right to education. Usually, that means public education. So, a lot more young people are going to school with people who identify as having disabilities. I think that’s having an effect on people and communities. Even when I’m talking to police officers, the younger ones are usually much more comfortable and receptive. Once I get them talking, they’ll open up and tell me things like, “Oh, yeah, my old boyfriend was autistic!” or, “My brother’s wife has autism.” That’s helping to break down the stigma—though of course it’s far from gone.

Itto: What do you think about media representations of people with autism and invisible disabilities?

Lu: There’s a lot of media coverage, especially TV shows that are fiction, where someone has autism, and it makes them a genius, and they have a really high-level career. That story sells toothpaste and cars, which is what TV is for, but I don’t think it helps people really understand each other, or understand invisible

disabilities.

Itto: So, on TV, it’s like a kind of toxic positivity?

Lu: You could definitely call it that. I don’t want to bash positivity—there’s value in positive representations—but they should be realistic representations, too. If something bad happens to a person, the first thing you say isn’t, “Oh, come on! Cheer up! Could be worse! At least it isn’t this or that.” That doesn’t help them process what they’re going through at all. It’s the same with the media.

Itto: Why do you think that is?

Lu: Most people with invisible disabilities are underemployed, which means they lack economic power. That’s why the media doesn’t like to pay attention to them. Then you have over-incarceration, which causes people with invisible disabilities to be even further marginalized. Those are the stories that aren’t getting told.

Itto: Why are people with invisible disabilities still underemployed if things are getting better?

Lu: It’s complicated. Some studies have shown that when people send employers their resumes, they’re a lot less likely to get hired, or even get an interview, if they say they have a disability. I think there are generational differences. People coming out of the education system nowadays have been around a lot of different kinds of

people, so they have a lot less bias, but hiring managers tend to be older and maybe retain more stigma.

Itto: The US is a very competitive country. Do you think that might affect employment rates for persons with disabilities?

Lu: I think it depends on specific hiring practices. For example, in some sectors, applicants have to complete an online logic test. If they pass, then they take a programming language test. Then maybe something else. People with autism tend to do well on those tests, but then they struggle in the interview because it's a social setting. Maybe they get confused because of small talk, maybe it takes them longer to process the questions, and the hiring manager ends up thinking they're not intelligent, but it's not about intelligence. Interviews just aren't a setting where they tend to excel. That said, I do think we'll eventually get more hiring managers who know about invisible disabilities, and that will make a difference. But that day's not today.

Itto: Do you think there are any specific American cultural attitudes affecting persons with disabilities? If so, what are they, and how are they affecting people?

Lu: We put a lot of emphasis on people self-reliance. Kids leave home at 18, and poof! They're supposed to be independent, but it's a pretty lofty goal, if you ask me, for anyone to become independent at 18, especially in today's economy. I know some people from India whose whole family lives together, all the different generations under one roof, taking care of each other. I think that's the norm in lots of countries, but not here. In the US, I think we have unrealistic expectations. For people with disabilities, it can really take a toll.

Itto: Would you say that American families are less supportive of their children with disabilities because of that emphasis on self-reliance?

Lu: In my experience, American families are very invested in their kids with disabilities, but they don't get enough support from society as a whole. For example, maybe their kid needs something—speech therapy, better nutrition—so they try to provide it, but they don't have the money, they can't get it covered by insurance, whatever. Then there's not much they can do. I'm currently running a support group for parents whose adult children have disabilities and are incarcerated, and that's probably the most emotionally strung-out group I've ever met. They've spent their kids' whole lives trying to support them, and then they still end up behind bars, where they might get beaten up or punished any day, and where they can't even see each other. It's awful. The families are invested. Society doesn't support them.

Itto: How could society do a better job? Are there things that could be done through NGOs?

Lu: NGOs, as far as I'm concerned, are already trying to

do a lot of work that the government should really be doing. All the money's in the government programs, so we end up fighting over scraps instead of using our time and energy to better support people.

Itto: Is that the only issue? Money?

Lu: I can work 24 hours a day, seven days a week, but I can't provide housing for someone who's stuck right now in crisis residential placement where he's overstayed by five months. NGOs don't have the money and resources to solve those big, societal problems. Can we influence policy? Yes. Can we educate people? Absolutely. That's better than nothing, but there's a lot more that we need to do.

Itto: What's the way forward?

Lu: Hopefully the government will start doing more, but we can't just sit around and wait for that. We have to listen to the people who're affected by these issues. And we have to put more people with disabilities in leadership positions. At Autism Connection, I'm governed by a board of directors, some of whom have autism themselves. When I meet with them, I try to listen more than I talk. That's the only way to know if my choices make sense, if our projects are helping.

I'm having a really hard time these days with the notion of "inclusion." I have ability privilege—for instance, I can drive a car, I have a job—and that means I have a responsibility to make sure people who don't have that privilege still get a seat at the table. But the idea that maybe I'll "deign to include you" is ableist, for one thing, and it leaves out the question, "In what capacity?" It's not enough to give people seats at the table. For these issues, people with disabilities, especially people of color with disabilities, should be at the head of the table.

Itto: What does it look like when that happens?

Lu: I'll end with this: I've got a friend, an autistic social worker—that's how they prefer to be known, as an autistic social worker—and their name is Cori Frazier. They started a mutual aid Facebook page with a colleague for disabled people in Pittsburgh, which now has maybe 700 members. It's intersectional and cross-disability. Someone can post something like, for example, "Hey, I need a trans-friendly gynecologist," and someone else will give them a referral. If they say, "I'm autistic, I don't know what to say on the phone," or "I'm completely deaf, I can't make phone calls," someone there can help them make the call. Whatever you need, there's someone there to help you. If they don't know how to help, they'll find someone who does. I think that's what it looks like. That's what we need more of. ■ **ABILITY**

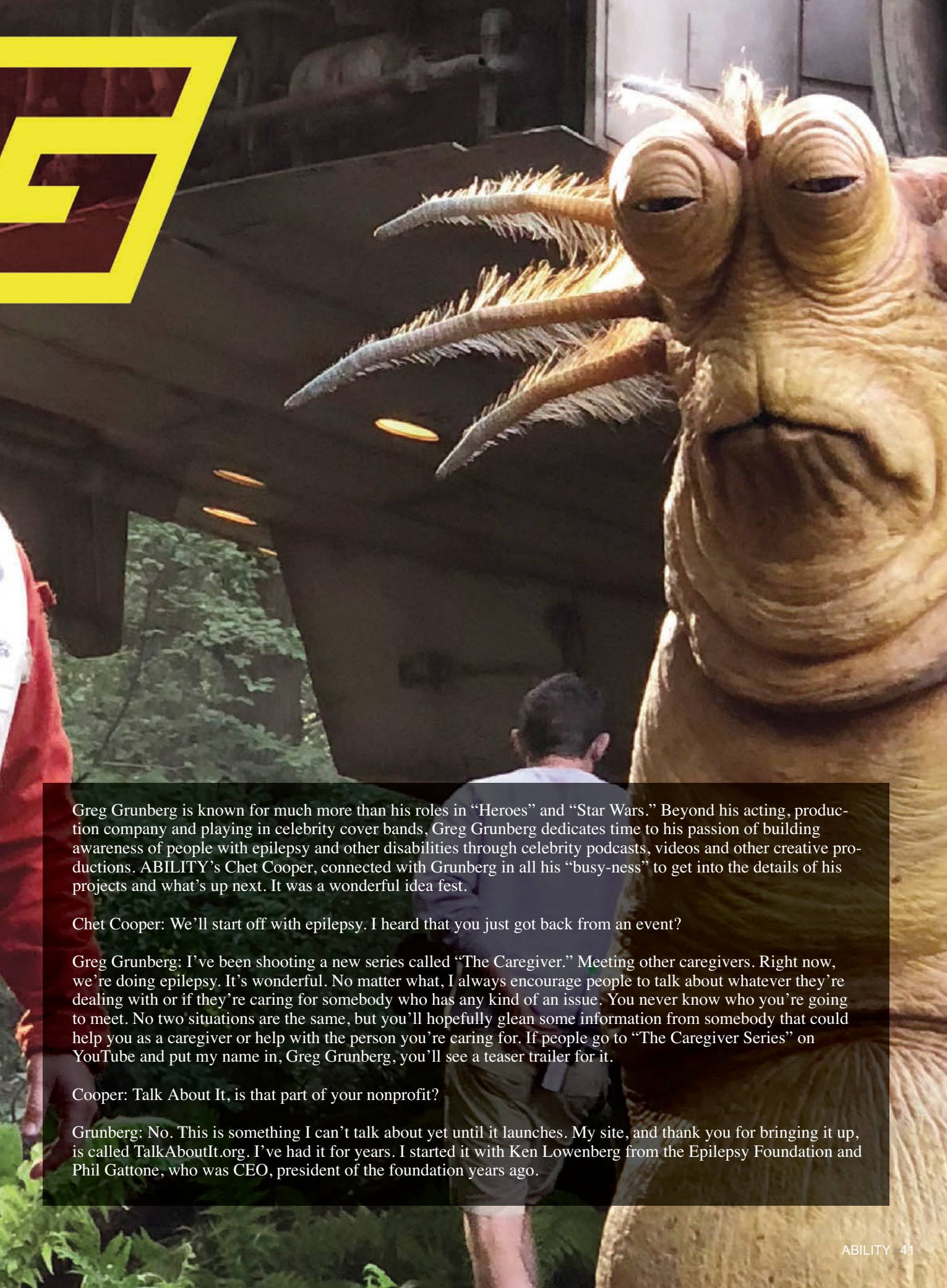
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STAR WARS

GRUNBERG



Greg Grunberg is known for much more than his roles in “Heroes” and “Star Wars.” Beyond his acting, production company and playing in celebrity cover bands, Greg Grunberg dedicates time to his passion of building awareness of people with epilepsy and other disabilities through celebrity podcasts, videos and other creative productions. ABILITY’s Chet Cooper, connected with Grunberg in all his “busy-ness” to get into the details of his projects and what’s up next. It was a wonderful idea fest.

Chet Cooper: We’ll start off with epilepsy. I heard that you just got back from an event?

Greg Grunberg: I’ve been shooting a new series called “The Caregiver.” Meeting other caregivers. Right now, we’re doing epilepsy. It’s wonderful. No matter what, I always encourage people to talk about whatever they’re dealing with or if they’re caring for somebody who has any kind of an issue. You never know who you’re going to meet. No two situations are the same, but you’ll hopefully glean some information from somebody that could help you as a caregiver or help with the person you’re caring for. If people go to “The Caregiver Series” on YouTube and put my name in, Greg Grunberg, you’ll see a teaser trailer for it.

Cooper: Talk About It, is that part of your nonprofit?

Grunberg: No. This is something I can’t talk about yet until it launches. My site, and thank you for bringing it up, is called TalkAboutIt.org. I’ve had it for years. I started it with Ken Lowenberg from the Epilepsy Foundation and Phil Gattone, who was CEO, president of the foundation years ago.



Grunberg playing the drums

The one thing I've found in this whole journey of being a parent with a child who has epilepsy is that people just don't want to talk about it. There's a stigma attached. It's very scary to see someone have a seizure. The more we talk about it, the less ignorant, scared or intimidated when seeing someone have a seizure. From the basics, to what to do in case you see someone have a seizure to knowing what's in the pipeline, how there's so much hope out there for new medications, new therapies. Great doctors are working on anti-seizure treatments. I hate to use the term "It's an exciting time," but you know, it's a hopeful time because of all the research that's being done right now.

Talk About It is a place to share information. I enlisted the help of every celebrity and actor I've ever worked with to help me get the word out, along with doctors, clinicians, nurses, nurse practitioners, and scientists. I'm meeting and talking to so many wonderful people. I have a podcast called "Talk About It." That's all part of it as well. I encourage anybody, just go to Talk About It, check out what we're doing there, and the podcast.

Cooper: You have great endorsements of people talking about it. The home page is a nice presentation of what's

happening behind the scenes. How many podcasts have you put out so far?

Grunberg: We've put out three or four episodes so far, and we have a bunch in the pipeline. Although Talk About It does have a splashy page, one thing I wanted to do was to have a celebrity face on there, but we want the information to come from real people knowledgeable on the topic. So, let's say Jennifer Garner or Milo Ventimiglia ask a question, or J.J. Abrams talks about something. They ask a question that we're all thinking in the community, about seizures or epilepsy, then they freeze, and we bring a doctor or an expert on-screen who answers that question.

It's tough. It's not called TalkAboutEpilepsy.org because I want to eventually — and we're doing that now — help a bunch of different causes. When you put a label on stuff, when it's public awareness, it eliminates a lot of people. "Oh, I'm not affected by that," whatever. Having all of these faces that you recognize will hopefully encourage people to go to the site. Because, again, I hope no one is affected by epilepsy, but over three million people have it in the U.S. alone. Their caregivers, friends, and families, that's 20-plus, 30 million people

out there who need to directly know what to do or be aware of what's going on in the community. It affects a lot of people. I don't mind "tricking" people to get to the site if they're like, "Oh, look, there's Hugh Laurie!" and then hopefully they poke around, and learn something along the way.

Cooper: That's the logic we had over 30 years ago with the magazine. We have celebrities on the cover of the magazines. It was to hook the people in. "What does So-and-So have to do with it?" The title is "ABILITY it doesn't say "disability."

Grunberg: Right.

Cooper: Had you talked with Tony Coelho?

Grunberg: Yes, I've known Tony for a long time. He and I see each other usually every year. I was going to the National Epilepsy Walk on the Mall in DC, and I would see him all the time. I also went and spoke to some of our government officials on behalf of the ADA and on epilepsy as far as getting more NIH funding. That was years ago. I've known Tony for a long time. I consider him one of my heroes. He's just incredible.

Cooper: Of course, without Tony, who knows if the ADA would have come together?

Grunberg: I know. And it seems that every year, every term, when new people come into office, they're always looking for a way to cut here and cut there, and the ADA inevitably gets mentioned, although it shouldn't, absolutely. That should be one of our cherished protections. Hopefully, that stays.

Cooper: You know what happened with the ADA AA?

Grunberg: No.

Cooper: The ADA AA—including Tony and others were pushing to get this relatively new established connection to the ADA. The term is unfamiliar, people just think of it as the ADA. But there was the lack of understanding by the courts of what a disability means, and epilepsy kept coming up. So, it went back to Congress for a re-write. One of the things the courts were saying, was "Look, you're on meds. You haven't had a seizure for a while, so therefore you're not protected under the ADA. You no longer have a disability." So, the ADA AA brought that to light and described specific issues that were defined under the ADA.

Grunberg: Is that going to forever have to be updated?

Cooper: No, they defined it, and it's part of the law now.

Grunberg: Oh, that's great.

Cooper: Epilepsy was part of that, and again, back to

Tony. If he hadn't been part of that push, who knows what the courts—the courts kept on chopping it down every time there would be a case. The things they were suggesting would limit the power of the legislation. (brief ringing sound) If that's for me, tell them I'm busy.

Grunberg: It's Tony!

[laughter]

Cooper: There he is again! He follows me everywhere! You've got so much I want to talk to you about, these issues that are close to both of our missions of how to change awareness.

Let's talk quickly about Bandwagon. Tell me about how that happened.

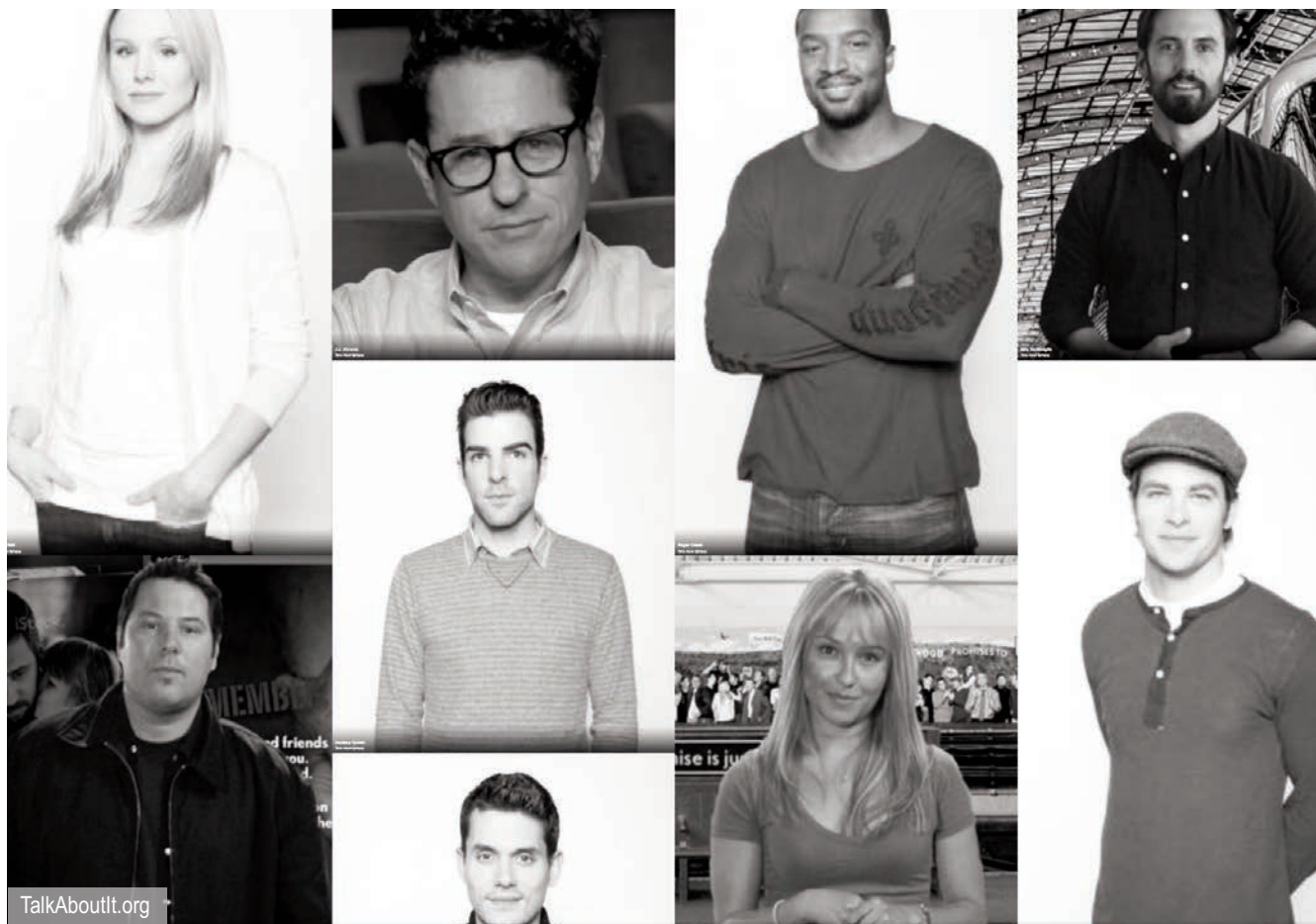
Grunberg: Bandwagon is my production company. That came about years ago while I was acting and writing at the same time. I was acting, then I would have an idea, and hopefully pitch and have to partner with other production companies. Large or small projects. I don't mind partnering, but some of them I don't need to.

I started directing, and you need a production company behind you. I was working with so many great people. One of them is Brad Savage whom I've known forever. We partnered, have a studio in LA, and Bandwagon's been around for many, many years. We produced a show with Kevin Smith that I did called "Geeking Out" on AMC. We have a bunch of other things, a few feature films.

It's my production company, but it's not in name only. A lot of actors have a production company, but they don't do anything with it. I do a lot at the building and outside the building. We're producing "The Caregiver" series as well. It's a resource I created many, many years ago. It's kind of like, if you build it, they will come. [laughs] A lot of people talk and talk and talk, but if you have something tangible, great people you've worked with, equipment, a building, a studio, it makes life so much easier. And people take you more seriously when you're pitching an idea.

Cooper: That's what I noticed. Just like you said, a lot of celebs have been in name only a production company, you've had brick and mortar, you have something that is there.

Grunberg: Yeah, it's a lot more responsibility. It certainly would be a lot easier to just act—And I've been very fortunate for the last 30 years to have made a living doing that. But I have so much more that I want to do, and I'm a hands-on guy, a bit of a control freak, as we all are. So, if I want to shoot something, I just want to go out and shoot it. I don't want to have to get somebody's permission. And now, with technology, if you shoot something on the iPhone, it looks just as good as



anything else. It really comes down to creativity and experience. Again, I love being able to have a tool box filled with all the toys that I need so that I can do what I want to do.

Also, there are so many friends of mine who are super-creative, and they didn't pour their blood, sweat, tears, and money into something like this. And I love hooking them and going, "Look, I love working with you. Come aboard, do what you want, and let's see what happens from there. If you want to continue working with me, here's a great place to try out what you're thinking about. Do a little sizzle for a TV show, record your podcast here." We have a lot of live performances. My band plays there. It's a lot of fun.

Cooper: That was another thing, music.

Grunberg: I've been playing the drums for as long as I can remember. I remember starting to play the drums right around 12, before my bar mitzvah at 13. I remember picking up the sticks with a friend of mine, and we played in the garage. So, I've always had that. But I never took formal lessons, so I was really good at playing cover tunes, listening to Tom Petty, some of my favorite—sometimes it was just stupid. I was one of those kids who would listen to Rush and think that I could emulate that. Or Stuart Copeland or something.

Over the years, I've played garage bands and stuff. And then I was asked to play at the House of Blues for a charity event when I was on "Felicity." I played one song, a Cheap Trick song, and Macy Gray was there—There were a bunch of people there. And then "TV Guide" had an Emmy party, and they said, "Hey, that celebrity band you have, we'd love to hire them." I was literally on the set of this small movie I was shooting—and I was like, "What are they talking about? I don't have a celebrity band." But I said, "Yeah, sure!" Because I'm thinking to myself, "I want to raise money for epilepsy, and I want to try to find a way, a sustainable model where I can have fun doing what I'm doing and I don't have to ask people for money. I enjoy doing this and I can turn that into a company that would make money, the proceeds, I'd love to send to epilepsy."

So, I said, "Yeah!" and I put together this quick band. I was shooting an episode of "House," believe it or not. I was a guest star, but I knew Hugh Laurie played keyboards and sang. So, I said, "Hey, Hugh, I played this thing at the House of Blues. Would you want to join me, just mess around?" He said, "Sure!" So, we rented a rehearsal space. I called James Denton, who was on "Desperate Housewives" at the time, and had asked me to do a table reading for a charity that he was doing. I said, "Hey, James, come join us!" "Sure!" He comes, I'm there, Bob Guiney, who was "Bob the Bachelor" at the time, great, great singing voice. Brad Savage, my

producing partner, who was in my garage band for years. Chris Kelly, Barry Sama, all these guys. We started playing, and we sounded pretty good.

Now, remember what I said. I'm great at playing covers. That's all people want to hear is covers. These celebrities who have bands that are playing original music, no one cares!

[laughter]

Especially at the party! No one cares! We played the post-Emmy party for "TV Guide". They paid us so much money, and it all went to our various charities. It was so much fun, and I thought, "Man, this is really something!" Twelve years and millions of dollars later, we're responsible for various charities. Epilepsy is mine.

I'm the drummer, and Scott Grimes is in the band, a major part of the band. We have two bands. One's called Band from TV and the other's called The Action Figures, where if you don't have an action figure from a character you've played in a movie or TV series, you can't be in the band.

Cooper: You're outta here!

Grunberg: (laughs) You're outta here! Sorry! It helps, maybe, because a lot of people are like, "I'd love to come up and sing," but it's not karaoke. We do a lot of rehearsal. We're really good, in our heads.

[laughter]

Cooper: We're so good!

Grunberg: We have such a blast. It's always a good time. Corporations have hired us for their parties. We've played a bunch of charity events. And now Comic-Cons.

Cooper: Oh, especially with "Heroes".

Grunberg: Yeah, with "Heroes", "Star Wars", "Star Trek", all of that. It's been great. So, I'll say, "Yeah, I want to come, sing and do my normal thing, but I would love my band to play." If they can afford it and we can plan it out! Let's say a shoe company's having a big launch party, hire us, and know immediately they get at least five or six real celebrity faces to come to their party. Great press. And we have fun! With the Action Figures, it's a charity, or not, depending on the celebrity, but with the Band from TV is all charity. It's been a real blast.

Cooper: So, they pay you in shoes? Is that what I heard?

Grunberg: (laughs) Exactly! I am the Imelda Marcos of celebrity cover bands.

Cooper: (laughs) If I could give you some advice to help raise money for other charities, I would probably come up with maybe an app idea, like a coupon app. What do you think about an idea like that?

Grunberg: You are so good at segues! Here's what happened. You're referring to the app that I created called Yowza!!, which is a mobile coupon app. It was one of the first. That came from a guy name Rick Yaeger and August Trometer, two really brilliant guys. One in design—he works for companies working on logos and things like that, graphic design—and August Trommeter, who's a coder and much more than that. It's creative. He's an actor, too. Just brilliant.

Those two guys contacted me and said, "Hey, we're big fans. We'd love to create an app for the band. So, you could just download the app, and every month (donations) could go to the person's charity who downloaded the app. We don't care, as long as it generates charity dollars." Apple does not have a model for that. There's not one charity app in the App Store. Not one. And no one knows that. You look up "charity." Nope.

Within certain apps you might be able to donate to your charity, like through Kickstarter. We wanted to create something similar. In the conversation, I said to them, being the entrepreneur that I am—very similar to my character years ago on "Felicity,"—I said, "I've always had this idea of creating an app where all of the coupons that you forgot at home were right there on your phone." So, it was born. And a year later, we came out with it. It was out for a few years. We sold it to a company in Phoenix. I don't know if it's still out there.

That was a ride. Going through that whole machine. That's when I learned to focus. Everything I do—I mean, you're going through this laundry list, and every time I do an interview, I'm like, "Man, I do a lot of things!" It's all fun. It's all creative—that was a diversion. I had the opportunity to go on "Ellen," on "The Today Show" and I could get people to download the app. And they did. I got a million and a half people to download it. Companies listed their coupons. We did well.

But it wasn't focused. I wasn't being creative in my world. I had the capability of doing business. I got that from my dad. I think I'm pretty smart at raising charity dollars and marketing. But you can easily get deluded creatively. And there's only so many hours in the day. And so, when we sold the app, it wasn't like a "Oh, my gosh!" a huge exit. But when that other company took it over and we sold Yowza!!, it was a huge relief. Most people lose money on the tech side, 99.9% of these companies fail, and the ones that make it are massive successes. I felt good about it. To this day I learned a great deal in business, but I mainly learned that whatever new idea I have, it'll be towards a movie, a script, a band — something creative.



Grunberg plays pilot Temmin "Snap" Wexley in Star Wars

△ PRISMA



Cooper: Within your wheelhouse.

Grunberg: Exactly. Organic to who I am. Having a child with epilepsy fuels and has for the last—Jake's 25, and he got epilepsy when he was seven. So, I'm always really concentrating on being creative to help the epilepsy community.

Cooper: Is your son going into acting?

Grunberg: He's acted a few times. He's played a young version of me a couple of times. We have three boys: a senior in college, a senior in high school, and Jake works in the movie business. He's working at Bad Robot (Productions) with his godfather, J.J. Abrams, which doesn't hurt. J.J.'s been so kind, and Jake loves it. Jake's doing everything at Bad Robot. He's got the opportunity of a lifetime being with the greatest company in Hollywood. The best. Everybody there is fantastic. Run by Katy McGrath-Abrams and J.J. He's shlepping,

doing the mail in the morning, cleaning trash cans, but he's learning what the editors do, what the graphic department does, the special effects department, the music. He's going to hopefully select something he wants to focus on, he's got a great gig.

My other two boys are baseball players. One's playing college-level baseball, I don't know what he's going to—He loves communications and the entertainment industry, we'll see. And Sam's in his last year in high school, he's committed to playing baseball at Chapman University. They have a great film department, but I don't know if he'll have time because he'll be playing baseball.

Cooper: They do have a great film department.

Grunberg: Jake's the only one who caught the acting bug, but I'm like, "Jake, stay behind the scenes, it's so much more solid and steady if you lock in with great

ability

Entertainment

disABILITY Talent in Front and Behind the Camera

abilityE

disABILITY Talent Source for the ENTERTAINMENT Industry



Grunberg played police officer Matt Parkma on *Heros*

people who want to work with you.”

Cooper: He’s following in his father’s footsteps and doing more than one thing.

Grunberg: I know. Who am I to say no? I’m not discouraging him, and I see where his strengths are. That’s what a parent does. “You’re really good at this, so why not try that?” He’s so great working on the set, and behind the scenes. We’ll see.

Cooper: Since 1990, we’ve been working to help businesses, governments and NGOs engage job seekers with disabilities. More recently ABILITY Corps, our sister nonprofit, is connecting actors with disabilities to the entertainment industry, called abilityEntertainment, abilityE.com. We are looking to have a talent showcase(s) — is your studio space large enough for a showcase of

performers with disabilities?

Grunberg: One hundred percent yes. It’s totally accessible. The stage is raised, but we put a ramp. It’s all on ground level. I’m telling you, that would be—oh, my gosh, it would make me feel so great to be able to do something like that. It’d be so much fun.

We need to talk about this website—it was started for epilepsy—called TalkAboutIt.org. It’s me and Ken Lowenberg and Phil Gattone. That’s 50 years of nonprofit and awareness and PR in this space. We can throw gas on any of these beautiful fires that are out there. If you say, “I’m having this event, and I really need...” Or someone says they have a cause they want to get the word out about, I have plenty of these friends. On the celebrity side, the celebrity says, “My child is dealing with this, and I see a need.” Now we go out and get

Accessibility has never been so accessible.

Sienna



Prototype shown with options and mobility services* adaptive equipment modified by a third party. Visit toyotamobility.com for more info.

companies, we do events, we attach ourselves and we get celebrities to support it. That's what we've done.

And I've learned over the years that the communication between corporate America, charity cause America, and organizations, they don't all speak the same language. Not that we're blocking for people, but when a company says, "This is what we want this basketball player to do," I say, "OK, let's not ask it that way." Because I know from personal experience what I'm comfortable saying and doing. It's been a really great way for us to be the go-to and conduit for this triangle. It's been working really well.

Cooper: I like the way you think. Who was the person who wrote "Airplane," one of the producers or writers of it?

Grunberg: Oh, yeah. Jim Abrams.

Cooper: When you said J.J. Abrams, I was thinking, wait a minute.

Grunberg: That was Zucker, Abrams and Zucker. Jim Abrams's son, Charlie, has epilepsy, and he started the

Charlie Foundation. He was one of the first people to go on the ketogenic diet and have success. I've interviewed him. I interviewed him on the podcast. He's amazing. Jim is one of the most talented guys. I did a movie with him, I believe he was part of it because it was the Zucker guys, too, called BASEketball, years ago. It was a ridiculous movie.

Cooper: I think I saw that.

Grunberg: I had a small part. It was really fun.

Cooper: You were the BASEketball.

Grunberg: (laughs) I was the BASEketball, yeah, look at this head!

I was just thinking: Imagine if you're watching a football game and, during the game, they highlight some of the people with disabilities who are making up their crew, a camera person—just to say, not for pity—but saying, "Don't let anything stop you. We are part of this. We are normalizing this." I don't know. There has to be more awareness.



Greg Grunberg and son Jake at Epilepsy Walk to raise funds for research and awareness

Cooper: Casting needs an easy access to talent with disabilities. That's abilityE.com's goal — having a known location studios and casting can tap talent. We already have thousands of actors with disabilities in the system.

Grunberg: That's great!

Cooper: Just this week we realized we have our first animal actor. We have a trained deaf blind puppy called "Piglet." His story is in the magazine. It's such a cute story. Piglet has close to 300,000 followers on Facebook.

Grunberg: Wow! Another thing about the way you should think about it because it's not called disability casting, which I love. abilityEntertainment. It shouldn't just be casting. One of the things we're doing at TalkAboutIt—we haven't started it yet—but I want to have a summit where creators can come and say, "OK, so the next time you're going to write something about seizures, here's what not to do. And here is how to properly do it." I have friends, David Shore, for example, is unbelievable. He's so amazing. He did "House," he's got another medical show on that's wildly successful now. He does his research. He cares. I'm not saying that you can't make a joke about any disability because that's normalizing it, too, not in a disparaging way. But

we joke. I'm like, "Jake, what do you want for dinner?" He's like, "How about seizure salad?"

[laughter]

We don't mind making jokes, you have to. But don't make jokes at someone else's expense. And certain things aren't funny to make fun of. I've taken up the cause sometimes. They'll say, "Oh, they made a joke about seizures." A lot of times it's like somebody's dancing on the floor? "Is it a seizure or a dance?" It's like, "OK, well, but that's physically what it looks like if somebody's having a seizure, but it's not funny to us in the community." So, I'll take them to task on that.

Because by the way, most of the time it's after the fact. I get a call saying, "Hey, we shopped this scene, I just want to make sure that you—" And I'm like, "Why didn't you call me ahead of time so I could say to you, no, you don't stick anything in anybody's mouth? That whole thing needs to be cut, it's not correct."

I think there are ways to work together. I love what you're doing. I support it a thousand percent. ■ **ABILITY**

TalkAboutIt.org



If you “Google” (why is this a verb?) the definition of “epilepsy,” the result is more confusing than it need be. The basic definition of epilepsy is a condition in which a person suffers recurrent seizures. The reason the search result is so confusing is that instead of just saying “epilepsy is recurrent seizures,” the writers are trying to include all of the many potential manifestations of a seizure. Seizures come in many forms and entail a variety of symptoms, a meaningful discussion of which is far beyond the scope of this discussion.



CLEAR DANGEROUS OBJECTS, KEEP PEOPLE AWAY



ROLL PERSON ONTO THEIR SIDE, CALL FOR MEDICAL HELP

Seizures can include a loss of consciousness, no alteration of consciousness or simply altered consciousness. Shaking, called “tonic-clonic” movement of one arm and leg on one side or all 4 limbs may occur. Loss of bowel and bladder control may occur. Often the afflicted person experiences phenomena of one or more of the senses (sight, smell, taste, hearing, touch). Vocal output may occur, anything from an incomprehensible sounds to words or phrases; even singing. Sometimes a person with seizures can tell when they are about to have a seizure. This is called an “aura” and is most commonly an unusual odor, but can be a sound, taste, or other sensation, even something seen.

The manifestations of a seizure are “all over the map” because on a physiologic level they are a condition of “out of control” activity of a group of neurons (brain cells). While this most frequently occurs in the temporal lobes of the brain, it can occur in any part of the brain, “controlling” any number of brain functions. Often the abnormal activity spreads throughout one side or even the entire brain, thus the possibility of any number of manifestations. Sometimes diagnostic tests of the brain,

for example, imaging techniques like MRI or electrodiagnostic techniques (EEG or electroencephalography) can localize, quantify, and qualify seizure activity.

The actual causes of seizures are varied and often poorly understood. Babies will often have a seizure when their fever is high. Young people will sometimes have a seizure after a hard blow to the head. Alcoholics sometimes have seizures when particularly intoxicated or more commonly when withdrawing. Remember, the occasional seizure is not epilepsy.

Seizures are generally not dangerous unless one’s consciousness or motor/sensory function are impaired while driving a car or climbing a ladder, for example. In most states, persons who have had seizures must be seizure-free (with or without treatment) for one year to maintain their driver’s license. On the other hand, the condition



CUSHION THE HEAD, TIME THE SEIZURE



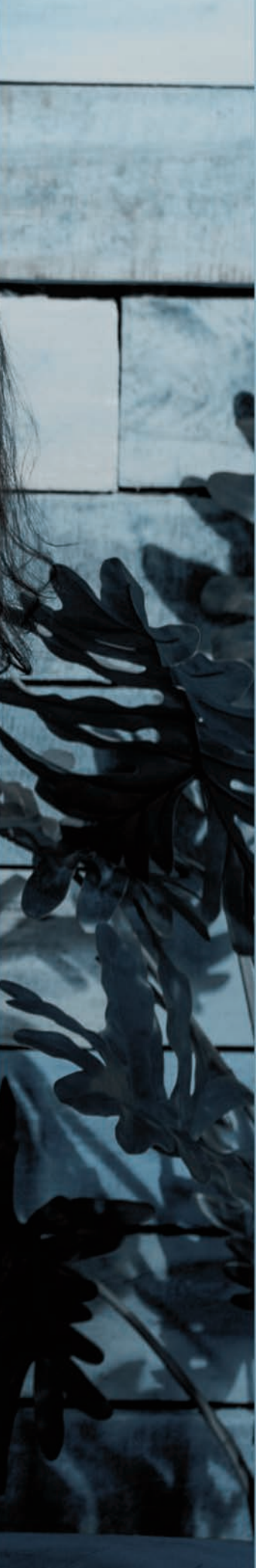
BE CALM AND REASSURING, STAY UNTIL CONSCIOUSNESS

of intractable seizures, repeated seizure activity that will not stop, often despite emergency treatment, called status epilepticus, can cause permanent brain damage. To the unfamiliar, observing a seizure in a friend or loved one can be particularly frightening, but seizures are mostly harmless. If one observes a person having a major seizure, simply remain calm, help the person avoid a major fall or accident, lie them down and wait. Nearly always, and typically after a period of drowsiness and confusion (called the post-ictal period), they will come around as say, “I had a seizure, didn’t I?” Do not stick your fingers or anything else their mouth to “pull their tongue out of their throat.” This is an “old wife’s tale.” You could lose a finger and it will not help the victim.

The diagnosis and treatment of seizures has progressed by leaps and bounds over recent decades. Most can be controlled with the regular use of medications with few risks or side-effects. Epilepsy that cannot be controlled with medication can sometimes be reduced with brain surgery. This requires a highly sophisticated team of experts, including a specially trained neurosurgeon and advanced technology. ■ **ABILITY**

Thomas Chappell, MD





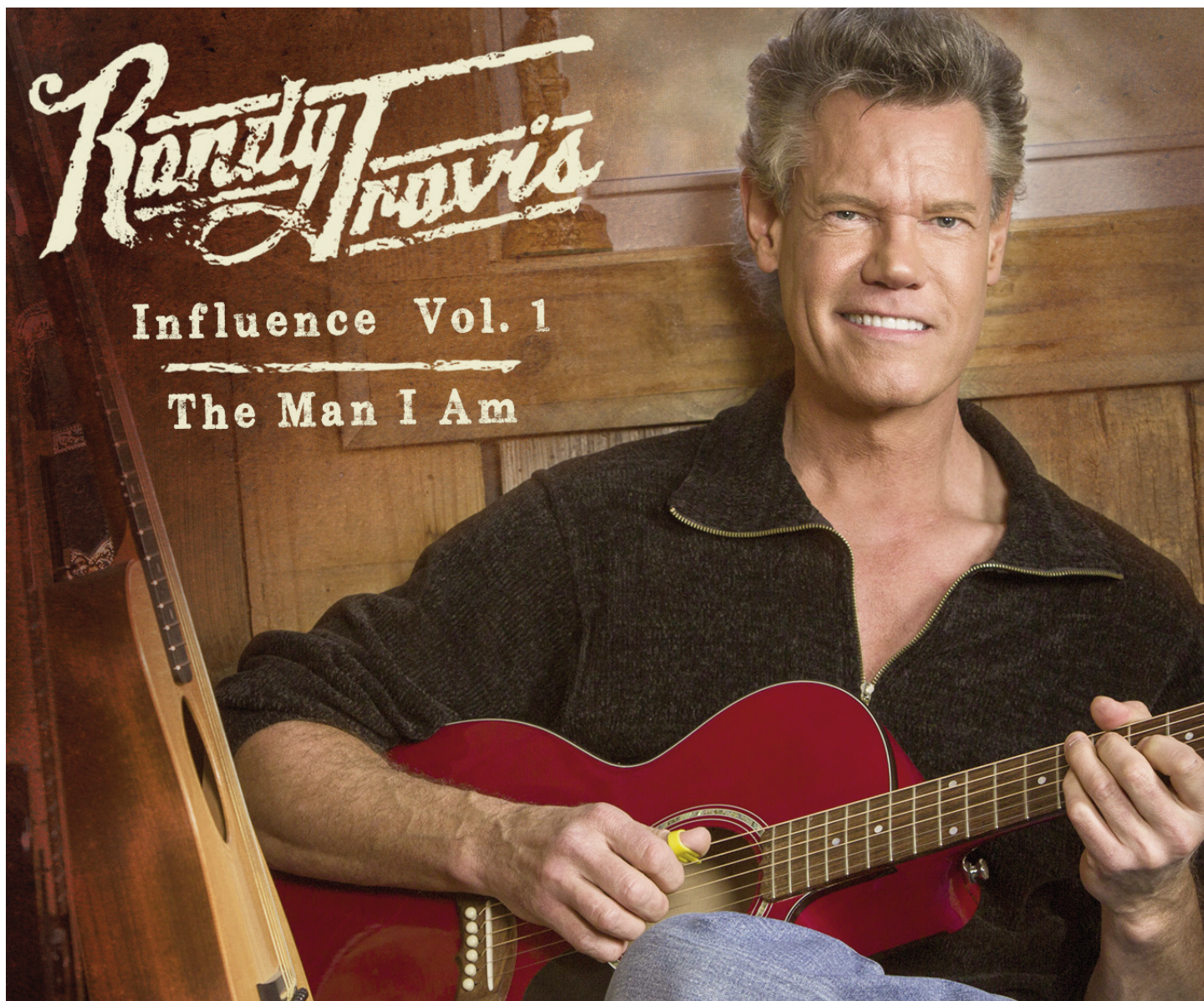
PART II

RANDY TRAVIS

Continued from the Randy Travis Issue

Chet Cooper: Is there a movie in the works about your life, Randy?

Mary Travis: There's been noise. They have a two-hour documentary. One hour of it was shot prior to the stroke, the second hour was shot after the stroke. We got the hour done before the stroke, of course not knowing you were going to have one—thank goodness we have that—



and we decided after the stroke to say, “This was then, and this is now.” It’s supposed to be coming out in the very near future. It’s finished, it’s completed, and from that, they’re already talking to people about doing a movie of his life and his music.

Cooper: That would be great. You’re controlling the documentary, then? You had your own filming going on before and after?

Mary: It was done by a guy named Shaun Silva, who’s the director. He’s out of Nashville. Warner had it done and yes, we were present for it. We didn’t do it, but we were there for it. We know what it is. It’s not a trash documentary. It’s not somebody who just put one together to trash an artist. It was great, very true to life.

Cooper: Are you living in Texas now?

Mary: We are in Tioga, Texas. It’s north of Dallas, about an hour and a half. That’s part of the reason we have

internet issues.

Cooper: Tioga? That’s Native American for “bad Wi-Fi.”

(laughter)

Mary: (laughs) It is Native American for a fork in the river, so maybe it’s just a fork in the Wi-Fi!

Cooper: (laughs) But you’re normally in Nashville?

Mary: We’re in and out of Nashville a lot. In the last two months we’ve been there on four different trips. But this is home base.

Cooper: Has it always been home base?

Mary: For the last 11 years.

Cooper: That’s a good amount of time for a home base.

I was going to talk to you about aphasia. I saw the video that you had conducted from a group with aphasia.

Mary: That was more recent than when we did the Houston aphasia one. We were back in Marshall, North Carolina, his home town, in September. Every year they have a Randy Music Festival in his home town with about 2,400 people.

Cooper: Did I see a childhood story about a stick and Randy's mouth? As kids he fell and a stick hit his throat?

Mary: That was with sister Rose in September. That was the first time I heard the story. There were six siblings. Rose was younger than Randy. And I'd never heard the story either, but she and Ricky were there; Ricky was the brother who was one year older than Randy. Rose had a stick that Randy wanted, so he was chasing her. She threw the stick behind her, and it just happened to hit Randy and went down his throat. I don't know how that happened, but she said, "The world can thank me for that." (laughs)

Cooper: Yeah, I knew I'd heard it. Randy, do you think that affected your voice?

Randy: No.

Mary: He always had that voice, from what I understand. He had a voice from early on.

Cooper: Did you always have a deep voice? Or did it develop after puberty?

Mary: It was pretty deep, from what I've been told by family. For a kid his age before puberty, they started taking guitar lessons when he was nine years old from a lady named Miss Kate Langer. Daddy had told Miss Kate that one of them has to sing. "They can both play the guitar, but I want one of them to sing." Rickie was a year older, and he said, "I don't want to sing, I just want to play the electric guitar." So Randy had to sing and play the acoustic guitar, which worked out beautifully.

Cooper: That's a pivotal point right there.

Mary: There it was! And Miss Kate said, "I think we have something here!" He was nine years old, so, evidently, he had something. And I did ask Rose and Dennis, his other brother who lives in Nashville, and Rickie, if he always had a deep voice or did it change, like you asked, with puberty? They verified that it was always deep, and it got a little deeper after puberty.

Cooper: Well, you started smoking cigarettes when you were four, right?

Mary: (laughs) Maybe that did it! We need to thank Marlboro! (laughs) funny!

Cooper: That's a bad joke. Did you ever smoke?

Randy: [Nods yes]

Cooper: You did?

Mary: At a very young age, you're right!

Cooper: Got to be careful with the jokes! Do you have animals on the ranch?

Mary: Oh, yes, we have dogs. You were asking about animals when the whole herd started barking. Here on the farm we have long-horned buffalo and horses. Randy was a great horseman. He trained horses himself. We still have those. It's interesting, because I can take him down in the golf cart and the horses will come over to the fence and lay their head on his shoulder. There's this relationship, the sweetest of emotion that goes on between him and the horses.

Cooper: Have you heard the term "hippotherapy"? Hippos in Greek means horse. Lots of people are benefiting from the horses' gait; somebody will get on the horse and through the programs these horse therapists use, it helps walking ability. Just as you said, whatever is going on with the horse and that connection—the bonding with the rider—there's another emotional therapeutic component to the relationship between the horse and the rider.

Mary: Absolutely. From what I understood with equine therapy, the gait of a human and the gait of a horse are very similar, so riding the horse gives the rider a sense of what their gait used to be. We've had a little horse down here in the arena a few times, so we've got that. My fear is that Randy just didn't feel like he could before, so I don't want to do it anymore.

Cooper: It's baby horse steps.

Mary: (laughs) That's right. So anyway, what we learned most out of this as far as all of the therapies was just getting out and doing what you want to do. We used a hyperbaric chamber, neuro-acupuncture, and we went through a few stem cells. I don't think we got to exactly the right stem cells—it's so limited here in this state—but I think that the greatest thing to do is living and doing what you want. It's hard, and I know there are just so many people who have these difficult medical setbacks, and they are or aren't comfortable in public, but I feel like they become introverts; they don't want to leave the house, they don't want to see people, they don't want to be seen. I think that's the worst thing you can do. Get out there and do the best you can and enjoy life, because it's so short, and it gets shorter every day. We're 62 years old now, both of us.

Cooper: So you're 31?

 2 M

 1.4 M

 122 K

 288 K

 2.6 M



RANDY TRAVIS

Country Music Hall of Fame & Grand Ole Opry Member

AWARDS

- ★ 7 GRAMMY AWARDS
- ★ 6 CMA AWARDS
- ★ 9 ACM AWARDS
- ★ 10 AMA AWARDS
- ★ 8 DOVE AWARDS

NOTABLE HITS

- ★ "DEEPER THAN THE HOLLER"
- ★ "FOREVER AND EVER, AMEN"
- ★ "ON THE OTHER HAND"
- ★ "THREE WOODEN CROSSES"
- ★ "DIGGIN' UP BONES"

NOTEWORTHY

- 25 MILLION RECORDS SOLD ★
- 23 #1 SINGLES ★
- 8 MULTI-PLATINUM RECORDS ★
- 4 GOLD RECORDS ★
- 40+ FILM /TV APPEARANCES ★

Mary: (laughs) 31, yes, if you divide by half twice. Just get out and live. Get out and do what you want to do. We do it all the time. We go out. The feedback we get about Randy is for him to be who he was and do what he did. It would be so easy to fall off that tall mountain and say, “Why me, Lord?” Poor pitiful Pearl, “Why me?” But Randy never, ever did that. He would say, “Why not me?” That’s Randy. That’s the heart I’m fortunate enough to be with, that man right there. “Why not me?” (near tears)

I wish more people would do the same. That’s what we did. People said, “It’s so good that you’re out. It’s good to see you out laughing and having a good time, in spite of it all.” We’re given different challenges in life and depending on which road you choose, that’s the landscape you get to see. And ours is still beautiful. It’s different. We’re not going from concert to concert, but we’re still doing what we probably wouldn’t get to do if we were still on the road doing concerts. So it’s OK.

Cooper: Are you familiar with a golf cart called the SoloRider?

Mary: Never heard of that.

Cooper: It’s a golf cart, but you could use it for anything. It is built for people with mobility issues. It has a mechanism that allows a person to play golf from the cart. It’s cool. The way you get in and out of the cart is easy, it’s a one-person golf cart. It is built with hand controls on either side, so you don’t need your feet to drive. It’s a universally designed vehicle. I think they’re made in Plano, Texas. It might be something to look into.

Have you ever gone to any events that are disability-centric, like the Abilities Expo and CSUN, which stands for California State University Northridge? CSUN is the world’s largest IT conference for people with disabilities. It includes assistive technologies, if you have no physical ability at all and can only use your eyes, you can experience eye gaze to browse the web or products. Stevie Wonder always shows up to learn the latest technology for people with blindness or low vision. I think you’d find it really interesting, it’s well worth the visit.

Another place to visit is abilityEntertainment. A website that you can post your acting profile.

Mary: [looking online] “abilityEntertainment, where your character makes the difference”?

Cooper: I like the way you read that. Can I record you?

Mary: (laughs)

Cooper: The site helps performers with disabilities connect with the entertainment industry.

Mary: That’s wonderful! I need to go on there and build a profile for Randy! He’s a SAG-AFTRA member already.

Cooper: That makes sense.

Mary: He was on “Matlock” and did several Western movies, everything from “Blue’s Clues” to “Touched by an Angel”.

Cooper: We interviewed Roma Downey for a cover story many moons ago.

Mary: What a beautiful lady she is!

Cooper: Yes. It was great casting. I remember that she was really sweet.

Mary: She’s wonderful. Randy knew her and the whole cast well. I think he did five different episodes, if not more. We still have the guitar he used hanging on the wall. I’m excited about that, because I’ve been wondering how to let them know he can do that kind of thing, so long as the part fits the disability.

Cooper: Absolutely. Before we leave, can you tell me about your background?

Mary: I was born and raised in Texas on a farm, milked cows, picked cotton, bailed hay, did all of the stuff on the farm all my life. Went to Baylor University, graduated there in ’81 in marketing and management.

Cooper: Wow, you’ve come full circle!

Mary: (laughs) And then I went into interior design, real estate, worked with my brother, and I was a flight attendant with Southwest Airlines for a while. I have two kids. Randy’s known them since the day they were born. Life’s been good. I’ve been a lot of places, but I’m still right here in Texas.

Cooper: Other than aphasia being a core issue right now, are there any other nonprofit causes you work with or support?

Mary: We have the Randy Travis Foundation we set up for creating awareness of aphasia and also for detection of myocardial myopathy. Also we support music in schools. When they’re cutting budgets, the first thing that goes are the arts, which I think is a terrible disservice, because had it not been for music, we wouldn’t have Randy.

Cooper: Have you tried music therapy?

Mary: Oh, yeah. Do you want to know something really interesting? When we finally were able to leave they said, “You can leave the hospital and go to therapy. Where do you want to go?” I immediately felt that we



needed to go back to Nashville. There's music there, that's what he needs to be around. That's where his band is, that's where he's been for the last 25 years, so we need to go back there. We got back to Vanderbilt, to their rehab, and they didn't have music. There wasn't anybody in music in the rehab. So there was a young nurse who was there in Nashville to play music, he came in on his lunch hour and he'd play the guitar and sing to Randy.

We ended up having to go back to the hospital after a staph infection and some other things that we think he'd picked up in the hospital. We ended up at Vanderbilt for another month and a half or two, finally got back to Texas when we stabilized, and when we were released again at Baylor in downtown Dallas, we went to therapy there. First thing I said was, "Is there music?" No, there wasn't any music. They had a lady who came in with a keyboard twice a week, she'd play and sing with Randy.

When we finally got out of there, right before Thanksgiving, we immediately started going to Select Rehab Rehabilitation in Denton, where we went for two and a half years. We got no music, but a young woman named

Stacy, who was head of the marketing department and a North Texas State University music major graduate. She'd come in after work, bring her keyboard and sing with Randy. She was ultimately the one who taught him how to sing "Amazing Grace," which he sang at the Hall of Fame induction.

But to go to three different, very well-recognized rehab facilities and find there was no music was beyond comprehension. It blew my mind. I thought, I cannot believe that these places don't have music because there are so many studies on music rehab and how it helps so many people with a lot of different maladies—music is medicine. I don't understand to this day why they don't have it, it should be part of their programs.

Cooper: We've done several stories on music therapy over the years. Are you still able to bring anybody into the house or do some music therapy today?

Mary: Sure, yes. We surround ourselves with music any time we can.

Cooper: Randy are you able to hold the guitar, play the

keyboard, making a tactile connection during music therapy?

Randy: No.

Mary: We've done that before. He can hold the guitar, he just can't strum with his right hand. But with his left hand, he can chord everything. So if someone will strum it, they can play a full song.

Cooper: That's great.

Mary: He hasn't forgotten any of the chording. People will come and ask him, "You know, on this song you had this diminished quarter. How did you do that?" And he'll show them the chording. They know how to strum, but they couldn't figure out his chording. He had some pretty masterful chords going on in his music that they recognized and they're wanting to download that out of him.

Cooper: I've seen a game where you connected a guitar to the computer. Do you know what I'm talking about?

Randy: No.

Cooper: It's called Guitar Hero. You're playing against the computer, there's a game element to it. That might be a really fun kind of brain-awakening, if you will, experience that you could do on your own. You don't have to wait for somebody to strum the other part of the guitar.

Mary: That's wonderful. Because the computer plays the strumming part, right? I'll have to look into those.

Cooper: You come home one night and he's just rocking out.

(laughter)

Mary: Singing in Spanish, doing things like that. That's great!

Cooper: This has been fun. Randy, I hope to see your profile up on abilityE. Let's stay in touch.

Mary: I don't think we talked bad about anybody, did we?

Cooper: I think we bad-mouthed Kirk Douglas a lot.

Mary: (laughs) Oh, no, I love that man! I should go a little farther with that. He sent his book with this kind note that meant so much to us at the time. It was right after we got home from the hospital. We were needing all the encouragement we could get, and then when you get this book and note from Kirk Douglas, you're like, "Oh, wow!" So I wrote him a thank you note for being so kind and sending the book, thinking about Randy. And he sends me back a thank you note for my thank you note! And I'm going, "Dang, this guy is amazing!" So I

wrote him back, just to let him know how Randy was doing. We've kind of stayed in touch over the years, until he passed. He was one fine man, and what a great actor over the years. We grew up with him.

Cooper: Want to hear my quick story about Kirk? I'm assuming you're saying yes.

Mary: (laughs) Yes, absolutely.

Cooper: Finished the interview with him. He signed a book for me, too, and I later opened it up to see what he signed, and he said, "To the comedian." I guess I joked a lot with him, which I tend to do. I got in my car and was about to leave, and I see him sitting outside of his house on his stoop. I get out of the car and ask, "Are you OK?" He said, "Yeah, I don't know what's happening. My driver's supposed to take me to go play golf." I said, "I'll take you." He said, "OK." It's a really low stoop, and he tries to get up, and I said, "Here, let me help." He takes my arm, I take his arm, together we're holding on to each other, and he also has his hand on a flower plant on one side. So I start to pull him up, and I hear all this cracking; it's like a machine gun going off. His back is cracking. You know how you crack your back and you hear a couple cracks? It is just going off. I'm midway through the pull where he's getting up and I'm thinking, "I don't know if I should let him down, if I should keep pulling." I immediately was thinking, "I'm killing Kirk Douglas."

(laughter)

He gets up and I ask, "You OK?" And he says, "Yeah, I'm fine" I take him to go play golf, and I hang with him part of the day, and he's hitting these driver shots like nobody's business. And I think he had one of the best days of golf because I had stretched him out so much!

(laughter)

Mary: He had his chiropractic therapy. That's good. I love that.

Cooper: (laughs) Right. He was in his late '80s and he was still playing golf when I met him.

Mary: He was an amazing man. Not many people can say they broke Kirk Douglas! (laughs)

Cooper: I cracked him up in more than one way.

Mary: That's awesome. That's a great story. You'll be hard pressed to find us talk negatively about anybody. There's always good in everyone. We've found that to be so true. Sometimes you have to look harder in some than others, but it's always there. You just peel the onion a little.

Cooper: Yeah, different layers of the onion. Did you



that way. Our home, we're blessed, because when this happened, of course, you don't even think about having your home handicap-accessible when you're 54 years old and in top health. That's the last thing you think about. Six months later, when we came home, it was nice because most of the house is on the first floor—the living area, the kitchen, no steps to get into the house, and we had an elevator. Of course, that was Christmas storage, stuff that needed to go up to the other level, so I had to clean that out. But it had an elevator, which we never thought we'd ever use. But that sure came in handy. And the house has wide doorways, wide hallways. The shower was just a little step-in shower with two doors. There was very little retrofitting we had to do for the house other than grab bars. That's pretty much all we had to do, drop the level of the bed, and we were

ever do anything with Habitat for Humanity?

Mary: We did something with Habitat for Humanity years ago. He did five Bob Hope USO tours all over the country, all over the world. He has a great heart for the soldiers. He went on his times off to Walter Reid Hospital to see the soldiers. He always got re-energized when he went up there to see those guys. He'd go in and be all smiles, they were so happy to see him. He said, "I'd just break down and start crying, for their service, and they're lying there with no legs, no arms, all for the service to the country. I go back and do what I love doing, singing, because of them." It's a real eye-opener. We love to do Wishes for Wings and the Make-a-Wish Foundation with the kids. We do a lot of those kinds of things. Those are dear to us, the soldiers, the kids, animals. Wherever we can make a difference. He leads the charge and I just follow. We like to go out and do what we can do.

Cooper: How is your balance?

Randy: [Shrugs subtly]

Mary: He's unsure of his balance. He can walk pretty well, but he likes to hold on to me. And he can't use the walker because of the right side paralysis.

Cooper: I think he's just using that as an excuse to hold you.

Mary: (laughs) No. Neither one of us minds, we'll put it

rockin' and rollin'!

Cooper: It's very lucky that you had the basics—not everyone has that. I'm in a one-story, but I have two elevators.

(laughter)

It's important to know about the term "aging in place." If you have a home that's built in such a way that it's hard to retrofit, aging in place becomes very difficult. Most people can't afford to put in an elevator, even though there are some new companies out there modifying very small spaces for elevator capabilities. But it's still expensive. If people are lucky enough to have that, aging in place becomes easier, and they might have to do something with the bathrooms and hallways. It sounds like you have the perfect scenario.

It was wonderful meeting both of you and talking to you. Maybe we'll see each other in person, or go to the CSUN conference and experience that world of technology. You would be so amazed at what is out there. Brilliant people working to make the world more accessible for everyone.

Mary: We'd love to do that. We have some friends out there. There's so much more to know about. ■ **ABILITY**

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Opening the Doors of Perception

A Young Deaf Woman Finds her Calling through Technology, Community and Education

When the Centre for Disability in Development (CDD) offered Sarna Shah an internship in 2018, she almost didn't take the job. "I needed it," she recalled as we spoke over Microsoft Teams in early 2022. "I really needed something. But I was tired of internships! I'd done two unpaid internships already, and I felt like I was getting nowhere."

Sarna graduated from the University of Dhaka in 2017 with an MBA in human resource management, but degree or no degree, she was a young, Deaf woman in Bangladesh, and things were looking grim. "The situation's not good in my country," she explained. "Not for anyone. There aren't enough jobs. There are so many young people graduating with advanced degrees, and then they can't find employment. That's true even for the non-disabled. And most Bangladeshi employers aren't very friendly to persons with disabilities."

Sarna lost her hearing at the age of seven to a bout of meningitis, an experience that she described as initially "traumatizing." "I shut down," she recalled. "I didn't speak for a year." When she had no choice but to communicate, she would use a pen and paper, but engaging with strangers always triggered anxiety. "When you have a disability in Bangladesh, some people might be scared of you or your family," she said. "They might

think someone in your family's a bad person: they must've done some bad thing, and God gave you a disability to punish them."

Despite societal pressures, Sarna's family showed her nothing but support and love. "They never stopped speaking to me," she said. "For this, I'm so grateful! I can speak now, by some miracle." Both of her parents worked fulltime as bankers. "It's really inspiring to have a working mother as a role model," she reflected, "but difficult, too, because she couldn't always be there when I needed her. But I think this taught me independence from a young age."

After a year, Sarna realized she was learning to lip-read. "It's not simple, though, like some people think. It's actually really, really hard!" Tentatively at first, and gradually with more confidence, she began to speak again. She also started studying Bangladeshi Sign Language, though without exposure to a signing community, she wouldn't achieve fluency until years later, after she was working for the CDD.

Upon resuming school, she faced bullying and discrimination, sometimes even from her teachers. "Once, in a Bangla language class, the teacher was covering idioms, and he came to my desk and stood over me, saying, 'Do







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you know what ‘deaf ear’ means? What is ‘deaf ear’? Of course, I knew the idiom. I also knew why he was asking *me*. These incidents made me feel terribly small.” Other teachers were kinder, but even those who did wanted to support her lacked training and resources. Years later, these experiences would motivate Sarna to work alongside educators, sharing resources and techniques to help them better support deaf children.

At the University of Dhaka, things took a more positive turn. “I discovered books,” she said, “and I realized that everything’s in them! Whole new worlds opened up. It was liberating.” Academic success bolstered Sarna’s confidence, as did her increasing social integration. With time, she started feeling “normal,” no longer singled out because of her disability. But, upon graduation, everything changed again.

“All my college friends were struggling,” she remembered, “unable to enter the workforce, and none of them identified as disabled. For me, it was even harder.” She sent applications and got no responses. “Or maybe they tried to call me on the phone, but anyone who knows me knows to text me. If someone’s calling, I just assume it’s a wrong number.” She struggled with depression and isolation. “By the time the CDD reached out to me, I was feeling hopeless. I almost ignored them. But then I thought, ‘Oh, well, why not? I might as well apply.’”

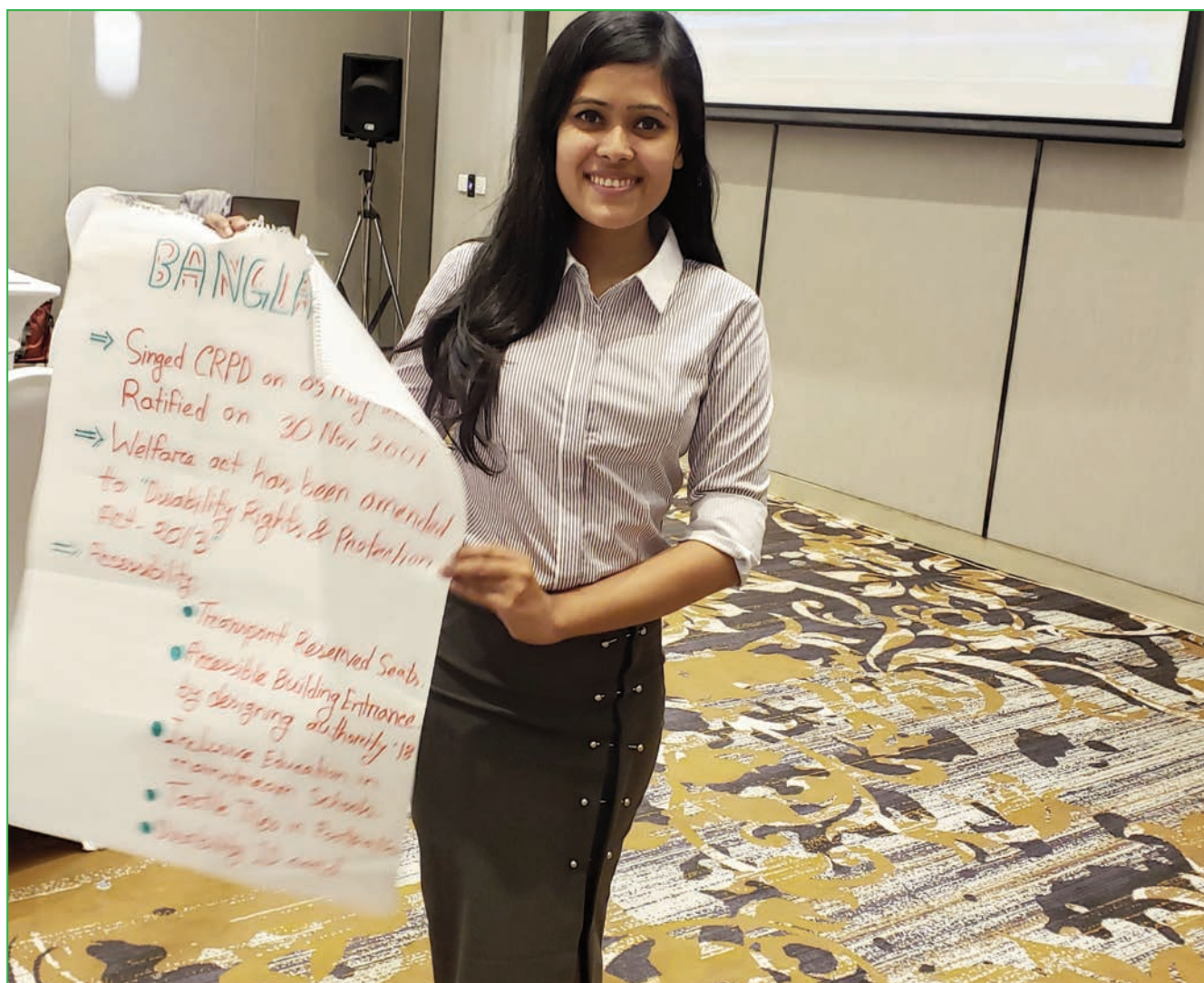
The CDD is a Bangladeshi not-for-profit organization founded in 1996 “to develop a more inclusive society for persons with disabilities.” They partner with over

350 organizations, both nationally and internationally, to promote inclusion of persons with disabilities and provide PWDs with community support and access to assistive technology and education.

“I started learning all about the disability rights movement,” Sarna said, lighting up as she recalled these revelations. “I hadn’t even known there was such a thing, and then all of a sudden, there I was in the midst of this huge, diverse community spread all around the world!” She started working on projects with people in other countries, participating in live events, even attending conferences and trainings abroad. “I learned about captioning technology, and suddenly, I could attend meetings and know what was going on! I learned about the Convention on the Rights of Persons with Disabilities (CRPD), and I thought, ‘This is amazing! Absolutely amazing!’”

Sarna’s internship began in 2018. In January of 2019, the CDD retained her as a technical officer focusing on inclusive education outcomes for deaf children in Bangladesh. In 2021, she started working with a team conducting accessibility audits while also serving as assistant coordinator for sustainable education support for deaf children.

“Deaf kids face a lot of developmental difficulties when surrounded by hearing people,” she explained. “We don’t want to keep deaf children segregated because sooner or later, they’ll have to interact with the hearing world. But throwing them in with no support is even



worse. They might struggle to socialize with their peers and end up feeling isolated. If they're not exposed to language, it can disrupt their intellectual development. I focus on getting children with deafness and hearing loss successfully integrated into classrooms and communities, providing them with tools and strategies for navigating the hearing world, and educating their parents, teachers and peers about how best to support them."

The CDD distributes Deaf-friendly teaching and learning materials and trains children and teachers to use them. They adapt textbook lessons to make them accessible and provide Bangladeshi Sign Language training to children, parents, teachers, peers, community members and government officials to improve communication between the Deaf and hearing worlds. In coordination with local partners, they organize campaigns to educate communities about deafness and combat social stigma, as well as inclusive cultural events and sports and drawing competitions. By sponsoring advocate clubs, they help cultivate empowering spaces where deaf youth and parents of deaf children can meet and mingle, discuss their shared experiences and find solutions to their common problems. Finally, they have Deaf

staff members stationed in three districts, serving not just as administrators, but also as role models for local deaf children, parents, teachers and communities.

Before the pandemic, the CDD operated three early childhood development centers for deaf children, each in a different district, but these are now indefinitely closed. With schools shut down, the CDD has shifted more attention and resources to supporting the parents of deaf children at home, especially in rural areas, as they struggle to educate their children.

For Sarna, visiting rural communities comes with its own distinct challenges. "There's a lot of stigma. And for me, as a Deaf woman, misunderstandings are bound to happen." Her disability can be invisible under certain circumstances, so if she's not speaking or responding when spoken to, people think she's just being polite or submissive. "This is socially acceptable," she noted, "but it's not what I want to project." Alternately, strangers sometimes think she's being rude when they address her and she doesn't respond.

In Bangladesh, there's no reliable way for Deaf people

to reach the police, compounding the risk of traveling alone. “There’s one emergency number for everyone,” Sarna said, “but if you’re Deaf, you can’t hear them if they’re asking where you are, for instance, or instructing you to do something. This is a really big problem, especially for women.”

Finally, there’s the work schedule. “I stay up very late sometimes,” she said. “I work with colleagues all around the world, in all different time zones. Sometimes I have meetings after one a.m. For me to stay up so late working, as a woman...it’s frowned upon.”

The pandemic has piled on even more obstacles. “Covid-19 has been terrible for the Deaf community. In the beginning, when everyone else was panicking, lots of deaf people didn’t even know what was happening. Some people don’t have stable internet connections. Some people don’t read. Of course, we can’t listen to the news unless we have someone interpreting. Most Deaf people get their news from each other. So, a lot of people were going around wondering, ‘Why are all the stores closed? What’s up with all these face masks? Is this some new fashion trend?’”

Information about the pandemic did eventually penetrate the Deaf community, but misinformation spread faster still. “Now things are just a mess. People with disabilities are especially isolated. When you’re deaf and people are wearing masks, you can’t lip-read. Transcription apps won’t even work because their voices are too muffled. And, of course, I can’t ask people to remove the mask. I don’t want to jeopardize anyone’s health. But it really leaves me in a bind!”

For Sarna, as for many others, technology has played a life-saving role, even with its limitations. “I can participate in events online, which helps me stay connected and engaged, and that’s amazing! But it’s not perfect. For instance, the internet’s not stable. Outages happen all the time.” She uses apps like Uber for ride-sharing, “but the drivers haven’t been trained to use the map to find you. They always want to call, and I end up needing help from someone.” The same applies to food delivery and online shopping. “And many apps don’t work in Bangladesh at all,” she adds, “or they don’t have captioning, or they have captioning, but only in English, which doesn’t work for people who read only Bangla.”

During our interview, Sarna, who knows both English and Bangla, used the Live Transcribe app on her phone, supplemented by text messages, because captioning on Microsoft Teams wasn’t working. Later, I discovered that the audio hadn’t been recording, either! The first draft of this profile was reconstructed from memory, and Sarna fact-checked and filled in the gaps, further demonstrating not only technology’s limitations, but also the creativity, adaptability and patience required to overcome them.

In addition to assistive technologies, Sarna finds special value in a suite of devices and softwares that most people, whether or not they identify as disabled, now consider mundane. “Google is really important because it lets me find information without having to ask strangers,” she said. “Google Maps, especially.” She uses the service to let her loved ones know where she is and whether she’s safe. “My mother was never too good with technology, but she’s getting better and better every day! Now, if she needs to know where I am, I can simply drop a pin on Google Maps and let her know.” Most smartphones now come with these features built in, but as Sarna pointed out, they’re expensive. She feels lucky to be able to afford one. Not everyone can.

Though financially independent, Sarna still lives with her family in their hometown of Tongi, Gazipur, near Dhaka. “We have a really good relationship,” she said, beaming. “We always have. This means so much to me.” Though her parents don’t sign, she’s become an excellent lip-reader and uses Bangla and English with her family, colleagues and friends. In the evenings, she and her family sit together and watch the news, and her parents repeat the newscaster’s words in case she doesn’t catch them. They’re proud of everything that she’s accomplished, but Sarna says she’s only getting started.

“I’m really, really excited,” she said, “because even though I haven’t done much yet, I’m getting closer. I’m finally working with the people and organizations that are focused on the projects and the issues I believe in. I’m learning about ways to help people. I’m building connections. I’m discovering all these things I have in common with strangers all over the world.”

Getting interviewed for an international magazine took courage, Sarna admitted, “but it was worth it.” She never used to like to share her story until one day when she was at the ENT clinic, and her mother started talking about her to a total stranger. “I was an MBA student at the time, and the stranger had a five-year-old kid who was Deaf, and I saw how it just filled her up with hope and inspiration when she learned that I was Deaf and studying at the most reputed university in our country. It made me realize how much you can inspire people sometimes, just by sharing your story. I hope my story does that. I hope it reaches someone out there who needs it and helps them.”

Now, Sarna says, her goal is to serve as a bridge between the Deaf and hearing worlds. “In a few years, maybe I’ll be doing really big things. Helping lots of people, giving back to the community, making things better for my country and the world. It’s my dream.”

■ ABILITY

by Mekiya Walters





Interview with Elizabeth SAMMONS

For over 30 years, the United States Information Agency ran cultural exchange exhibits in Russia, a project that spanned the bulk of the Cold War and ending less than a year before the break-up of the USSR. In all that time, Elizabeth Sammons was the only blind American woman to serve as one of the program's cultural ambassadors. "I never thought of myself as a pioneer," she recalled as we conversed by phone one morning in January, 2022. "I just thought, 'I want to do this, and I'm going to find a way.'" This theme runs through her entire life, linking her time as an exchange student in Switzerland, a Peace Corps volunteer in Hungary, a teacher and disability advocate in Novosibirsk, and a writer and human rights activist in her native Ohio. Her adventures and achievements are too numerous to name, but you'll get a taste below as we discuss topics including arts and literature, international marriages, disability in the USA and Russia, talking to strangers, and traveling with extremely low vision.

Itto Outini: Can you start by telling us a bit about yourself? Who is Elizabeth Sammons?

Elizabeth Sammons: (laughs) Let's see. I'm a person of faith. I'm a globalist, by which I mean a citizen of the world. I'm a woman, and glad to be a woman, and I really enjoy the arts and writing and meeting new people. Those are probably the most important things about me.

Itto: I heard a story about a doctor giving advice to your mother.

Elizabeth: Yes. I was born in 1966, and I was blind. A



doctor told my parents they should put me in an institution, but I was fortunate because my mother was a nurse, and my father was a librarian, and they loved me very much and didn't listen to the doctor. Later, a couple of operations gave me basic color and shape detection in one eye, but I use braille and always carry a white cane.

Itto: Where did you grow up?

Elizabeth: Mount Vernon, Ohio. It's a small town, and most people there didn't have any connections to the international community. My family was the exception. My mother was a military child and spent five years in Japan as a girl, and she loved experiencing other cultures, and my father was very compassionate for the international students who were struggling at his college. On Thanksgiving and Christmas, we'd always have people over.

Itto: And that exposed you to people and cultures from around the world at an early age.

Elizabeth: Yes! The world came to me before I went to the world. I had so much curiosity and so much desire to learn languages and discover other cultures, and I think that had a little bit to do with being blind and growing up before the ADA. I wasn't always welcome at social functions. Sometimes the other children wouldn't play with me at school. I always felt—and still feel, sometimes—like an outsider in my own country.

Itto: This explains how you became a world traveler.

When was the first time you traveled abroad?

Elizabeth: I visited Canada and Mexico with my family, but my first real adventure on my own was when I was 16. I graduated high school two years early and did an exchange year in Switzerland. I'd studied French and loved it, and I lived with a French-speaking family for a year while studying at an academic high school. It was difficult at that age, but also wonderful. It really opened up my world. That was 1982.

Itto: You went alone? Your family didn't go with you?

Elizabeth: I went alone. My parents were probably braver than I was because they knew much more about the world than I did, and they still let me go.

Itto: Can you tell us—if you still remember—when you boarded the plane, were you afraid?

Elizabeth: I'm not afraid of anything!

[laughter]

Itto: That's great! How about excited? What were you feeling?

Elizabeth: I was so excited! I was the only student with a disability in the program, and it didn't matter! I didn't even think about it. I just thought, "After all the books I've read, all the hours I've studied French, my dreams of traveling are finally coming true!" There were about 30 of us going as a group from the USA, all bound for different European countries. We had a big pillow fight on the plane!

Itto: That's a fun way to start the program! Once you were there, did you feel homesick?

Elizabeth: Of course. But I've always loved meeting new people. That tempered the homesickness somewhat.

Itto: How do you go about meeting people?

Elizabeth: Oh, I meet people all over! The other day, for example, I was in a café, and I heard a woman singing along with a song very softly, and I stopped and said, "You have a lovely voice." I found out that she's a fellow writer. Then she started introducing me to other writers in the city.

Itto: That's lovely.

Elizabeth: Sometimes, if I hear someone speaking with a foreign accent, or speaking a language I know, I'll go to them and say, "May I help you?" I'm not afraid of strangers.

Itto: I was just having a conversation with someone, and we were discussing how, for blind people like ourselves,

you don't even think about it; you just go and talk to people on the street! Offering help, or asking for it, or just making conversation.

Elizabeth: Oh, yes! Some people offer me help out of nowhere, when I'm just walking along! I think it's always best to be polite, whether you need their help or not. Sometimes some people with disabilities get angry about that, like, "I don't need your help! If I needed help, I would've asked!" But think about it this way: what if, next time, that person sees someone who really does need help, and they don't offer it because they're afraid of offending someone, because *you* blew up about their good intentions?

Itto: I agree. Somebody once tried to tell me that if a stranger tries to help me, I should yell and hit them with my cane! And I was just like, "What are you talking about?"

Elizabeth: It makes me sad when people with disabilities react like that when someone tries to help them. 99 percent of the time, that person's simply being kind. Sometimes they need to help you as much as you need help, or more. The only time to be wary, in my experience, is when someone seems *overly* helpful. Some people really do have ulterior motives. But usually, no. My advice is, be careful, but be friendly whenever you can.

Itto: You've traveled all over the world, and that's worked for you?

Elizabeth: That's worked for me.

Itto: Getting back to Switzerland—you said it was 1982. You didn't have WhatsApp, text messages, iPhones. How did you keep in touch with your family?

Elizabeth: I wrote letters every week. I used a typewriter. In the whole year, we had maybe two or three phone calls.

Itto: Wow!

Elizabeth: Phone calls were expensive!

Itto: You must've been strong.

Elizabeth: There was no alternative. Today, when people leave the country, everyone expects a lot of communication. We didn't have that expectation then. I think it gave me a better immersion experience. If I was tired of speaking French, I couldn't just pick up the phone and call my family; I had to keep speaking French until it started feeling natural. I'm grateful for my French immersion.

Itto: What did you do after the exchange program ended?

Elizabeth: I went to college and double-majored in

French and Communications, and then I went to journalism school and got an MA. But I was eager to go abroad again. In college, I spent time volunteering with immigrants and refugees. The older ones would never really pick up English, so if they needed a letter written, for example, or a phone call made, I would help them. And that helped me, too. It kept me thinking internationally. I also had some pen pals, some young girls in Poland and what was then Yugoslavia, and I knew some students in Czechoslovakia. When I finished my Master's in 1988, I decided to take a trip alone and visit them.

Itto: How did you connect with them in the first place?

Elizabeth: You know, it was so strange! Back in high school, my cousin sent me a list of people who said they wanted to correspond with people in the West. I wrote to all of them. There were maybe seven or eight, but only three or four wrote back to me, and we kept writing back and forth. It was just really exciting, receiving those letters with beautiful stamps and envelopes with different textures, different smells, from those faraway countries. When we first began to correspond, I never imagined we would meet, but after college, I had just enough money to make it work. First, I went to Poland, then to the Czech Republic, then to Hungary, then to Yugoslavia, and then to England to visit my college roommate. Now, when I look back, it seems amazing. But at the time, it was just like, "Well, I know these people, they're friendly, they're my age, so why not?"

Itto: You ended up living in Europe for a while. Why was that?

Elizabeth: After that trip, in fall of 1988, I went to Washington DC to study. At the church I attended, I met a woman who'd worked on the US Information Agency's cultural exchange exhibits in the USSR. She told me about "Design USA," the exhibit she worked on, and she said they needed guides. Cultural ambassadors, basically. And then she said, "You'd be perfect! You really should apply!" This was 1989—

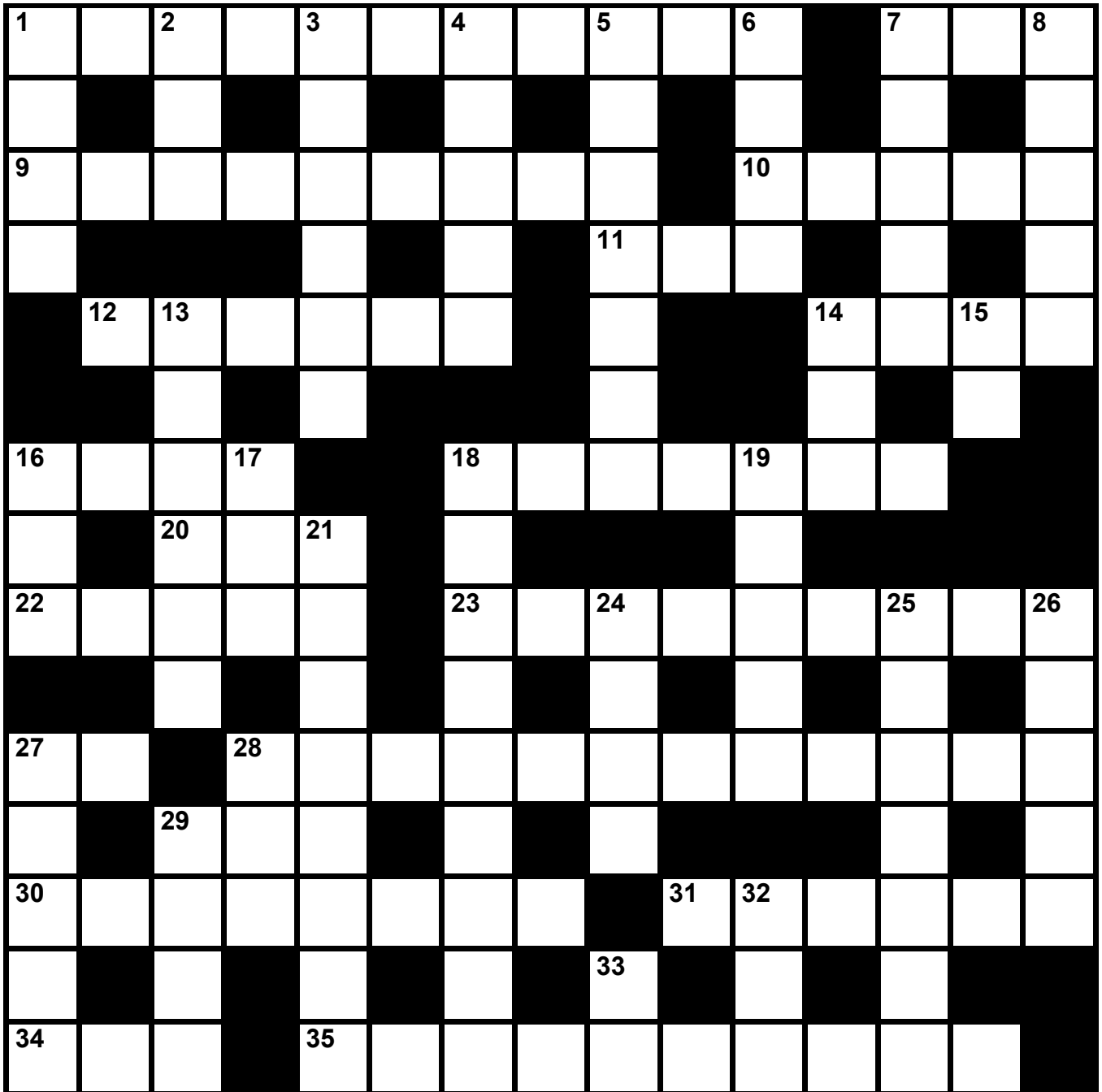
Itto: That's the year I was born!

Elizabeth: Perfect! Good things were happening that year. I thought, "I have no chance of getting this job, being blind. I have no chance at all." But I told her, "That sounds great!" The next time she saw me, she asked if I'd applied, and I said, "Well...no." And then we met a third time, and she said, "You know, I've already spoken to the people who direct this exhibit. You really need to apply, if you haven't already."

Itto: What were the application requirements?

Elizabeth: You had to pass some health and security checks, and you had to be bilingual in English and Russian, which I'd studied by then. Volunteering with the refugees had helped me greatly. You had to pass a

ABILITY'S



Crossword Puzzle



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ACROSS

DOWN

- 1 Disability rights activist from Germany, Raul ____
- 7 Zhenglu ____: founder of the International Art Education Center for the disabled
- 9 Teachers
- 10 Actor with cerebral palsy who plays Walter White on "Breaking Bad", R.J. ____
- 11 TV network that cast Peter Dinklage (has achondroplasia) as Tyrion Lannister
- 12 Multilingual accessibility advocate and human rights activist from Morocco, Itto ____
- 14 Major musical composition
- 16 Fisherman's lure
- 18 Johnny Depp stars in "Edward ____ hands"
- 20 Collarless shirt
- 22 Desired future
- 23 Available assets
- 27 Trademark, for short
- 28 He's traveled 500,000 miles on his bike and raised almost \$300,000 for MS, 3 words
- 29 Calf's mother
- 30 Italian singer, composer and author who is a advocate for removing architectural barriers for persons with disabilities, Federico ____
- 31 Protagonist in the film "The Green Mile" - John ____
- 34 Time period on a financial statement, abbr.
- 35 Ensuring the survival of an environment

- 1 Hold onto
- 2 ____ Dhahi
- 3 Country music great recovering from stroke, Randy ____
- 4 Garlic flavored mayonnaise
- 5 Japanese raw fish
- 6 Animated Disney character with fin, that he calls his "lucky fin"
- 7 Relax, 2 words
- 8 Special ____
- 13 Brings people together
- 14 Or best offer.... in classified ads
- 15 Skywards
- 16 Hospital unit
- 17 Contents of some bags
- 18 Uphill battles
- 19 Halloween decoration
- 21 Gives qualities or abilities to
- 24 Rise above the ordinary
- 25 Chinese lady who overcame having no left arm to become an artist and leader in the fight against COVID-19, Zhang ____
- 26 Madison Ferris, a disabled actress, starred with ____ Field in "The Glass Menagerie"
- 27 Senator who is a triple amputee, ____ Duckworth
- 28 Portion of land
- 29 Convention on the Rights of Persons with disabilities, abbr.
- 32 Oprah's network
- 33 William Penn state, abbr.

Crossword Puzzle

answers on page 74

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

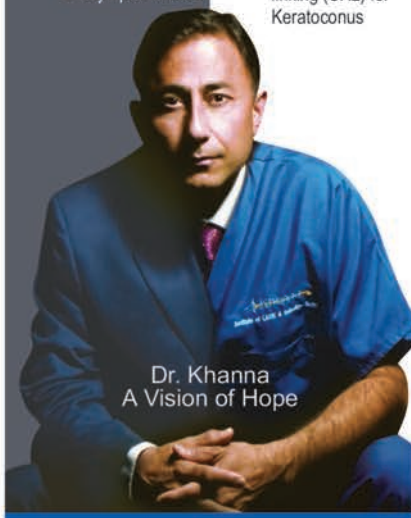
ABOVE 65

- Pi in Eye
- Laser Cataract Surgery

OTHER THAN

LASIK

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



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