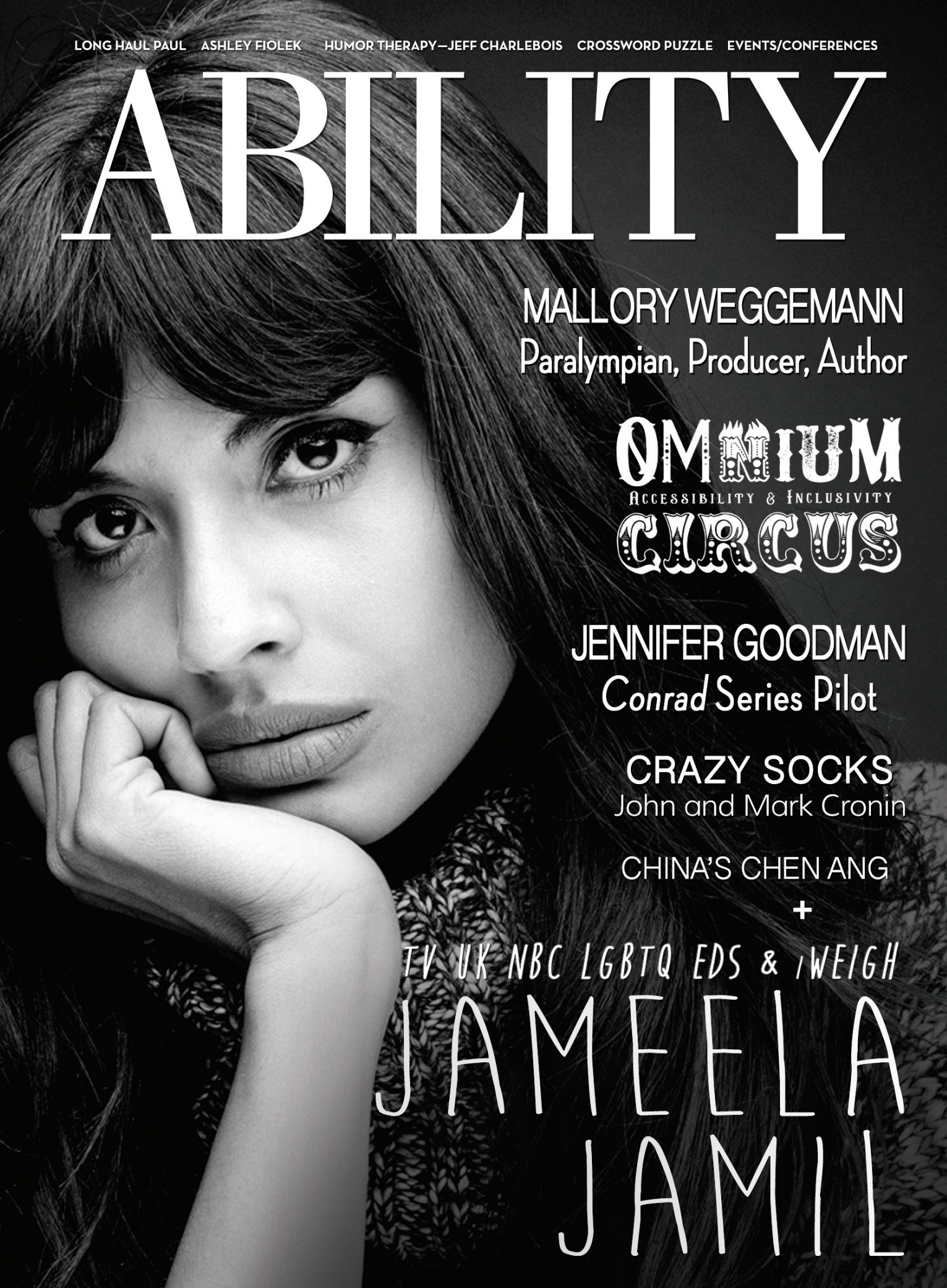
LONG HAUL PAUL ASHLEY FIOLEK HUMOR THERAPY—JEFF CHARLEBOIS CROSSWORD PUZZLE EVENTS/CONFERENCES

ABILITY



MALLORY WEGGEMANN
Paralympian, Producer, Author

OMNIUM
Accessibility & Inclusivity
CIRCUS

JENNIFER GOODMAN
Conrad Series Pilot

CRAZY SOCKS
John and Mark Cronin

CHINA'S CHEN ANG

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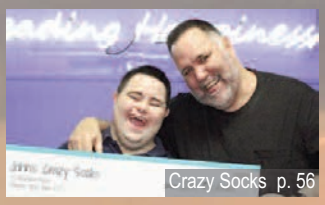
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The Arc
California


Weggemann p. 20


Goodman p. 40


Crazy Socks p. 56

Omnium Circus p. 28

CONTENTS

6 ASHLEY FIOLEK — Masks and Deafness

8 HUMOR — Mommy

10 CHINA'S CHEN ANG — Rehabilitation, Reshaping Life

16 LONG HAUL PAUL — Bikes and Cowboys

20 MALLORY WEGGEMANN — *"Limitless"*

28 OMNIUM CIRCUS — Accessibility, Inclusion and Funtastic!

40 JAMEELA JAMIL — Actor, Radio Host, Advocate: Ehlers-Danlos syndrome

50 JENNIFER GOODMAN — Actor, Producer, Activist: Autism

56 JOHN'S CRAZY SOCKS — Father and Son Business: Down syndrome

62 ABILITY'S CROSSWORD PUZZLE

66 MARKETPLACE

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MANAGING EDITOR
Gillian Friedman, MD

MANAGING HEALTH EDITOR
E. Thomas Chappell, MD

HUMOR WRITERS
Jeff Charlebois
George Covington, JD

EDITORS
Melinda Chilton
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Pamela K. Johnson
Carol Brown
Sylvia Martirosyan
Lia Martirosyan
Josh Pate, PhD
Maya Sabatello, PhD, JD
Karina Ulrike Sturm

HEALTH EDITOR
Larry Goldstein, MD

CONTRIBUTING WRITERS
Ashley Fiolek
Eileen Grubba
Geri Jewell
George Kaplan
Regina Hall
Myles Mellor (Crossword Puzzle)
Paul Pelland (Long Haul Paul)

WEB EDITORS
Marge Plasmier
Karina Ulrike Strum
Bob Williams (Interactive Puzzle)

MULTI-MEDIA
Karina Ulrike Sturm

GRAPHIC ART / ILLUSTRATION
Scott Johnson
Melissa Murphy (Medical Illustration)

PHOTOGRAPHY
Sophie Hart
Bai Fan
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Nancy Villere

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Sandy Grabowski

TRANSLATOR
Jing Hu
Emily Deng

MARKETING/PROMOTIONS
SOCIAL MEDIA
Faith Chrishelle
Lia Martirosyan
Tamay Shannon

ABILITYJOBS.COM
Sabrina Bertucci
Vicky Dupree
George Kaplan
Marge Plasmier
Casey Mims

EDITORIAL
editorial@abilitymagazine.com

PUBLISHER / EDITOR-IN-CHIEF
Chet Cooper

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The days are just flying by, SX (supercross) is in full swing and I have been watching every second of it. Unfortunately, right now they are on a three week break so that is kind of a bummer I have to go back to watching Netflix and not SX! I have even made my mom watch with me and she doesn't even like to watch, why is that? haha..... I do get a little emotional about it so does my dad and we both yell and scream so that is probably why my mom doesn't like to watch with us

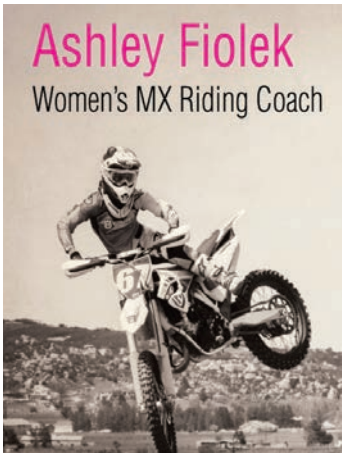


I have actually been training for a woods race. I haven't done a whole lot of training since I left racing. I have been working on my cardio and doing some mountain bike riding to prepare me for riding thru the woods on my dirt bike. I even went with my mom to a Pure Barre class to help me out but that was so hard, how does my mom do it?

It's finally getting warm again in Florida, it has been so cold and dreary here it is not usually like that here so it has been kind of sad. My wife is in Utah working with her brother on finishing carpentry so I have been stuck here. My mom and I decided to go on a mini "girls" trip so we headed down to Orlando for a few days. The weather was a lot warmer in Orlando than Saint Augustine so we had a chance to sit by the pool and soak up some sun. There is a new Margaritaville resort here so we decided to check it out. It was really nice we were kind of in between Spring breaks so it was not too packed and we were able to get some lounge chairs. That is the hard thing about Florida we have to contend with everyones spring breaks from all over the US because they come here! Even more now because we have a cool Governor :-)

We are driving back home now and we are going to celebrate an early Easter because my mom, dad and brother are headed back to Michigan to visit with my grandma and grandpa and I'm staying home to watch the dogs. Oh and also the deer and feral cats we have a lot of animals!

So masks? Ugh, do any of you Deaf people struggle like me? I'm a lip reader so the whole mask thing is making me crazy! Especially when you tell people you are Deaf and they still keep talking thru their masks! I'm like hey I can't hear you and now I can't see your lips or facial expressions! Some people get it and remove their mask so I can see their face and I really appreciate it, just wondering if other people are experiencing the same thing as me?



Back to my training tomorrow, hope to see you all at a class this summer. I'm moving back to the West coast for classes this year so keep an eye on my website if you want to hang with me. ■ ABILITY

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Mommy Loves Best

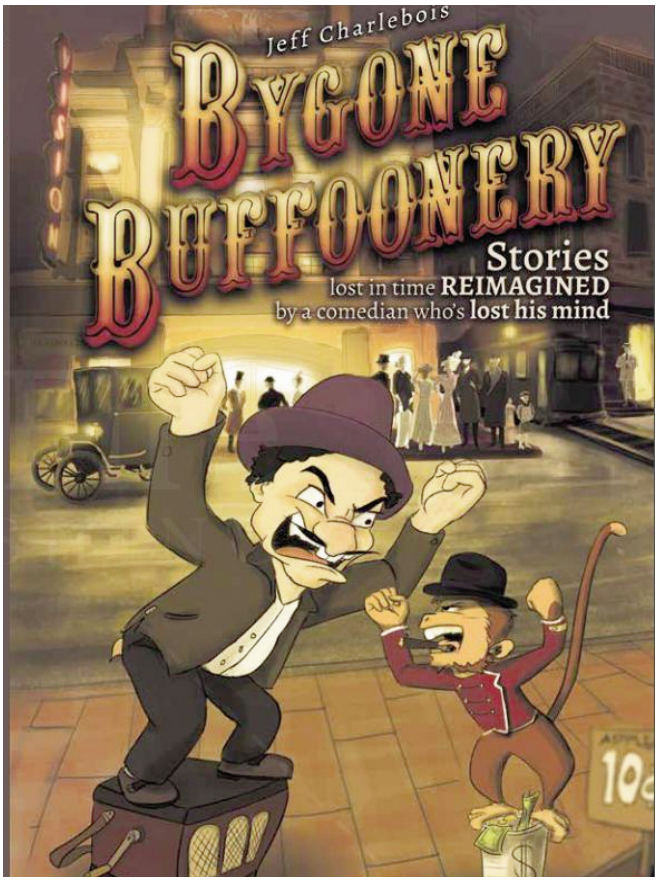
With Mother's Day coming up I got thinking… how in God's name did my mom do it? How did she raise four bratty, snot-nosed, dirty kids and keep her sanity? For close to twenty some years we stole every waking minute of her life with our wants and needs only to move on with to her sleeping minutes. Of course, back then, we thought that's what we were supposed to do. That's like chapter one in the kid's handbook. How to Be A Selfish Rug Rat.

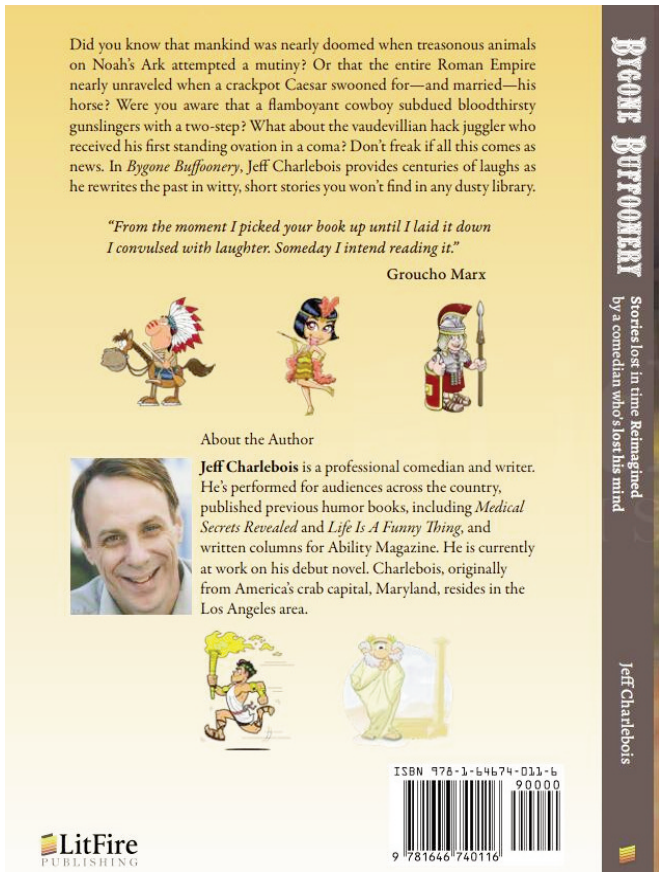
Most men cannot multi-task so that in-and-of itself renders these inept ape's incapable of being a mother. The best thing these useless creatures can do is stay out of a mother's way. These women are freaks of nature. They can make a meal out of a carrot and an old shoe. Fix a zipper with a bobby pin and wad of chewing gum. Fold clothes with their feet while nursing a baby and doing a crossword puzzle. Mothers are amazing. They are the best jugglers in the world. Within a two-minute span they can change a diaper, iron a shirt then race in the kitchen and flip the grilled cheese sandwich on the stove. Men would just iron the sandwich and wait for someone else to change the diaper. That someone being the mother.

Somehow my mother got four kids out of bed in the morning, dressed, made breakfast, packed lunches, gathered our books and threw us on the school bus. I'm exhausted just writing that sentence. She actually liked when her kids got in trouble and had to stay after school. It gave her an extra hour of peace. Before kicking us on the school bus she'd say, "Now don't be afraid to be a wise guy in class." Sadly, I wasn't. I accumulated enough hours after school to equal another school year. I was on a first name bases with most of my teachers, starting in second grade. "Hi Bob, I'd appreciate it if we could cut the detention a little short today. Me and the boys are building a treehouse. So, how's the wife and kids?"

Once a mother gets the kids off to school, you'd think she'd have some time to relax. No, the fun is just getting started for her. There's a mountain of dirty laundry calling her name and she wishes she could change her name. Before she can even vacuum the carpet, the strewn toys need to be picked up. Yes, it's easier to just vacuum the Legos, dolls, and plastic soldiers but then the vacuum breaks and it's just another headache for the mother. Every so often it crosses her mind to just vacuum up a kid or two to make life a little easier but there's probably laws about that.

At some point kids get a little older and develop various interests and get involved in extracurricular activities like baseball, karate, Girl and Boy Scouts, piano lessons, etc. and guess who has to drive the little monsters to these things? The beaten down mother. To top that off, she had to remember to pick them up. My





mother never forgot us. A day or two might pass but, eventually, she'd recall that something she knew she forgot and pick us up, well most of us. I think my brother is still waiting in a mall parking lot somewhere.

There were times when my mother had a "today you die" look in her eyes when I neglected some things like cleaning my room, feeding the cat, putting the fire out in the garage I had started but, at some point, she'd come back to her senses. I was always glad I had siblings that I could throw under the bus and have them take the fall. Yes, us ungrateful kids could push my poor mother to the limit. I could fully understand if the judicial system changed some laws and dropped "killing your kid" to a low-level misdemeanor charge. The haggard mother would stand in front of a judge and say, "You have no idea what I've had t deal with. He sleeps to noon. Plays video games. Never makes his bed or puts the dishes in the dishwasher. Do you know he almost burned down the house?" The judge then says, "Woman ya did the right thing. Case dismissed!"

After feeding, bathing, and getting the kids into bed a mother can finally have some quiet relaxing time and cuddle on her couch with her best friend – a bottle of Merlot. Hopefully, she has a kind, supportive husband who will make himself useful and open the wine for her. That down time is so important for her to re-charge and do her best to get some sanity back because she knows come 7 am the hell starts all over again. Yeah, you drink up, mommy. You deserve it.

The most important occupation in the world is that of a mother. It is a never-ending, low paying job. They just do what they do, with no thanks or accolades, and what they do is truly amazing. Everyday I reflect on my childhood and it astounds me. Of everybody on this planet I was blessed with the best mother in the whole world. I can't believe it. The odds are astronomical, and I never forget it. If I could only have one thing in life it would be my mother. That would be all I need. A mother's love of her children is limitless. If cops came to our house and told my mother your three boys are suspects in a bank robbery, my mother would vigorously deny it. "Not my boys. They know better." The cop might say, "We have them on video tape. You can see all their faces." My mom would fire back, "That's some other mothers delinquents. My boys were raised better. They're all angels." After the cops left, she'd spank us with her trusty yardstick then demand half the money. She's no dummy.

My mother must have raised her kids well because not a day goes that I don't think about all the endless sacrifices she made for me. Even though she lives across the country from me I keep her close. Her arms enfold me. Her voice is in my ears. Her smile is my eyes. And her love is in my heart. Thank you, mommy. I love you

■ ABILITY



Jeff Charlebois

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陈昂：康复，重塑生活

Chen Ang: Rehabilitation, Reshaping Life

“Easy. You may feel your muscles stretching a bit, but it’s okay. I’ll take care of that.” The patient’s upper arm was held up in one hand, the wrist cupped by all five fingers of the other, so that her glenohumeral joint could be rotated gently in rhythm, as it was now, overseen by a pair of eyes full of focus and care behind the silver rim of spectacles. In the Rehabilitation Department of Peking Union Medical College Hospital, on the 7th floor of its outpatient building, Ms. Yang was receiving physical therapy for her left shoulder, which could not be elevated to the level for radiotherapy after breast cancer surgery. Her therapist was a man named Chen Ang.

Chen has been working in the PUMCH Rehabilitation Department for a decade, providing professional rehabilitation services for a wide range of physical malfunctions and building close relationships with many of his patients like Ms. Yang.

Not a Massage Therapist

One of China’s early rehabilitation undergraduates, Chen studied at Capital Medical University and graduated in 2011. In his sophomore year, he began to work as an intern at Beijing Bo’ai Hospital, China Rehabilitation Research Center, and then moved on to PUMCH after graduation, pursuing his Master’s degree with Chen Lixia, director of the Rehabilitation Department. As her earliest disciple, Chen could be said to have had a “head start”.

Back then, the study of rehabilitation in Chinese universities had a shorter history than other areas of academic interest. When Chen was admitted to Capital Medical University, there was only one class for the entire enrollment of the year – less than 50 students. In his junior internship, the hospital facilities were far from


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Rehabilitation Center in Chengdu

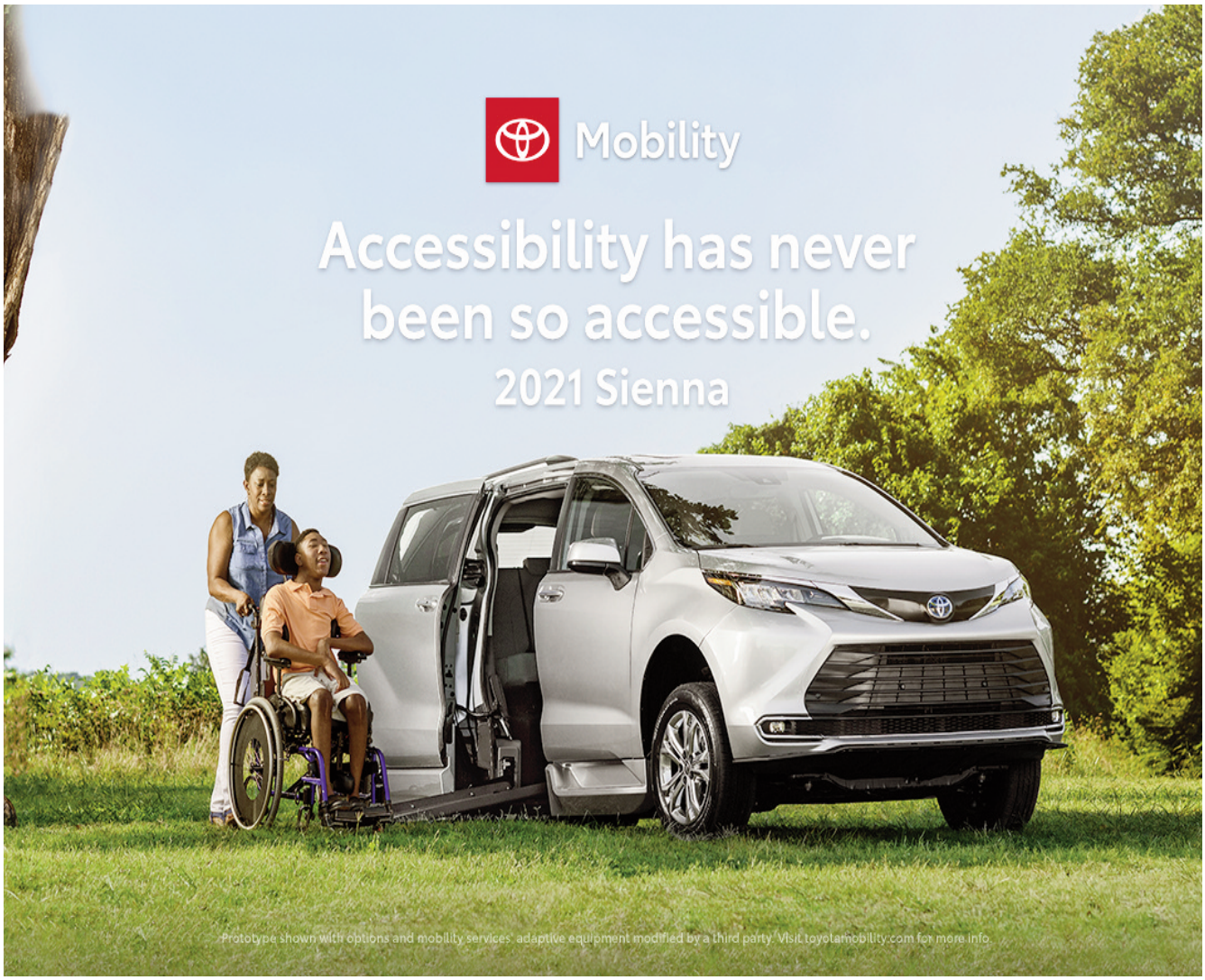
enough to meet the needs. Chen's days revolved around one diagnosis and treatment bed and several sets of rehabilitation equipment to help different patients. In times when there was only a dim public awareness of health, the term "rehabilitation therapist" was not well known. Chen would be addressed by other titles such as "masseur" or "massage therapist". The young and aspiring man was uncomfortable at first. He felt that what he was doing was not understood, but as he saw the patient's improvement from being helpless to confident, bedridden to slowly turning over, sitting up and even to standing without any support, a sense of accomplishment washed away whatever discomfort had been caused by all the misunderstandings. "For many patients, rehabilitation may take up to six months, and it takes everyday exercise. They are more like friends to me than patients."

Repeating over and over what is normal to healthy people may not be as easy as it seems. Rehabilitation is a long-term process. If you don't pay attention to details, it may not only be ineffective, but detrimental to the patient. Therefore, "rigor", "detail" and "patience" have become the principles that Chen must hold at work.

The most fundamental technique is the maneuver of the glenohumeral joint that requires applying the right amount of force to the shoulder, "Straighten out your elbow, relax your body, easy on your wrist". Chen would repeat these key points hundreds of times a day. And he was very strict in guiding patients to do these every time, with little deviation allowed. "The way I see it, rehabilitation is like a 'sculpturing process'. The more careful you are when carving those lines, the more vivid your final work will turn out to be. When each action is done properly with the right muscles involved, you will see a real difference at the end of the day. For patients who come to work on their legs, I will also consider the toes and the body in general, instead of just looking at the affected area. The strength or weakness of the toes can greatly affect the gait. " Chen's almost paranoid rigor has brought remarkable changes to his patients, winning more of their respect and recognition.

Beyond hospitals

Rehabilitation medicine aims at eliminating and alleviating physical dysfunctions, losses, or deficiencies. It is the "lubricating oil" across medical divisions in hospitals.



Other hospital departments may save lives whereas the rehabilitation department works to improve lives. Take people who had strokes for example. They might be resuscitated through some form of surgery, but they might also be left with various physical or cognitive disabilities which, if untended to, might render them dependent. One of the goals of rehabilitation is to help patients recover their abilities to live on their own as soon as possible, taking the burden off of their families.

Chen usually helps nearly 3,000 patients on an annual basis. As he worked with more patients, he found problems. Many patients who had done well in his hands were found to have a lot of regression during check-ups six months later. Some patients could walk independently in the rehabilitation room, but when they were discharged, they became home-bound again. This problem arose as not enough rehabilitation resources were made available, a clear gap between hospitals, families and communities. When they returned home, patients and disabled people lost access to the correct and effective rehabilitation exercises that they did back in the hospital. "The quality and durability of rehabilitation largely hinges on work outside the hospital."

To solve this problem, Chen began to engage with his classmates and colleagues in supporting communities, nursing homes and special education centers in 2014, and providing free rehabilitation training and guidance for patients in need and community medical workers. He taught the affected families, community workers, and volunteers how to use daily objects as tools. "An empty plastic water bottle can be used as a prop for grip training. As the grip becomes stronger, empty cans can be used instead. The things we use in everyday life may be good rehab apparatus."

In 2016, Chen spent his holidays studying community and senior rehabilitation practices in Tokyo. He learned that prior to discharge from a rehabilitation center or hospital, local professional and technical workers would visit the individual's home and offer suggestions on improving accessibility to facilities and making things easier. They would also provide guidance and help both physically and psychologically. This was done not only in the hope that the individual can live independently, but also to help with the return of social interactions. "Good rehabilitation is not only to restore the patient's lost or damaged physical functions, but also to cultivate

their confidence in social interactions."

To this end, Chen also learned counseling. Strict as he might be as a rehab therapist, he is all attentive and supportive to the patient's frame of mind. "In their rehabilitation sessions, patients and disabled people may spend more time with me than with their families. It is an enduring process, both physically and psychologically, and I want to help them overcome obstacles and get out of trouble as much as I can."

Community-based rehabilitation

As an intern, Chen had provided physical therapy for children with cerebral palsy. And he still remembers a young patient by the name of Kang Kang, a cute little boy with fair skin and soft curly hair, who worked very hard to follow Chen Ang's instructions step by step in each session. In one of the sessions, Kang Kang suddenly burst into tears and, when asked, said that he was bullied by someone at school due to his uncoordinated movements. Though effective, the sensory integration approach usually involves repeated, one-on-one therapist-based practices, with the absence of playmates the same age. Once back at school and in social activities, the child tends to get nervous and intimidated. "Many children affected by cerebral palsy physically, not mentally, like Kang Kang, may end up quitting school or resorting to day care centers just because they feel unworthy or rejected by other children."

In this process, Chen constantly changed the way he did things at work. From the literature, he learned that the per capita cost of institutional rehabilitation in other countries approximated 100 US dollars, achieving as small as a 20% coverage, whereas community-based rehabilitation only cost 9 dollars per capita, with an astounding 80% coverage. He was determined to promote community-based rehabilitation. "Rehabilitation resources in China have always been limited given the huge number of patients in need. At this point, it is very difficult to offer hospital rehab services with a focus on life-oriented and self-care tasks. We need to find breakthroughs elsewhere."

In 2017, as part of the PUMCH Talent Training Program, Chen studied children's rehabilitation and recreational therapy in Spaulding Rehabilitation Hospital, Harvard Medical School, Boston, USA. This experience, along with his own at work, led to his design of nearly 100 games and activities which are easy to use, effective and fun in home settings, without the need to rely on professional help or complicated apparatus.

These simple rehab activities gave Chen and his partners a new direction in helping people with disabilities. Chen learned that there are nearly 500 "Activity Centers" in Beijing, offering a wide range of public services to address the needs of local disabled communities. He decided to start from there.

While working with the " Activity Centers", Chen designed a little game that involved pinning buttons on cloth boards to represent subway stations. "Taking buttons out of the box can help the patient improve the flexibility of their fingers, recognize the names of subway stations, and train memory and cognition. When they learn the map, remember the names of the stations and feel a sense of accomplishment, they will want to go out into the real world and try it for themselves. For patients who suffer from strokes or other disabilities, such little games can boost several levels of function at the same time, at a cost of only a few yuan." In addition, it is also supplemented by a social system. After completing one round, you get one token and then go on to play other rehab games. When you have up to 10 tokens, you can get a free rehabilitation treatment on weekends. "This kind of rehabilitation treatment is provided by our volunteers free of charge. This way, the patient will be motivated to interact more."

Chen and his partners have been doing this for seven years. The original two-person operation has become a 100-strong team, serving nearly 300 disabled people on a daily basis. "As the numbers of elderly and disabled people are going up, so are the needs for rehabilitation. The government is paying more and more attention to the development of rehabilitation medicine. It is a joy to be part of it, to use what I have learned, and to find my place in society."

Chen Ang:

He was born in Beijing in 1989 and works as the Chief Therapist at the Peking Union Medical College Hospital. He is a national certified Grade II counselor who has won the honorary titles of "Beijing Youth Model 2019" and "Expert-nominated News Personality for Helping the Disabled 2020".

Picture: The 81 Rehabilitation Center in Chengdu, China, as part of Health China Plan 2030 promoted by the State Council. Rehabilitation medicine has gained more attention over the years with social development. (photo by Zhang Ximeng)

■ ABILITY

SPRING BREEZE

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*

Translation provide by Jing (Jenny) Hu


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Bikes & Cowboy Boots

When the Coronavirus hit the fan, I was at Daytona Bike Week. Exactly one year later, I was back in Daytona, working the Yamaha Demo tent, sanitizing bikes between rides and keeping my masked face six feet away from everyone else. The 80th anniversary of the iconic event was certainly different this year. The enormous crowd expected for the milestone year wasn't. It was rather quiet, the streets were not packed with bikes or traffic, the restaurants were nowhere near capacity, and everyone I spoke to or saw were following the rules or staying 10 feet away out of respect. For the first time in ten years, It didn't even rain. I was glad to be back on the circuit again, but rusty at being on my feet for 8 days straight. Trade shows look like lots of fun on the outside, but those who work the events know differently!





Daytona wasn't my first bike trip this year, I attended a fundraiser in Dallas the week before. It was an interesting event, a sort of motorcycle comedy show I devised to raise money for MS.

It started with an invitation to join a loosely organized group of misfit long distance riders. Because of their desire to ride so many miles every year, they beleive they must share some sort of genetic mutation. They called themselves the Defective Gene Pool. Riders get together from all over the country in Dallas each year for lunch. Some riders log 1000 miles each way just for a BBQ sandwich!

2021 was their 10th anniversary so they decided to have a big event including a dinner the evening before, and invited me to be the headliner. In addition to having me join their group, they informed me they had decided to induct me into The Defective Gene Pool Hall of Fame.

The event was to be a fundraiser, collecting donations for my presentation. I had a few different presentation ideas floating in my head, but it was only after explaining to my wife what exactly I was being inducted into, did I start to devise an entertaining, if not brilliant plan.

"Defective Gene Pool Hall of Fame? That sounds like the Oscars for Idiots."

She wasn't wrong. I decided I was going to decline the award. Not only would I not accept the accolades, but the plan was to show up in person to refuse and deny; pleading innocent to the charges that I possessed any such defective gene.

My presentation became a mock trial, where I was the defendant, representing myself against the charges of being defective. My legal team would prove all the motorcycle rides and activities I do were perfectly normal. I had character witnesses, whistle blower testimonies, pictures and video of all the crazy stuff I have done over the years to raise money for MS. It was sort of like roasting myself, by my attorney, who was also myself! The group provided a Judge, a prosecutor and

the audience was the jury, deciding my guilt or innocence. Voting was $10 -$100 depending on how guilty they thought I was. We also provided a live feed on social media for so others could watch and cast their judgment for The Trial of the Century.

It was a bit crazy, but apparently a little silliness was what everyone needed after being isolated for a year. The Defectives donated the dinner and beer, and by the time we rode to Ray's BBQ the next day, I was found overwhelmingly guilty on all counts, but was also handed a giant check for $6500!

The motorcycle community has always been a generous group, willing to help out those in need. The Defectives must have enjoyed my presentation as they already booked me for next year. That's a good thing, as I should be ready for my first mock parole hearing by then! ■ ABILITY

longhaulpaul.com




WEGGEMANN

WEARING A LOT OF SWIM CAPS

Q&A WITH PARALYMPIAN AND NEW AUTHOR

MALLORY WEGGEMANN

2021 was supposed to be an off-year for Mallory Weggemann. She should have recently competed in her third Paralympic Games. She should have been focusing her time on family. She should have been planning for having children. And she should have had some extra time to promote her newly released memoir, *Limitless: The Power of Hope and Resilience to Overcome Circumstances*.

Instead, she's in full training mode since the 2020 Tokyo Summer Paralympic Games were postponed due to COVID-19 and will now be held later this summer.

She's swimming six days a week. She's in strength and conditioning training two days a week. She dedicates time to sport psychology and mental performance, body recovery and "prehab" to prevent injuries as an elite athlete at age 32. She's the co-CEO (along with her husband) of a social impact agency and production studio, TFA Group, that promotes and supports brands within the disability sport movement. She's a motivational speaker. And, oh yeah, there's the book promotion tour right in the middle of reaching that peak performance for the Paralympic Games.



"I feel like I've kind of got a lot of hats on, but I love everything that I'm doing," Weggemann says. "I think that they all fuel each other."

Chalk it up to another adjustment due to COVID-19. But Weggemann is no stranger to adjustments.

A swimmer at age 18 who was experiencing lingering effects from shingles, her third and final epidural injection for pain left her with paraplegia and loss of movement below her abdomen in 2008. Three months later, she was in a pool again. By 2009, she was breaking world records in the pool. She won gold in the 50-meter freestyle and a bronze medal in the 4x100-meter relay at the 2012 London Paralympics.

In 2014, she endured nerve damage to her arm after a hotel accident. She still competed in the 2016 Rio Paralympics and has maintained her focus toward the Tokyo Paralympics—even after setbacks, a pandemic, and a schedule that looks like we're talking about an entire swim team instead of one single athlete.

"I think it's been a little bit of a blessing in disguise being able to release *Limitless* at this time in our society and everything that we've gone through this past year," she says. "It's my biggest hope that it can be a light for people and a story that allows other people to not just hear my story but more so my experiences in a way that can empower them to honor their own journey."

Ability Magazine recently spoke with Weggemann between a swimming session and a pop-up bookstore signing about training for her third Paralympic Games, her new status as an author, and how to change society's perceptions of disability.

Josh Pate: Going into a Paralympic year, athletes schedule their training to be at peak performance at the right time. Then all of a sudden that got unplugged for you last year. How did the postponement of the Paralympics impact your preparation?

Weggemann: It's interesting. One of the biggest things I noticed is that my body kind of goes autopilot, if you will, when we get into that six-month time frame. It's interesting. I start to lean up. My strength starts to kick in in the weight room. My power starts to show up. All those things we've been building for, that started to happen last February of 2020, which is about when it kicked in going to Rio in 2016 and when it kicked going to London in 2012. It's like clockwork. And then March came around and facilities shut down and it was like, OK. The hardest part was the first few weeks before the Games were postponed. We had lost access to training, and I was in my garage, just trying to figure it out. There was a lot of, I would say, making adjustments to reset the system, if you will. The one thing, though, that I found in that is, as Paralympians, we've had to overcome so many different aspects in our lives. We have mastered the power of adaptability. We understand pivoting. We get that in a very real way.

Josh Pate: People with disabilities make a living out of



making adjustments in whatever way fits their lifestyle. You're not immune to setbacks throughout your life and throughout your career. How do you summarize that and provide that hope or positive side for an audience?

Weggemann: There's a lot that goes into anyone's journey. At times it feels like you climb and you get a setback and you fall again. When I was 18 years old, I never in a million years saw my paralysis coming. It's the last thing I would have ever thought could have happened to me. But it did. And that's life. And yeah, it sucks. Let's just be transparent on it. It was not easy. But we have to find ways to move forward beyond that, because life will have its blows. We'll get knocked down. And we've got to find the strength and courage to get ourselves back up and realize that we are more than our circumstances. I was the 18-year-old girl who walked into a clinic for a procedure and never walked out. That was my story. But I'm not defined by that day or that moment in time.

Josh Pate: One way to view disability is that it's a characteristic, just like hair color or eye color. A lot of times the general population takes a different tone toward disability. How do you combat that tone? How do you spread the message of, "This is just a characteristic of life, and meanwhile there are dozens of other great things that are going on. Let me tell you about them?"

Weggemann: First of all, when you have a disability that's visible for people to see, it often feels like that's the first and only thing that they see. I had to find a way to be extremely confident in my own skin and understand that there were certain things I was going to now have to do to allow myself to stand out as a person rather than stand out as an object with my wheelchair. I'm really proud of my disability, and I don't need people to feel comfortable—like, I don't need to walk again for people to feel comfortable. But I think there's a normalizing of the perspective of it, like changing perception of what it looks like.

I tell people all the time there's a difference between having a disability and being disabled. They're two very different things. I proudly am a woman with a disability, but I am not disabled by my disability in any way, shape, or form. And so it just comes down to education. The biggest crossroad I think we're at in our society right now is sparking a conversation in our society in a manner that changes perception of what disability is. Because we have it in our head as a society that individuals with disabilities are not equal, contributing members of our society. And that is completely and holistically untrue.

Josh Pate: You can achieve incredible success in a variety of different ways, and there's still this elephant in the room of general society who just sometimes doesn't see that success, even though it's front and center in a gold medal, an ESPY Award, an entrepreneur, an author ... By any other measure, that's going to be a defining success for everyone.



Weggemann: And it's interesting, because I think that when you live with a disability, people forget that we as humans are multidimensional. We are not one thing. I am not just a woman with a disability. I am a wife, a co-CEO, an executive producer, an athlete, a speaker, an author. All of these things. I'm not just someone in a wheelchair. It's very interesting, and it's something that I've talked a lot about too, even just for women. Women, more often than not, get pegged into where we need to choose our one thing. You're either a mom or a businesswoman, but you can't be both. It's like, well, yeah, you can!

It's very similar when you talk about disability. It's interesting, because it's kind of like society has put us in this bucket that we're just one thing, and that one thing is instantly our disability and nothing else, because that's the label that's been stuck.

Josh Pate: It should be easy to answer to this question: What moved you to write this book? Obviously, life scenarios. But there's a difference between living that and then sitting down to write the book, or to work on this massive project and undertaking. What led you to say, "This is the time we need to share my story"?

Weggemann: For me, first and foremost, I've always wanted to write a book, but I think in order to do that in the way that can hopefully have the largest impact possible for readers, I had to be at a point in my journey where I was ready for what that process would be, mentally and emotionally. And sitting down and writing a book on your journey when there's been a lot of trauma and grief and adversity that you've had to overcome through that journey, you have to do it at the right time so you can fully honor it for what it is, not what you think it's supposed to be.

For me, it's been something that's been kind of sitting on the backburner for a number of years, always on my radar, and always with the idea that I'll know when the time is right. Spring of 2019 felt like the time was starting to come about. We started working on the proposal process, and next thing you know, I got an offer in December of 2019 and I was writing in January of 2020. For me, that was a very important thing, because for me, *Limitless* isn't just about telling my story, it's about sharing it in a way that can empower others to honor their journey. Because I do believe that "limitless," as an idea and concept, it's not this cutesy fluff statement, and it's not meant to be ironic like, "Oh, I'm a girl in a wheelchair, I'm limitless!" For me it's really about understanding that we all have circumstances that we'll carry in our lives, and we also all have to understand and know that we are more than those circumstances. That, to me, is kind of a pivoting moment, when we all find our own inner limitless potential.

I think the timing was making sure that I was in a place where I could authentically honor that in a way that would allow me to tell my story and share it with readers in a fashion that could empower them. That's what this process is about. It's not about writing a book so I can say I'm an author. It's about writing a book so that I can put my story together in a fashion and my experiences and the lessons I've learned to help impact somebody and give purpose, something good out of that day in 2008.

Josh Pate: Was it difficult at times to go through that?

Weggemann: It was. I journaled my entire process. The first journal I found from after my paralysis was three days following, when I was in the hospital. Going back and reading those journals, I don't think I understood how much pain I was in in the moment, because I was in survival mode. Going back and reading the words of my 18- and 19- and 20-year-old self who was finding her way in this world was very empowering at times, because I'll tell you, even then, that version of me, man, she was a firecracker! She was like—my younger self was not taking no for an answer from anyone. Some of those journals were just fantastic, I was like, "Oh, not a lot's changed OK! I get it!" But she also—there were those moments of just heartbreak, not knowing what the path forward would be. Reading that was challenging. But I'm so glad that I did, and I'm glad that I was able to have those to turn to, because I wanted *Limitless* to be authentic to what my journey was, not what I perceive it to be 13 years later.

Those journals guided the whole process. That's how the chapters came to life. Each chapter title is a theme, and there were themes that were just constantly themes during that time in my life in my journals. That's how I formed the titles and the journey within. It was challenging but also very liberating.

Josh Pate: When you think about the Paralympic Games, your own personal journey to get there multiple times and be successful, the stories that other people have had who are also in that arena, it's special; the Games are a special place. We hear the personal stories of overcoming and success and inspiration, and then we fail to honor the gold medals, the training involved for elite athletes, and the lifelong dedication. As you're saying, you're postponing children because of your elite status as a swimmer. How do you think our society can move toward that greater appreciation for the elite sport that the Paralympic Games are?

Weggemann: I think it really comes down to, every Paralympian has a backstory. Every individual has a backstory. But when you're a Paralympic athlete, your backstory is very visual. We can all see that there's a backstory there. And so it's something we've all had to learn to be very open with. I think that with that, there's a balance of understanding and appreciating the journey of a Paralympian that maybe got them to where they are today and put them into the Paralympic movement in the first place, while also respecting the work and the elite nature it takes to be a Paralympian and not allow the circumstances that qualify them to be a Paralympic athlete, whatever their impairment or disability might be, to diminish the success they have on the field of play.

I like to look at the Paralympic movement as a beautiful catalyst, to completely flip the narrative of what disability is and transcend the field of play and change perception in our society. Individuals who have physical disabilities are often looked at as if they're physically inca-

pable of doing something. That's kind of how it goes. And when you watch a wheelchair rugby game or somebody who's a double amputee running down the track on blades or a swimmer who's paralyzed or a visually impaired alpine skier, completely blind, flying down a mountain with a guide and in the inner ear a microphone, you start to realize, "Wow! Not only are they doing it, but they're excelling at it!" It's not a secondary consolation prize for living a fulfilling life. People with disabilities are not only living, they are thriving. And just because our stories are marked by maybe an adversity or a hardship or being born with something that seems to be "a little different" than what we've coined to be normal doesn't mean that that elite athletic accomplishment should be diminished.

That's where I look to the Paralympic movement as changing that and getting people to realize that disability isn't just a one-size-fits-all cookie cutter way of living. People with disabilities are, pardon my language, bad-asses, like other people, right?

Josh Pate: Yeah! For sure, I'm into that!

Weggemann: I love these conversations because, mind you, as an athlete, I think there's something so cool about seeing the power of sports, like I was just saying, to just completely flip the narrative. But also what I'm doing outside of the pool. My husband and I co-own a social impact agency and production studio. Our entire production studio is built off of telling stories, particularly ones of individuals with disabilities, in a way that changes perception and sparks that conversation. What we've found is a lack of representation in media, and we're doing our part to carry that torch in our little corner of the world, to change that. I love this conversation because, like I said, individuals with disabilities in our society aren't just living, they're thriving. And we need to tell those stories, because that's what changes the conversation.

Josh Pate: Was there anything that caught your eye and caused you to say, "We need to fill this gap, and we're going to do it"?

Weggemann: When I was 18 and newly injured, I had that immediate feeling of going out into the world and realizing that I didn't see anybody I saw myself in. I could go to the Mall of America and shop for the day and not see anybody I saw myself in through the individuals moving about the mall to the employees working in the stores to the window display, on down the line. Nowhere did I see somebody I felt like I saw myself in.

As I got further into my journey… if I feel lost in this because I don't see a path forward as a 20-year-old woman, what does a 6-year-old girl feel like for her future? She needs to know that there's a path forward for her. I still reference last year, in 2020, I had the honor to go to the Golden Globes. When I was there, I was so struck by the fact that the entire day, going through the red carpet, the awards show, the events following, I didn't see a single other person with a disability that was visual. It was me and only me. The struggle we had of even accessibility on the red carpet. There were a few times when I literally had the gentlemen who were with me lifting my chair up steps with me in it to put me where I needed to be. It's not that anyone did anything wrong, but it shows the unconscious bias that certain people didn't even think about needing accessibility because they've never encountered a need for it. Which means that the epicenter of our entertainment and media industry, in an awards show, it's an entire population of our society that's not represented. And media is how we form perceptions. The stories we watch on TV, scripted or unscripted, whatever it may be, it's like, a little kid deserves to sit on a couch and watch a movie with their friends and feel like they're seen. I think that motivates us so much each day. It's my motivation as an athlete and in my career outside of the pool to do my part so that that next generation doesn't have to ask, "What about me?" I think that's a really powerful part of this conversation.

Josh Pate: If we fast-forward 20-plus years from now, what does that perfectly accessible world look like? How would you envision that?

Weggemann: I think in a perfect world, say 20 years from now, you realize that it's no longer about how we need to make it accessible for people. It's about universal design. It's just there. We don't even think of it as being something that's this special thing we need. It just exists because we have full inclusion in our society. Accessibility is one thing. It's fundamental for a majority of people to even have a spot at that metaphorical table, if you will. We need accessibility so people can get to that table, and we need equal representation at that table.

But to have inclusion and true equality, that's when voices are heard and respected at the table. In a perfect world, it naturally happens. We don't even have to stop and make sure we think about that because it's so ingrained in who we are that these are the various different ways that people move about our world, and we need to make sure that universally it is accessible for all. It's not the back door at a restaurant out there because we don't want to do it at the front door. It's just there. I know infrastructurally there are challenges, but in a dream world it would be literally true inclusion, where we are all equal and accessibility is something that just universally exists.

Josh Pate: Hopefully we'll get there in 20-plus years. I'll hold you to that, OK?

Weggemann: Oh, gosh, I sure hope so! ■ ABILITY

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Lina Liu: Umbrella Foot Juggler



Omnium Circus is one of the brightest innovations borne out of 2020. Founded by Lisa B. Lewis, it is a nonprofit circus of diverse, multi-abled performers that includes an aerialist born without legs, a clown who is deaf, a contortionist, and much more. Omnium's mantra is accessibility and equity for all. And the talent is dazzling! Launched just as the pandemic hit, Lewis decided to take the show online. Their customized streaming platform allows viewers of all ages and abilities an accessible experience by offering a menu of virtual options: closed captioning, audio description, American Sign Language, and plain-language interpretations. *ABILITY* recently caught up with Lewis via Zoom to chat about the challenges of creating a fully-accessible circus, Omnium's foray into formal education, and their future plans.

Chet Cooper: So tell me, how did you end up doing what you're doing?

Lisa B. Lewis: My dream had always been to create a show that was not only inclusive for the audience, but that gave equal opportunity to all of the performers, not only physically, but whatever abilities, all races, all ethnicities. Not an all-Chinese circus, not an all this circus, not an all that circus, but a truly diverse and inclusive company of the best people in the world that I could find, so that no matter who you are in the audience, you see someone in that show with whom you can identify.

So that's what I did. I created a brand. I started everything with the pandemic, so our first production, which we thought would be live, didn't happen, so our show is virtual. We intended it as a one-day



Noemi Lee España: Hula Hools

showcase, but it turns out people really wanted to see it. So we extended our season. Then we got the New York Times review, which called us "genuinely extraordinary," which I love. That woman is so nice. And so we've extended our season until April.

What we're hoping is that in that time period we get a broad enough reach and a broad enough name recognition of our brand to then be able to take the next step, which is dependent on vaccine rollout. Do we create another digital version? Do we do a hybrid version? Can we put up a tent? We're exploring all options right now. Different ones have different budgets, and it's really very dependent upon COVID.

Cooper: If it works out to where audiences can come back into a theater, where do you plan to hold your events?

Lewis: We have a tent. We're planning to be a tented show, and our intention is to play New York, Boston, and DC, among anywhere else who will have us, but those are the markets we know, and those are, I guess, the low-hanging fruit. We know how to sell those and how to do circus in these markets.

Cooper: And do you have the equipment to move the tents and all that?

Lewis: Oh, yeah.

Cooper: So if you go any further, there's extra expense?

Lewis: Yeah. And we can. We can go anywhere, it's just a matter of time and money. If we have the time and the money, we can do anything.

Cooper: Right. Tropical island?

Lewis: Sure. I need it a couple weeks for free. I can get everything over there on freight. Know how to do it! (laughs)

Cooper: Oh, that's good! Have you ever thought of taking what you've created onto a cruise ship?

Lewis: That's a totally different market. Cruise ship are a very different business model. Could I? Sure, if someone says, "Here's a cruise ship contract, fill me a show," yup, I could absolutely do it.

Cooper: So we'll depart Tuesday? (laughs)

Lewis: Sure! (laughs) I mean, I've got a great company together. In fact. I just reached out to someone else today. If you can see the show, I'd love to invite you.

Cooper: Is it streaming live, so you can watch it again later?

Lewis: It is streaming. It's recorded because we had to be able to put in all the access. So when you log in, you have your choice of four different access platforms, and you choose your experience. You can choose the "typical" experience, you can choose the American sign language captioned experience, and you can choose audio description. We have two audio describers who've been with us for years, although I just listened to it today, and they forgot to introduce themselves. You'll just have to know that they're audio describers, because I just realized they never said, "Hi, we're your audio describers." But I suspect people figure that out fairly quickly. And the last one is a plain language format, which is a simplified language format for people on the autism spectrum, for English language learners, for three-year-olds, for people who are more comfortable in that environment. It reduces some of the sensory stuff, but that's as close as we could get in a virtual format to accommodating people. Those were the needs that we found to be the highest on people's priority list.

Cooper: Can we dig deeper into that? First, how did you know there was a need? How did you come up with your solution?

Lewis: I've been working in this industry now for close to 25 years, and this is my population. These are the people I serve. When I first started in 2012, I had five shows to give away in three places, and I had such a waiting list. And they said, "Oh, you have to monetize this." So I grew from serving 5,000 to serving over 30,000 people, because people kept wanting tickets. I kept having a waiting list. They would say, "OK, I love Circus of the Senses, and it's great, but my kid has autism and it's too much sensory. Can you adjust?" I had taught students on the autism spectrum, I had taught circus, and I trained and learned how to create with TDF [TDF Autism Friendly Performances]. I also learned how to create a show for families with members on the autism spectrum. So I created that.

With each one, it occurred to me more and more as I listened to families that they don't want to have to come just one day a year. If one member of your family—you know the stats, one in four. So that means somebody in your family is always left out. You should be able to go to any show at any time, not just on the day we have an interpreter, or the day we've adapted the program. Access should be all the time in order to truly bring families together. And I started a dinner and a show in the dark where I had the most wonderful experience of a young man who is blind leading his sighted grandfather and giving him a tour of the circus show, because he'd been there so many times that he was comfortable and knew it. It was the most beautiful thing.

Cooper: That's great. And that's somebody who's blind. But back to the sensory and the autism, you're having these people come in person?



Dupla Mao Na Roda: Hand Balancing

Lewis: Mm-hmm.

Cooper: Can you give some examples of what challenges you've had, and what you did to deal with the triggers that might occur for somebody on the spectrum?

Lewis: You mean in the live version or the virtual version?

Cooper: Both.

Lewis: OK. Virtually, there's really not much you can do. They have control of their own computer screen. They can change the volume and the lighting. They control their environment. What we did digitally is to put out the plain language format, which makes the verbiage more comprehensible for them. And that's a lot for people with developmental delay as well.

Cooper: Are you saying "play" or "plain"?

Lewis: P-l-a-i-n, as in "plain."

Cooper: OK, because in the captioning it kept saying "play language."

Lewis: Oh, I apologize for that.

Cooper: No, no, whoever is doing the captioning, they should apologize.

Lewis: (laughs) Is it an auto-captioner?

Cooper: It's AI, and we abuse that poor AI person. (laughs)

Lewis: There you go. I'm not sure if I speak properly for AI, but I will adjust myself accordingly.

Cooper: (laughs) OK, so in plain language. It's not done through AI, right?

Lewis: No.

Cooper: You're having people who are educated in a way to best describe the experience that's going on?

Lewis: Completely, yeah. The woman we have doing it is the person who created what's called the Yalon method; her name is Sherry Yalon. She created this system of plain language.

Cooper: So you found the founder as the person who's using her own method with you?

Lewis: Mm-hmm. In the live version, we can do a lot more. We can adjust lighting, sound, temperature. We

create chill zones so if people do have an issue, they have a place where they can chill. They're fully stock with weighted items and sensory things to help people get themselves back to center. So live, there's a lot more you can do. Our story for the digital version is two pages, because there's not that much to say.

Cooper: You mentioned you had been with Big Apple Circus?

Lewis: Yes. It was in the New York area.

Cooper: I'm not familiar with it. Were they also dealing with disability issues at that time?

Lewis: I was. That was my job.

Cooper: Within that company, you were heading up the initiative? Now it's making more sense. So that's where you have those 25 years of both circus and accessibility experience?

Lewis: Yes, exactly.

Cooper: Was this something that you went to school for? Or did you learn in the school of hard knocks?

Lewis: School of hard knocks.

Cooper: (laughs) I have several diplomas.

Lewis: (laughs) Obviously, I went to school, but my formal education is in stage management and in circus history. I was a performer for many, many years, and these were always my favorite audiences. So in order to make their experience better, I just kept learning.

Cooper: Can you move your chair back and let me see what kind of performances you can do? (laughs)

Lewis: (laughs) In the corner of my living room? Probably not!

Cooper: What did you do?

Lewis: My other company is called Super Scientific Circus. We use circus skills and magic tricks to explain science and make it more visual and comprehensible to students nationwide.

Cooper: Oh, I love that! But I was asking, did you perform in the circus?

Lewis: I'd walk on stilts; I'd balance on a ball. I used to do wire-walking.

Cooper: Wow! Wow! OK, you could show me some juggling. (laughs)

Lewis: What do I have here to juggle? My internet at the moment. (laughs)

Cooper: You can do one at a time? That's good! (laughs) And you didn't drop it!

Lewis: There you go! I didn't drop it! (laughs)

Cooper: I see on your wall you've even printed your logo on a mask.

Lewis: Yeah! We did that before our premier. I wanted to send it out to higher donors; I wanted to give them gifts. So we got masks printed up. I've got—where did my magnets go?

Cooper: Oh, that's a magnet? Does it stick to your screen? (laughs)

Lewis: (laughs) Yeah, we got magnets printed up.

Cooper: What time is your next show of Super Scientific Circus?

Lewis: In about an hour. We have shows at 12:00 and 4:00 pm, I believe. Let me look at the schedule.

Cooper: How many shows are you putting on?

Lewis: We have a full schedule, Wednesday through Sunday. Because it's Presidents' week, we had a full school show at 12:00 pm. We had one at what they call District 75 in New York. In New York they classify anybody with an IEP as belonging to District 75, which is a nonphysical district.

Cooper: Oh, interesting. I didn't know that.

Lewis: They basically lump anybody with a differentiated learning style into a District 75 school. Which is within—meaning it services within whatever district you live in, your home district. It's a weird system here.

Cooper: So you have contracts with different schools to have these performances?

Lewis: Yes. And we have a full 36-page STEAM and DEI-based [?] study guide.

Cooper: A study guide? A curriculum of sorts?

Lewis: It's a complete curriculum to go along with the show.

Cooper: I had no idea! That sounds really good. What's the age range?

Lewis: Basically K-9, although it's loose, because in pre-K there's plenty you can get out of it, and we have



Jen Bricker Bauern: Aerialist

21-year-olds with developmental delays who love it. So that's relative.

Cooper: And you try as much as you can to do the plain language within the curriculum?

Lewis: Not so much. It's written mostly for teachers.

Cooper: Oh, OK! So you have the curriculum for the teachers to present, and they have that guide to present as well?

Lewis: Exactly. There's no way I could write a course description or a class without knowing the students, and our goal is to reach 30,000 students. I can't possibly individualize it. So we created it for the teachers, and it is up to them to adapt it for their particular students.

Cooper: So District 75 is basically a client?

Lewis: Not yet, but I'm hoping they will be. Right now I'm just doing individual schools. But I would love for them to be a client.

Cooper: Is this scalable? Could you do this nationally?

Lewis: We could totally do it nationally. Given the opportunity, we could absolutely a hundred person be in every school in the country.

Cooper: In my early years, when I was still in school, I was involved in the marketing for a company that put on theoretical performances—and their core audiences were school districts. We would have performances to demonstrate learning modalities, specifically for at-risk youth. We got the New York Department of Education to be one of our clients.

Lewis: Nice!

Cooper: We'd have live theatrical performances. We'd color code the performers and then the staff, the faculty, and the student body would go to the plays and they could start identifying through color code their personality temperaments. Basically, the pullback of all this was, we were getting the teachers to understand the different learning modalities, especially of at-risk youth, because they'd self-identify with the color code. The orange were at risk. It comes out of Myers-Briggs, basically the Jungian theory of temperament and personality types. It was really successful. We were doing them all over the country. There wasn't a curriculum per se, but there were materials they could buy into, including bringing us in to do stage performances.

Lewis: Nice! I'd love to get to that point. We're a new start-up company. I certainly have tentacles out there trying.

Cooper: Once you have these 30,000, will you be able to build a database of contacts and emails?

Lewis: Right now I have about 11,000 contacts. Our social media reach is growing daily. People who are buying tickets are buying them from California, Minnesota, Florida, Georgia, and obviously a lot in New York, Boston, and the DC area, because that's where we are, Pennsylvania. We've got schools coming in from Jersey, Pennsylvania, California, Virginia. We're developing a national—it's not like a lot of people everywhere, but we're definitely hitting different spots around the country.

Cooper: I just thought of something. As I mentioned, we have our nonprofit, ABILITY Corps. Maybe we could talk about the idea of us trying to get you more business. There'd be some financial reward to the efforts of ABILITY Corps. And, of course, we would abuse the magazine to push that. (laughs)

Lewis: (laughs) That makes perfect sense!

Cooper: I like what you're doing. I haven't seen a show yet, but the concept's great, and I like the pictures I've seen so far. If we build this story out, can you have portions of the performance edited in a video format that can be embedded into the article?

Lewis: We have the promotional video on a link you can embed anywhere you want. But I don't want to put anything out unless it's completely accessible. Because I can't overdub it with an audio description, we put the image description in an attached PDF. The description for the video is on our website. I can show it to you.

Cooper: OK. When you put on these shows for students or anybody online, how are you managing that. Are you using a Zoom format?

Lewis: I have my own platform, so they log onto our platform so they can have all of the access channels. We did Beverly School for the Deaf, and they chose to log in to the American sign language one. We did Perkins School for the Blind. They chose to log in as a school to the one with audio description. Perkins School has a division of low-vision kids who also have autism. They chose plain language for that part of it because that particular group of kids had enough vision to see the show, but they needed the language more. So we did that.

Cooper: Interesting! Do you have anything that demonstrates your four different platforms? Have you built that out yet? Are you going to?

Lewis: Honestly, I hadn't thought about it, but that would be interesting.

Cooper: It's really unique what you're doing, and if you're saying you're on your own platform, that's also novel. You've got a bunch of novel things happening


Maxim Fomitchev: Clown

here that I find very interesting. Kudos to you for having created that! When you go into each of these different spaces are students seeing the performers live?

Lewis: No, it's all taped. We had to tape everything. I don't have the budget to pay everybody to perform live all the time.

Cooper: OK. When you say you have one show at 4:00 pm, basically you're opening up the portals at that time?

Lewis: Yes.

Cooper: I don't know who your host is, but when we do our career fairs, we have to open up broader portals for more bandwidth, if you will, so there's a new cost every time we do something that's really big.

Lewis: I bought a platform with a 50,000-login bandwidth.

Cooper: Ours is not just login. The bandwidth includes a bunch of stuff. When we have a career fair, we literally have a hundred or a thousand people who are in there producing their own videos.

Lewis: Oh, that makes sense. Ours are simpler than that.

Cooper: I don't know exactly what you're doing there, but do you have an IT person working on it, or did you contract out to the posting company?

Lewis: I have both. I partnered up with Disability Unite. Our original fiscal sponsor was a company called Art Beyond Sight. They've created a subprogram of that called Disability Unite. And he had just created this platform when we met and needed a showcase for it, and I said, "Well, guess what? I'm your showcase!"

Cooper: Nice!

Lewis: So then we started working together, and so we've teamed up. They're one of our biggest sponsors in terms of time and energy, but not necessarily giving cash.

Cooper: In-kind. What are they using as a platform for it? What was their intent?

Lewis: To showcase anybody else who wanted to do an accessible production.

Cooper: A production. So their wheelhouse is theater?

Lewis: Theater, video—I honestly don't know. I don't know what other events they produce on there.

Cooper: I haven't heard of them. I'm surprised.

Lewis: I think it started maybe two, three, four years ago.

Cooper: So it's still pretty new.

Lewis: Yeah. Art Beyond Sight has been around for a while.

Cooper: How did you find your talent—the performers you have?

Lewis: I dove deep into my community. "Who do you know? Who do you know? Who do you know?" And everybody sent me someone. A couple of the performers I'd worked with previously in my hand balancing act are from Brazil. Jenn Bricker Bauer I just randomly reached out to, and it turned out she'd been dying to work with a circus. She's on our board.

Cooper: Which one is Jenn?

Lewis: She's the aerialist who was born without legs.

Cooper: And she had been performing on her own?

Lewis: This is a new act for her. They created an act specifically for the show. She's been performing her other act for many years.

Cooper: What is her other act?

Lewis: It's still aerial, just a different act. But all the circus performers train their whole lives. It's all people who are out there and people know them.

Cooper: And other than what I just heard about the performer from Brazil, are they all basically in the New York area?

Lewis: No. Alan and Rafael are from and still live in Brazil. Our contortionist is from northern Africa; she's in Ethiopia and is still there. Jenn is in California, and Jason and Jonathan are both in Florida. Brandon's in New York. They're all over.

Cooper: When it comes back to where you have a live audience, will they all be coming to the States, to the New York area?

Lewis: Yes.

Cooper: Do you have any relationships with hotels yet?

Lewis: Not yet! I've got to get some! Either that or pick up a bunch of trailers. Most people live in trailers. Most people would rather stay on-site in trailers.

Cooper: Do you have any relationship with Winnebago?

Lewis: Not yet!

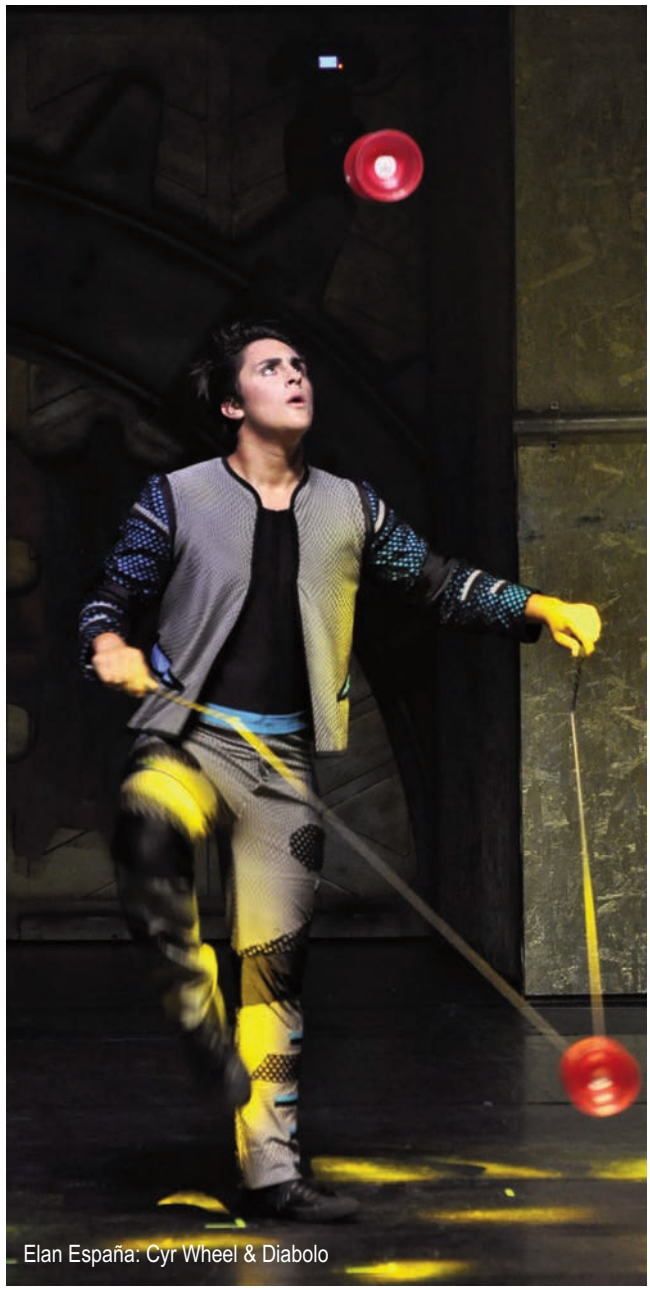
Cooper: They've got the new versions now that are accessible?

Lewis: Ooh! Maybe they want to do some promotion and give me a couple of those! I've got two wheelchair users.

Cooper: We tried to do something with them, but they were a little hesitant to hand them over. If you go to ABILITYMagazine.com, type in "Winnebago" in the search box, you'll see "Winnebago's Accessible Road Trip."

Lewis: Oh, that's fun!

Cooper: It used to be with all these RV companies, you'd buy the standard unit, and you'd have to modify



Elan España: Cyr Wheel & Diabolo

it. They've switched it now to where they have four different models. But they're not cheap. That's a problem.

Lewis: I'm sure. The last time we got one, we bought a used one. I think it was only $13,000.

Cooper: That's good, depending on how many miles and how abused it was.

Lewis: For us, it was fine. It didn't matter.

Cooper: What are the things you would like people to know about what you're doing?

Lewis: I would like them to know what we're doing.

Cooper: (laughs) Is there anything you think we missed?



Jason Span: Pole Artist

Lewis: No, the mission of it is complete diversity and inclusion. Like Jonathan says in our show, "We're born diverse. We choose inclusion." And the whole mission of our show is to create a platform, an experience in which everybody who wants to can enjoy it. If you don't want to have fun, that's your problem. But everybody who wants to enjoy it can, and we create a common ground for the world so that you can learn to talk to each other, so communities can learn from other communities. "Oh, you're this and you're this? Well, we can share this together." Circus has always been a mass market entertainment, and it has the ability to reach a huge variety of people. That's what we want to be. That's what we want to do, to provide world-class entertainment that is completely inclusive, completely accessible, not as a freak show, but as a genuine quality product that honors everybody involved and all of the stories involved.

Cooper: When you say all the stories involved, do you bring out storylines of the individual entertainers?

Lewis: Yes. That's mixed in with our show.

Cooper: How I'm understanding your way of promoting this is a combination of an educational format through school systems, and on the other side a more general audience participation as in any circus.

Lewis: Right. Exactly. And we can edit it down for corporate events. We have a couple of those coming up.

Cooper: And in the corporate events, I know at the moment it's virtual, but do you see corporate events also possibly being in-person?

Lewis: Later, yes, for sure.

Cooper: And do you envision, or have it connected to, some team-building concepts?

Lewis: Mm-hmm.

Cooper: You literally get people to come out and try to do tightroping without a net?

Lewis: I do tightrope with the students who are blind, deaf, whatever. We do that for the kids. For the adults for team-building, we do more experiential things where I'll blindfold sighted adults and have them do trust walks, teach them to do them together, teach them how to juggle with one hand tied behind their back or on one foot. It's empathy-building and teaching them to really value each other for who they are.

Cooper: Juggling with one hand while blindfolded? (laughs)

Lewis: Good luck!

Cooper: On a tightrope?

Lewis: Exactly! That would be the practice part.

Cooper: It sounds like you've thought a lot about what you're doing, integrating some important elements, not just entertainment but experiential activities.

Lewis: Yes, there's so much we can do. There's so much potential. ■ ABILITY

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JAMEELA JAMIL

Actor, Radio Host and Advocate

Jameela Jamil, known in the UK as a TV and radio presenter, gained popularity in the US for her role as Tahani Al-Jamil in NBC's The Good Place. In disability circles, she is recognized as an advocate for disability rights, LGBTQ rights, body neutrality, and her work around social justice. Jamil lives with several chronic illnesses, including Ehlers-Danlos syndrome (EDS), an invisible disability. She also identifies as queer. Jamil spoke with *ABILITY Magazine's* Karina Sturm about her passion for advocacy work, as seen in her new podcast iWEIGH. With candid moments of her life, Jamil shares her journey to champion understanding, self-worth and unity.

"I am an advocate first, and everything else last."

Karina Sturm: Good morning, Jameela. I have been following your work for a while now and am very thankful to have you here today. And by the way, happy





birthday! I saw your birthday was a couple of weeks ago.

Jameela Jamil: Oh, thank you!

Sturm: First, I wanted to talk a bit about your background. You grew up in the UK, but now you live in the US. Tell me a bit about how you ended up here?

Jamil: I was twenty-eight, and I had just sort of done everything I could ever have wanted or hoped to do in the United Kingdom. And I knew I wanted to do more and to explore more, but I was afraid because, as a woman, you're told just to eat what you're given and that if you achieve anything, you're very lucky. And it must have been some sort of a fluke. So, you shouldn't rock the boat and try and start again. At 28, I was considered too old to start again. It's as if you've made your bed, and now you have to lie on it. I just thought there might be something new out there for me. And I'm never one to do what I'm told. So, I decided to book a one-way ticket after a health scare where the doctor found a lump in my breast I had to have removed. I booked my ticket exactly six weeks from the date of the operation, which is when it's safe to fly. I had no agent, no contacts, no visa. I had no plan. I just wanted to prove everyone wrong.

Sturm: That's really cool. You've done so many different things throughout your career. If I am not mistaken, you started out as a TV and radio host, and then you switched to acting, even though you were planning to be a screenwriter.

Jamil: Yeah, I was a DJ, too.

Sturm: In what role do you see yourself the most today: Actress, activist or more as a presenter?

Jamil: I think I'd use the word advocate more than activist just because of the way that activists often lay their actual lives on the line in activism. I want to be careful not to take up that space. But I would say that I am an advocate first and everything else last. I moonlight as a performer, but my biggest cause in life since I was 19 has been social justice.

Sturm: I could clearly see that on your social media profiles. So, let's talk about your advocacy. I don't know if you know, but I have Ehlers-Danlos syndrome myself.

Jamil: Oh, no way.

Sturm: Yeah, and a lot of other conditions.

Jamil: EDS is a real bitch, isn't it, when the weather is bad?

Sturm: It is. And if you are on your period, which for some reason, I always am when I have important interviews. (Giggles).



Jamil: Your period is worse because of Ehlers-Danlos syndrome? Is that why my periods are so bad?

Sturm: It's usually the other way around for me. If I have my period, I'm just in more pain, and my joints are more unstable.

Jamil: Oh my God, that makes so much sense. I can't get out of bed for a couple of days before my period.

Sturm: Same here.

Jamil: I didn't know that was linked to Ehlers-Danlos. How cool. I learn something new every day.

Sturm: It meant a great deal to me that you decided to speak out about your health challenges publicly. Would you like to tell me why you decided to share your health journey with your followers?

"I felt a sense of duty to use my platform to speak out about this and start raising awareness [for Ehlers-Danlos syndrome]."

Jamil: I'd wanted to speak about it my whole career, but I was always told not to because it would be harder to employ me if people knew that I had an invisible disability. As my career grew, I just finally felt like I was powerful enough to do it. I had always planned to say it when I felt safe in my career because, unfortunately, that's how it goes. I knew it would mean a lot to the young people that followed me, and I also heard that the research funds are dwindling. There is less and less awareness, and the toolkits are being removed for doctors to be able to use to identify Ehlers-Danlos syndrome. All of these pieces of information from around the world and seeing how little awareness there still is now– I was diagnosed in 1995–I felt a sense of duty to use my platform to speak out about this and start raising awareness. Maybe we can start raising money for research. A lot more people have this than they even know because doctors don't know what to look for. Often, they think we are hypochondriacs or that we have Munchausen syndrome because we present as very healthy on the outside. You look like the picture of health, for example. so, no one would believe that we are physically fragile or vulnerable.

Sturm: I know some people attacked you for 'faking' your illnesses. That's something I and many people I know are very familiar with. We get dismissed and belittled every day. Can you tell me how you, as someone who stands in the public, deals with those ableist comments? Publicly, but also internally, as these must be really painful.

Jamil: It's really hard whenever it happens because someone's trying to convince you that you are imagining this pain, but it's very real. I have very real swelling. I go to bed every single night completely swollen, and I wake up in the morning swollen and in pain. And I have to go out of my way every single day in order to do



even half the things that my peers are able to do naturally. I have to live my life constantly taking precautions. People might ask why I never drank. It's why I never smoked or did hard drugs because I can't risk falling over. I can't risk something going wrong the way a person who doesn't have EDS can. Ehlers-Danlos syndrome is always at the forefront of your mind because it affects every single cell in your body, and so every micro decision you make is in consideration of Ehlers-Danlos syndrome. For someone to discard that just because you look "OK," according to their own Bible of ableism, it's very hurtful. I was very lucky that I was diagnosed by one of the leading consultants in the world, Professor Rodney Graham, when I was nine years old, and he looked after me for 20 years. So, I was lucky that I always had him to write an angry letter to my school or to my work to explain my limitations or to fight discrimination for me. I can't imagine what it's like for people who only get diagnosed later in life. But since I had that, I felt quite protected, and I felt quite believed because if an expert believed me, I didn't need anyone else.

However, when it happened on a global scale last year because some female journalist, who literally only goes after women, raised that issue and then social media took hold of it and ran with it, that was overwhelming for me because the world was laughing about something that has made me struggle my entire life. Also, who's ever gotten a job from saying they're sick? Who's ever gotten a beauty campaign from saying they're sick? Who's ever gained popularity from that? We live in an ableist world that considers sickness and sexiness to be mutually exclusive. What benefit would there be for me to lie and make this thing up that would only make my life harder?

Sturm: Exactly.

Jamil: So that was painful. However, mostly I was sad for the people, especially for the kids out there who were reading that and felt like this would further the doubt and stigma for them, for their lives. I think that's what people don't realize: When you're mocking me and my mental health and my physical health, I'm probably not going to see it. But who is going to see it? Other people that follow me. And those people might be sick, or they might have sick children, And they're going to be harmed. They might be a sick person who thinks that they won't be believed now because they've seen what your real attitude is towards someone with an invisible disability. I'm sad at how it went down, but it raised awareness on the issue, and that's OK by me. I'm fine now. So maybe it was for the best. I still think that everyone who contributed to that is a trash human.

Sturm: Did you have any specific coping mechanism to deal with this?

Jamil: I take very strong anti-anxiety medication. (Chuckles).

Sturm: Well, that's something. (Chuckles).

Jamil: I think it's very important not to pretend that you are just a stoic, strong, perfect person. I had to go on very strong anti-anxiety meds to cope with the global shaming and ridicule. But I'm fine now.

Sturm: I'm glad you are, but it still sucks you even had to face those allegations.

Jamil: Unfortunately, these conversations almost always have to happen in the worst and most clumsy and vio-

lent way in order for the most people to hear about it. Outrage sells. And I guess that's how that story was able to make it onto global front-page news. But now we at least have a dialog about the fact that you can't tell if someone's sick, just by looking at them; just in the same way that you can't tell someone's health just by looking at their weight. If someone is living in a fat body, that doesn't mean that they aren't healthy, or they aren't fit or they aren't going to live a long life. We need to stop diagnosing people with our eyes.

"Unfortunately, these conversations almost always have to happen in the worst and most clumsy and violent way in order for the most people to hear about it."

Sturm: Yeah, that's a very good point. How do you think growing up having this perspective on disability and illness has influenced you as an adult and professional later in life?

Jamil: It's made it harder for me, but it's also made me much more grateful for everything that I do have. I think I have my feet on the ground more than most of my peers because I'm so grateful to do the things that they often take for granted. It has gotten in my way many times, but that's alright, and I don't have a resentful relationship with my body like I did when I was a teenager. I used to look at my body as though it was working against me, whereas now I realize that I was just born with a genetic condition, and it's doing its best. Now I look at my body as my best friend; my ride or die. I do everything I can to try and look after it.

Sturm: What do you feel is the biggest challenge being a chronically ill woman and an outspoken advocate who belongs to different minorities in Hollywood, especially compared to your non-dsabled colleagues?

Jamil: I don't really know because I've only just said something, so no one else knew until now. For me personally, it's very easy to resent other people who don't struggle the way that you do. It just means everything's harder. That's the truth. I have to work harder. I have to plan more. I have to be more careful. I hurt more. But at the end of the day, I'm so lucky to have been able to break into this industry with this condition, with all these setbacks, with these health problems. And I always worry that when young people with Ehlers-Danlos syndrome see me out there looking fine or wearing a pair of high heels, they think I'm just gliding through and that there's something wrong with them. I want you to know that I'm struggling. I'm wearing those heels for fifteen minutes, and then I'm going home, and I'm lying down in between every take so that my fluid can move from my ankles up towards my leg. It's not easy for me either. I'm just doing it because even though it's really hard, I have a point to prove.

We don't have much representation of disability in this industry as it is, even though mine's invisible. The world makes so many judgments on us, and doctors tell us what we can't do. And sometimes they tell us we have more limitations than we have. I would like to take back whatever autonomy I can and prove to young people out there that maybe you can have your dream, maybe people can know that you're sick. If I end up on the cover of magazines and people can show my stretch marks and my scars and my bendy joints, I want young people to feel that at least some of their dreams can come true, too. I want them to feel represented in me. Once people know that you're sick, they just write you off, and they just hope you survive rather than expect you to thrive.

Sturm: And they don't think you can be successful if you're chronically ill.

Jamil: I don't want to look at Ehlers-Danlos syndrome as a death sentence or as a prescription of how much joy I'm allowed to have. So, I take a lot of risks with my body, but I am also looked after well by doctors, and I'm just doing my best to show that we have as much right to joy and adventure as anyone else.

Sturm: And we can be happy. I think that's a very important message.

Jamil: We can be happy. We can be in love. We can have sex safely and carefully–

Sturm: If we don't dislocate our joints. (Laughs).

Jamil: And we can have a wonderful social life and understanding friends to help look after us. The biggest thing for all of us is learning how to accept that there are some things we can't do, and that's OK. I'll never ski, for example. I'll be in the après-ski, having a hot chocolate, waiting for my friends.

Sturm: Sounds much more comfortable anyway.

Jamil: When you have a disability, and then you see people who are non-disabled do these things with their bodies, like that guy who climbs that cliff without a rope, I get angry. I get mad when I see people taking risks with their bodies like that. I don't understand what anyone's doing. Why are we ice skating? Are you kidding me with ice skating? (Laughs). Are you kidding me with being on wet ice on a knife - like, gliding on a knife through wet ice? What the f*** is going on? So, I am very grateful to Ehlers-Danlos syndrome for keeping me away from these stupid activities that I would definitely participate in otherwise.

Sturm: Oh yes, even hiking is risky for me because I fall all the time. I can't really imagine doing anything else. (Laughs).

Jamil: I live a super safe, comfy life, and I have stopped longing for anything other than that, especially now


Fight for Gender
Mental
Family
Glitter
Leader
dreams
Lovely relationship
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since I'm getting old. Eventually, this shit catches up with everyone.

Sturm: Hey, come one, you're my age. (almost 35).

Jamil: Yeah, but I'm getting old, and I don't think old is bad. Everyone my age, whether they have a disability or not, is wanting to be a bit more careful with themselves. So, we're all kind of leveling out anyway.

This scale of work and education can only be achieved by thousands of people. It can't be achieved by one.

Sturm: That's true. Now, you aren't only raising awareness for EDS, but your work also focuses on body positivity, trans rights and so much more. How did you get into those fields?

"I just felt left out in so many different ways and felt like this world wasn't built for me."

Jamil: No, not body positivity. Body positivity is a different social-political movement that is hugely important, but not mine. I advocate for body neutrality, which has more to do with eating disorders. I'm definitely someone who supports body positivity, but it's not really something that I'm actively engaged in the way I am with eating disorder awareness and body neutrality, trans rights, LGBTQ rights, racial justice, feminism and disability rights.

I grew up very marginalized and very lonely and feeling a lot of shame around the state of my life as a result of our society ostracizing anyone who was different. And I was sick and brown and secretly queer, and a girl and taller than I was supposed to be for a girl and chubbier than I was supposed to be for a girl. I didn't have cute little white Eurocentric features. So, I just felt left out in so many different ways and felt like this world wasn't built for me. And now to suddenly find myself accepted by the world –This is the same face. I didn't have any surgery. It's the same face that was rejected for the first 20 years of my life–And suddenly being on the cover of a magazine means that I have this platform where people are listening to me, where people will hand me a microphone to speak. I just want to use it to raise awareness about all the things that 12-year-old me cared about. I feel as though if I work in this industry that contributed so much to her erasure and her low self-esteem, and I don't use every opportunity I have to try and fix what was broken when I was little, then I will let down my 12-year-old self.

Sturm: So, that's why you started your iWEIGH movement? And now you also have a podcast with the same name. Can you tell me a little about those projects and what you want to achieve with them?

Jamil: iWEIGH started as a rant online where I was sick of the way that women are still–20 years since I first



developed an eating disorder–valued by the number on a scale. I couldn't think of photographs of men with their weight written across their bodies unless they were UFC fighters, and yet I could see countless pictures of female celebrities with their weight written on their bodies. These women have amassed billions of dollars or won countless awards or broken world records, and the only thing we care about is how little space they take up in the world.

I was very offended by that. So, I spoke out about it, and it must have touched a nerve because 10,000 people, mostly women, wrote back to me that same day as a response to a post I wrote about what I weigh, which is I weigh my relationship, my financial independence, my friendships, my contributions to society, my failures, my triumphs. Within three days, I started an Instagram account. I thought it would be a phase. Now, I'm here three years later, and we've turned from being an eating disorder awareness company to being a social justice and allyship company. I think a lot of people realize they're not really doing enough to help other people who don't look like them, and they don't really know where to start. Rather than punishing those people for being a product of their environment, it would be more of a solution-based approach to give them somewhere to start.

What I've tried to create with iWEIGH is a safe space on the internet where you won't be judged for what you don't know, which is going to make you feel excited to learn. And there's a lot that I don't know. I learn publicly from great educators on the podcast and the YouTube channel. I'm super proud of the YouTube channel. I think it's so radical and special. And I make it with a great team of people. I'm happy for us to be that starting point wherever you are because you feel less lonely when you're connected to people from all different walks of life, because really we're all just the same.

Sturm: What kind of topics do you discuss on your podcast?

Jamil: Everything, truly, everything. Immigration, disability, mental health, shame, eating disorders, body image in general, race. We're trying to cover absolutely everything there is. We're currently looking to speak to both people with autism and people who are experts on autism, so that we have both sides of that story, rather than just having a non-disabled expert speak for autistic people. We want to try and do both in the same episode, but also not put someone with autism under a magnifying glass for an hour to have to speak for everyone, as if people with autism are a monolith. We're trying to slowly but surely get to every different type of group, every different type of religion, and just bring the world closer together because I feel as though that's the exact opposite of what our governments want. The rise of fascism depends on our division. And the only way to combat that is with unity. That's what I'm trying to do. People are learning a lot from the podcast. I am learning a lot. And people are making friends via interacting over the podcast and over the iWEIGH account.

Sturm: That's really cool.

Jamil: It's one of a few nice communities online. There is no trolling. If we put a picture up of someone in a bigger body, a disabled body, or with dark skin, we will be monitoring the comments very, very carefully and make sure to protect the person online because that person is not the only one who gets harmed when you see trolling–So is also anyone else who identifies with them, who's reading the comments too.

"All I plan for the next ten years is to do my best to help my own mental health and to help raise awareness

around the mental health of others."

Sturm: How do you handle belonging to so many intersectional communities and the challenges that arise due to trying to satisfy all of those with your advocacy and work?

Jamil: I think two ways. One, I recognize that I'm only one human being, but the other thing is that I'm really not the star here. I'm not at the forefront. I pay for the company. I fund everything. I come up with the ideas. I'm the creative and the CEO, but it's not really on me. It's on the extraordinary educators I bring on. My job is just to make sure that I represent as many as possible. I don't consider this to be all about me. I share the glory and the burden with as many other people as possible because this can only be done by a community. This scale of work and education can only be achieved by thousands of people. It can't be achieved by one.

When people try and make activism all about themselves and take everything on alone, they just burn out, and they end up not really being able to help anyone. I've never wanted to do that. I'm very lucky that I have access to all the best educators in the world, and I get them to do the work and learn from them. I'm here as the pupil, not as the teacher or the leader. Well, the pupil and the bank. (Chuckles).

Sturm: I also read that you never ever photoshop any of your professional images. How do those photographers or the magazines react if you tell them you won't allow them to do that.

Jamil: They used to tell me to f*** off and refused to shoot me when I was younger, or they would force me to do it, and I would have to. Otherwise, I wouldn't be able to promote whatever show I was promoting. I was very young and new, and I didn't have any power.

When I turned 30, and I had The Good Place, I said, I'm just not doing this. I'm not going to allow for them to edit my images. I'd rather not be shot. I had nothing to lose because I didn't plan on having a big career here or being famous. There was a big appetite for me as soon as The Good Place took off, so I knew I had the power to say, 'No.' So, I did. I wish I had exercised that power and been firmer when I was younger, but I was scared. Today, I have an excellent team of really empowering women around me who help enforce all of these things for me. They back me up fully. It's really good not just for the self-esteem of the people who follow me to see my real stretch marks all over my breasts or all over my body or to see my cellulite or my wrinkles as they grow, it's important for me as well so that I don't compare myself to digitally enhanced images. That's the problem with editing: It doesn't just f*** with other people who are looking at our pictures. It really messes with our minds. We are comparative creatures. We can't help it. So, I think it's really important to try not to engage in editing if you can possibly avoid it.

Sturm: I agree. I have two last questions for you. The first one is: Where do you see yourself in ten years from now?

Jamil: I have no idea. I don't ever plan, so I'm afraid I have no answer for that. With Ehlers-Danlos syndrome or with many chronic illnesses, you can't really plan. You learn very young not to plan. Honestly, with EDS, I have no idea if I'll still be able to walk the way that I can now in ten years. I'm just going to keep going and doing my best to protect myself and as many other people as I can. All I plan for the next ten years is to do my best to help my own mental health and to help raise awareness around the mental health of others, to make them feel supported. But I have no finite plan because why would I? How can you?

Sturm: I love that answer. It's very honest, especially with EDS. I always love to end interviews with a random funny question. If you were given a free 60-second advert slot at the Super Bowl, what would you use it for?

Jamil: I would talk about Ehlers-Danlos syndrome 100 percent. It's the thing that most needs to be spoken about. No one gives us any time because it's not considered a dramatic condition. I want to raise awareness about EDS.

I also would like to show disability in a sexy way. That's something that I feel really passionately about, that I've been working towards. I was a guest editor of a Playboy magazine and was able to put a friend of mine in that magazine who is an amputee. She was shot so beautifully, and she looked so incredible. She's partially nude in some of the photographs, and you can see her prosthetic, and she just looks gorgeous. That's another thing that's really important to me: showing disability in a sexy light.

Sturm: Oh, I love that!

Jamil: People see people with disabilities as untouchable. And it's so not true. Many of my friends with cerebral palsy have wonderful sex lives, they get married, and they may be going to have babies. So, I'll keep working towards showing disability in a sexy light.

Sturm: Well, I will keep supporting your work in the future. Thank you for all you do!

Jamil: No, thank you! Have a great day! ■ ABILITY

Karina Ulrike Sturm

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JENNIFER GOODMAN

Jennifer Goodman Karum is shifting perceptions of people with disabilities in entertainment. Goodman, an autistic actress, writer, producer and creator, collaborated with Ryan Atkins, himself a producer and creator, to found Lakefront Pictures. This Chicago-based production studio aims to amplify unheard voices. In their work, diversity and disability are evident in the talent, both on the screen and behind the scenes.

ABILITY Magazine met with Goodman and Atkins to dive into Lakefront Pictures and their latest project, *Conrad*. Currently a pilot TV series, *Conrad* is a compelling crime drama that features Goodman as an autistic female detective battling corruption and human trafficking. Goodman's character is based on her own experiences as a strong, driven autistic woman. Goodman and Atkins described how it all came together.

Autistic representation in the media has always been a hotbed for controversy, mainly because the rare instances that the autistic community actually gets the Hollywood spotlight tend to perpetuate harmful beliefs and stereotypes. In light of this phenomenon Goodman is trying to shift the narrative towards authentic representation and inspired by her own struggle to be heard and taken seriously as an autistic woman, she has poured her heart and soul as the writer/star of Lakefront's biggest project: *Conrad*.

Attracting the attention of multiple studios and networks, *Conrad* is a developing TV series focused on an autistic female detective battling systematic corruption that disproportionately harms immigrants and enables human trafficking—all the while discovering the truth of her traumatic past.

ABILITY: Could you tell us about your experience growing up with autism and how your family shaped that experience?



Harry Lennix and Jennifer A. Goodman in Conrad series

Goodman: I was diagnosed with autism as a child and genuinely was pretty much misguided by my family's interpretation that I would never make it in society. I've come a really long way from where I started. I've had a lot of trials and tribulations and I've overcome a lot of it through just getting up again and really believing that I will make something happen. I think I've really kind of had a knack for believing that good things will come to those who build it. But just with my mother's chutzpah and my grandfather's chutzpah–as far as I like to say–I think I've really kind of had a knack for believing that good things will come to those who build it. It comes from my father, who is an entrepreneur, and he is absolutely determined for success. But it hasn't been easy for me.

ABILITY: What does your father do?

Goodman: My father is a real estate developer. He started his business thirty-nine years, forty years ago.

ABILITY: And your grandfather?

Goodman: In terms of my chutzpah from my grandfather, he was a radio host for many, many years after he came back from World War II. He was also a professor at the University of Wisconsin and so was my uncle. They love to talk and they love to help people. And I think that that's where I get that energy that I seem to always have.

ABILITY: How has your background led you to be where you are today?

Goodman: I've been performing my whole life, but one of the things that I really kept to myself was the fact that I am on the spectrum, especially because it was so taboo. I have anxiety because of my inability to understand people and that there are certain ways they do things. Sometimes, I push boundaries in ways that can be a bit surprising to people I'll ask something, and they think, "Wow, she's really bold to ask that." But I always feel like it's better to ask than to not ask and never know if it's a yes or no. Something that I've worked really hard on is trying to improve my skills through therapy and by building relationships and struggling in them. Having a lot of people give me feedback is really what's helped me become who I am. I've had a lot of things happen in my life that I've had to find ways to overcome.

I was very lucky that I had the opportunity to get involved in a project with Ryan. Ryan is also very determined and believes in helping the underdog. I was able to audition for something he was producing and after I was cast, I offered to write and expand the script that I loved about a female interrogating a male suspect. I liked the women empowerment aspect because it really kind of resonated with me, as someone who has never really had a voice and has been made fun of for her voice. And so, I was determined to bring something to life.

I come from a background of sales so I have a lot of connections in the sales world, and I have a lot of actor friends, while Ryan has a big crew background. Then, we were able to build what Conrad is today: a full blown forty-four minute pilot with the three seasons, a show bible, and a three season episode arc breakdown (story line). What we have has impressed networks and studios. We also have a full production with Harry Lennix and Eric Roberts, who joined our project and



said they would do it again in a heartbeat because of how they felt about the project and the way that they were treated. The family dynamics of our team were so strong, that I would do this over and over again.

I feel very blessed that I was able to work with such incredible, talented, gifted people who had the patience and understanding to help me learn what most people learn in film school or most people learn in kindergarten of how things work. I've grown exponentially and I really am trying to get myself out there as an actress. Ryan and I, we started a production company called Lakefront Pictures, which our mission is we amplify unheard voices and tell untold stories that change narrow perspectives. And it's just really important that we elevate people who don't have a voice. We're continually growing and creating content.

ABILITY: How did you and Ryan decide to work together when you mentioned that he had an audition?

Atkins: I have a long history. I mean, usually someone in my field will work as a one man band doing it all until you grow bigger. But I was looking to do a demo scene–because I did it for several other actors–and wanted to do it myself. You can easily make it look quite fake and I guess you could say cheesy, but I wanted to do the opposite, make it look real and hopefully generate some interest. So, I got inspired, really, to write a short script that is about two pages. And I was inspired by a couple of movies that have pretty strong female leads. I just wrote what was coming to me, what felt right, and what was interesting to me.

Then, Jen pretty much stole the stage on the character. I wasn't expecting her to perform as well as she did in her audition. Essentially, what happened was my writing had some–it just kind of lands you in a scene. So Jen asked if there's any more to the character. Once she did that, I felt there was somewhat of a transition of power she was unaware of. So, I was kind of sweating underneath my boots a little bit because I'm thinking, "Oh, crap, she actually wants to see more." I decided to be honest and just said I had some vague ideas, but nothing too concrete right now. In response, she asked if she could provide some ideas for the character. Eventually, with her input, it ended up a really long feature. We decided that it would be better as a television series.

Jen's ideas really surpassed my abilities to keep up with it. This was all during a time when even I had no clue that she was even on the autism spectrum. I thought this was just who she was. But there's a whole lot more greatness that comes from her than what meets the eye. And so, we collaborated until I realized that she just really needs to take this thing over. We were expanding into lots of different things, and I needed to focus on some of my areas of expertise. The rest is kind of history.

We made a pilot, which is not easy, but we did it. Jen did a fantastic job. She really did, all things considered. I do feel that her being on the spectrum helped out in many situations. If we wouldn't have had her chutzpah, we wouldn't be where we are today.

ABILITY: Ryan how are your own experiences reflected in *Conra*d,?

Atkins: I happen to have reading comprehension issues, also issues with learning comprehension in general. I



Eric Roberts and Jennifer A. Goodman

have my own method for retaining knowledge. So, we both have our ways of combating challenges.

Goodman: We've overcome a lot. We were able to make something pretty unique that has globally become a huge marketable project, that people really see potential with this character on the spectrum who's been doubted when she uncovers this corporate operation. It's really parallel to my life and Ryan's in terms of how he's also had to overcome certain obstacles. We're just trying to get this project in the eyes of the right people who will really see the value of what we can bring, and hopefully inspire other people while also being able to get opportunities for ourselves.

ABILITY: And prior to this, you both have been working independently, doing things to move your careers forward. Before this you were learning your craft?

Goodman: Before, I was working in sales making a pretty good salary and commissions for 15 years, but I was unhappy and anxious because I was constantly trying to meet a quota. As an actress, I got paid gigs here and there, but it wasn't a full-time thing. I was never in a position to be able to do that.

ABILITY: Right. And what were you doing Ryan?

Atkins: I had a range of jobs, either contract or full-time, kind of half and half of video production or information technology. My skills definitely helped with the project, but I also had to keep those lights on, too. I have done a handful of freelance gigs, but I also was not able to find a sustainable living with that. I had to keep a job in addition to working on the project.

Goodman: We were very lucky that we were able to raise capital, and that I already had that experience due to my background in sales. But we were very lucky that Harry and Eric really put in the patch and saw the passion that we brought. We did not pay them what normal market price would be to bring someone like them out. But we did take care of their airfare and hotels and housing in order to get them to be here in Chicago, as well as Hishem Taufiq and Neotel Areca, who are also fine actors and non-actors. We're very blessed to have people who believe in us and project what we stand for and what we're trying to achieve.

ABILITY: And this is pre-COVID?

Atkins: Yes.

ABILITY: And what are you thinking about now?

Goodman: Well, we are doing a feature about a young woman who is bullied essentially to her death, and it's a horror thriller/spiritual thriller that is slated for filming in August. Hopefully, most people have been vaccinated at that point, but we will be following COVID protocols. We don't have the budget to check people every single day, but we're hoping to be in a position to get tested in the beginning, have safety measures, and have hand sanitizer and masks on set. We're hoping at that



Kelly Tidmore, Jennifer A. Goodman, Harry Lennix and Ryan Atkins

point we don't have to do a test every day.

ABILITY: Right, right. So, how are you sending your reel to other networks?

Goodman: I spent the entire summer with Ryan looking up contacts, going through CRM—we are making our own CRM database, which is a customer retention database that we worked on LinkedIn and Facebook. We did everything we could to do the research and we sent out emails. We hired an assistant. We put our pitch together. We've been very lucky. People are very intrigued by the autism spectrum, and companies like Netflix are very interested in talking to us about our production company, Lakefront Pictures. They're looking if there's a studio that can help us elevate a little bit to fit more of the mold of what they're trying to do. but everything else is kind of in the air. And we're still out there trying to get it pitched.

ABILITY: What does diversity mean to you and how are you trying to make it prominent in your show?

Goodman: For me, I think having a quality of including people from many different ranges of different societal and ethnic backgrounds, different genders, sexual orientations. What makes something diverse is having not just Caucasian, and just the same type of people, but really–cross vertically–bringing in many different people. We made sure to do this on both sides of the camera. Including those in the LGBTQ+ family, we make sure that people with voices unheard have an opportunity to be lifted. We had production assistants that wanted to be in coordinating positions and so we trained them to fulfill those types of roles and be promoted within. So, there were many ways that we brought in diversity and inclusion by treating everybody fairly. It's really, really, really important for our work to have.

ABILITY: What inspired you to have immigration, human trafficking, and female empowerment as the main focal points of the show?

Goodman: I think the biggest thing about 'female empowerment' is–you know, we hear that word all the time. What seems to be something that a lot of people throw back and forth, but what does that really mean? And it really means amplifying unheard voices. You find that women in a lot of industries are undermined. Female directors, female writers, women in everyday work and even in marriages need to be lifted. I mean, the world was thrilled to see a vice president as a woman. That is a huge, big change. That will give women more of a voice, which is what I think society needs.

Regarding the other issues, Ryan and I, together, came up with the realities that are the real dark places that people don't talk about: trafficking, immigration. These are worldly experiences that are happening every day in our lives that people don't want to look at. But by not looking at it, you're being a part of the problem by ignoring it. And here's one person (Kate Conrad) who's trying to bring it to the surface. ■ ABILITY

by Melissa Ancheta

jenniferagoodman.com



In the business of spreading happiness

Donuts, sushi, cute kittens or funny quotes: If you need a creative and fun pair of socks, John's Crazy Socks will likely have what you are looking for. John Cronin is the co-founder and face of the most diversely stocked sock company in the world. Together with his dad Mark, John is on a mission to spread happiness and raise awareness of what people with disabilities can do. By now, his company is a multi-million-dollar social enterprise that supports charities, changes disability policies, and, of course, sells "Socks, socks and more socks."

Food truck or sock store? That's the big question.

"Let's open a fun store!" John tells his dad. "A business that makes people happy." And that's exactly what he did. John is the face of Crazy Socks, a multi-million-dollar sock empire. Together with his dad Mark, John created the world's largest variety of colorful socks, with 2300 different designs–a sock lover's dream. They aren't just any socks though, they are fun socks! So fun, these socks have been adorned by high profile sock wearers like the late President George H. W. Bush and Prime Minister Justin Trudeau.

John and Mark Cronin opened the store's virtual doors on December 9, 2016, in New York and shipped 452 orders in the first month alone. Their quick business success proved a





good choice over John's original idea to open a food truck. When they figured out that neither father nor son can cook, "John had his Eureka moment," Mark emphasizes. "Socks are fun! Colorful! I wore crazy socks my entire life," John adds. And the idea for the store was born.

The 21-year-old cliff.

The reason behind Crazy Socks' existence, however, is based on a challenge many people with developmental disabilities face. "Throughout the state, when you have a disability, you can stay in the public school system until you either graduate or turn 21," Mark said. "This is sometimes called the 21-year-old cliff." He explained that for as long as the children are in school, all the services they need are available, but once they leave the system, they are on their own.

"I have been looking at jobs, but I didn't find an option I liked," John said. "The reality is there aren't a lot of good choices for people with different abilities," Mark added. But John showed he was a natural entrepreneur.

Instead of seeing his situation as a problem, John saw it as an opportunity to create his own store. "I wanted to work with dad, so I said, 'Let's have a nice father-son-business together,'" John said. John and Mark were convinced, if John loved his crazy socks so much, others might too, and they went into business together. "I love working with my dad because he is really fun, and I love when he tells a joke. He is just my favorite," John explained. John continued by turning to Mark, "I love you, dad."

"Socks, socks and more socks."

John and Mark set up a website, created some Facebook videos of John talking about socks, and John came up with the company's new slogan, "Socks, socks and more socks." John delivered their first orders himself to his local community. Mark explained John's dedication, "Sometimes, we would be there at 10 PM at night, and John was knocking on doors to deliver socks." John added, "Customers looooooved our socks!" Four years later, John's Crazy Socks is a thriving company selling crazy socks… and spreading joy.

Every sock is packed with love. Each box includes a piece of candy and a personal note from John. They also put in a sticker with the names and photos of the people who packed the order. By the way, pickers are called sock wranglers, and the packers are happiness packers. All of the employees put a lot of thought into the packages. "One of our packers comes to me and says, 'Listen, we are sending candy to every customer, but we also sell socks to diabetics. What are we doing? We are sending candies to diabetics!'" They solved the issue by having a supply of sugar-free candy to satisfy the different customer's needs.

Mission: Happiness

"Do something for others because we, here, have a mission to spread happiness." John's Crazy Socks has both a social mission and a business mission, and those are inseparable. "If all we did was sell socks, nobody would hear of us," Mark explains. John and Mark always look for a personal connection with their customers, which distinguishes John's Crazy Socks from other businesses.

Giving back is one of the pillars the company is built on.

John doesn't only sell socks; he also wears a specific pair each day. Saturday, for example, is poop emoji sock day. John's favorite design is the Down syndrome awareness sock that has a little cape attached to it, a design he created himself. "It just comes out of my head," John said describing how he gets the ideas for the socks. Mark added, "We have a diverse organization, and that's important. We want different tastes, different opinions."

John's Crazy Socks is a social enterprise. "We are not

really a sock store. We are more in the business of telling a story, and the socks become the physical manifestation," Mark explained. Giving back is one of the pillars the company is built on. In addition to their awareness socks, they also donate five percent of all earnings to the Special Olympics. Overall, they have donated $400,000 to various charities.



"Showing what people with different abilities can do."

Today, John's Crazy Socks has 30 employees, of which 21 have a disability. By hiring people with disabilities, the company wants to inspire and create hope. "People have an emotional connection right away. It meant so much to see someone with Down syndrome starting and leading a business," Mark says. "The most important thing we do is showing what people with different abilities can do."

Besides their work with the business, John and Mark give five to six school tours per week–virtually at the moment and in person before the pandemic. They speak at events all around the world. "This week alone, we spoke to a group in Wisconsin, Israel, Ghana, the Ozarks, Maryland. It's wonderful!" Mark says. They both work from 9AM to 6PM in the business, then they personally deliver socks to customers or have other events online at home after hours. They attend events over the weekends as well.

Almost two years ago, John and Mark had a fundraising event in New York City and didn't make it back home until 2 in the morning. Mark told John to sleep in the next day and just rest and recover. Mark explained, "So I go to the office about 10 o'clock in the morning. Who is walking in? John! And he says, 'I took an Uber here; I got things to do!'"

"We have a responsibility."

Mark and John use every chance to be politically active. When they went to an event at Capitol Hill, a customer called and to Mark that her mother works there and is a big fan of John's Crazy Socks. The customer asked if it was possible for them to stop by and see her mother. "Sure," they said.

The customer's mom happened to be Speaker of the House Nancy Pelosi. "We walk in, and what we often forget about our elected officials is that they are all just humans. She is a grandmother! So, we come in, and she immediately takes out pictures of socks that she gave to former President Bush," Mark explained.

They all quickly bonded and had a great time. However, Mark and John also knew they had an obligation. "So, we say, 'Ms. Pelosi, this is very nice, and thank you, but we really need to speak about eliminating the sub-minimum wage.'"

In February, John presented President Joe Biden, who supports eliminating sub-minimum wage, rescue dog themed socks. And One of John's latest designs, Unity Socks, were given to Congressmen Andrew Garbarino (R-NY2) and Tom Suozzi (D-NY3), during a company tour.

How to spread happiness during COVID?

2020 was a challenging year for John and Mark. COVID-19 impacted both business and personal lives. On a business level, they faced hurdles related to safety. They established a rigorous program to keep their employees as safe as possible with temperature screening, mask-wearing, constant cleaning and rearranging offices. They brought in the head of infectious disease from a local hospital to show the staff how to wash their hands. "Then we needed to figure out what new needs and opportunities were out there. We wanted to support the healthcare workers and created healthcare superhero socks," Mark says. To keep spreading happiness, John organized an onlined dance party held every Tuesday. Twice a week, they did a Facebook live show, telling jokes.



"But then, as careful as we were, we still contracted the virus. My wife, John and I, got the virus right before Christmas," Mark says. They all got sick the Monday before the Holidays. Since people with Down syndrome are more likely to develop severe life-threatening complications from COVID, Mark mainly focused his attention on John's health.

"By Thursday night, John was really struggling to breathe. By Friday, we took him to the hospital," Mark says. His oxygen levels had dropped, and John was immediately admitted. Right away, John received a cocktail including oxygen, steroids, Remdesivir, antibiotics, and blood thinners. Sunday morning, John was waking up, gasping for air. His oxygen levels had fallen further. "They discussed putting him on a ventilator," Mark explains. He was moved to the critical care unit and allowed Mark to stay with him for the whole time. "But who knows why, all of a sudden, all the meds kicked in, and he turned a corner." John came home on New Year's Day.

Giving back to the hospital.

To show appreciation for the dedication of the healthcare staff, John and Mark decided to give back and donate socks to the hospital. "We not only used that event to give back to the hospital workers but also to raise awareness for Down syndrome," Mark said. People with Down syndrome are not more likely to get the virus, but they are five times more likely to end up in hospital and ten times more likely to die from it. "People with disabilities are undertreated, especially those with developmental disabilities. Some of this is lack of access, but much of it is they have trouble articulating what's going on, some may be non-verbal. And medical professionals often don't have the time to understand." As general advice to people that work with persons with Down syndrome, Mark said, "Focus on what people can do. Don't underestimate them. John is a capable person. He started a multi-million-dollar business."

John made a full recovery and is already back in his business, spreading joy and happiness with his customers, hosting dance parties, and sending out socks. "All of this adds up to happiness," Mark says. "I am never happier than when I step outside my door and see this building filled with people working," Mark adds.

■ ABILITY

johnscrazysocks.com

Karina U. Sturm

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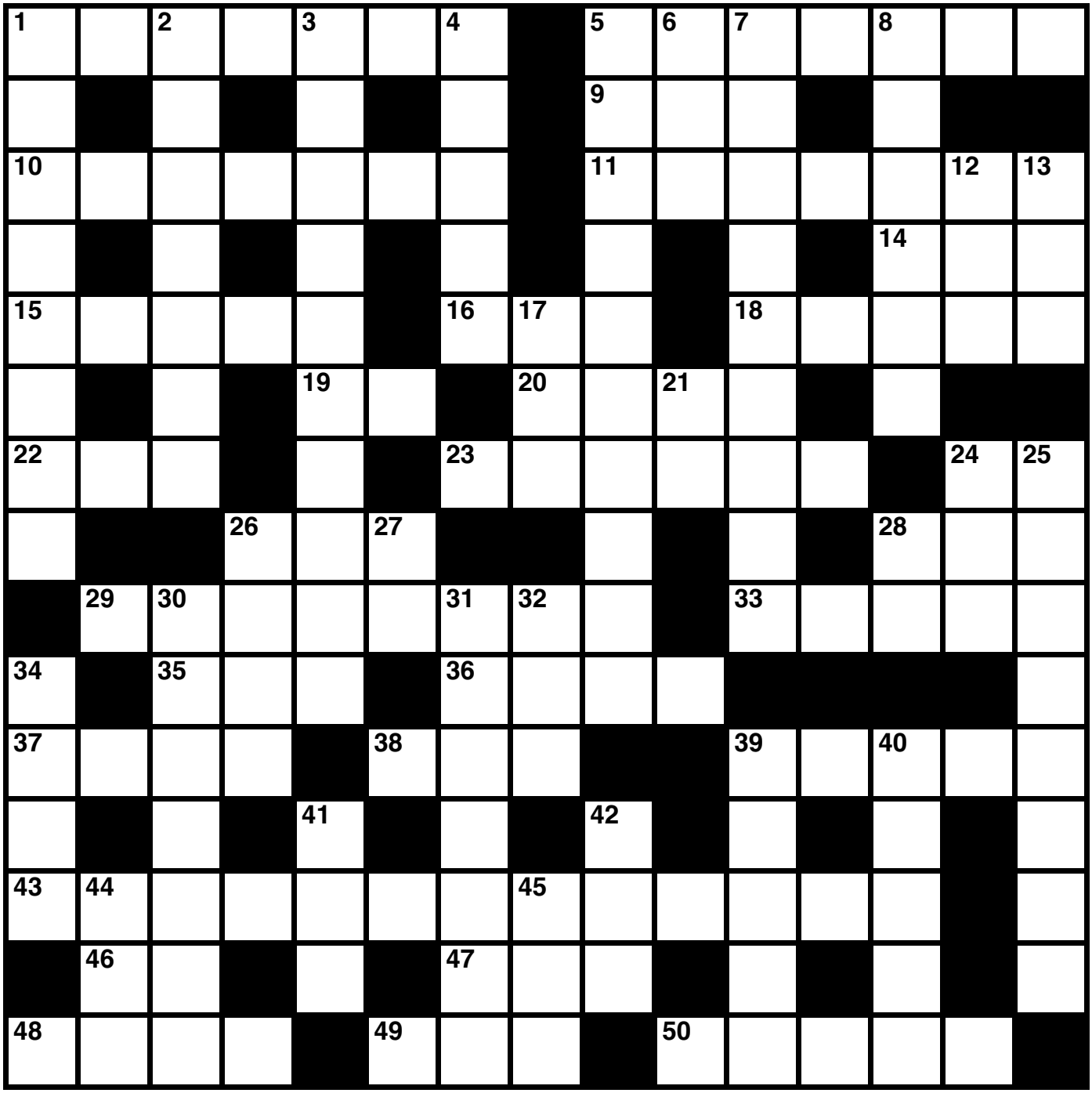
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Crossword Puzzle

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ACROSS

1. "Pretty Little Liars" star & advocate for lupus, Ian _____
5. AAPD Chair, Ted _____ Jr.
9. Canadian neighbor
10. Party favorite for office
11. Determination
14. Very long time
15. Chopper blade
16. No, in Shakespeare's English
18. Opinions
19. "Life of __" movie
20. Painter of limp watches, Salvador ___
22. "On the rocks" substance
23. Values
24. "We're in this love together" singer, Jarreau
26. Pet rocks, for example
28. Challenge for
29. Friendly
33. Additional item
35. Compass point, abbr.
36. Old name for Ireland
37. Olive or Canola substances
38. Cause of wrinkles
39. Breakfast strip
43. First actor who uses a wheelchair to land a leading role on Broadway, 2 words
46. Detroit's state
47. "From Russia with Love" author Fleming
48. Def Leppard drummer who lost his arm in a car crash and learnt to play drums with one arm, ___Allen
49. Place for a happy hour
50. African nation known for its marathon runners

DOWN

1. It provides support on stairways and escalators
2. Breaking Bad actor who has cerebral palsy, 2 words
3. Tranquility in oneself, 2 words
4. Environmentally friendly
5. Below-the knee amputee who had a role on Sons of Anarchy, 2 words
6. Vane direction, abbr.
7. Big city for Country music
8. Actress who has roles in Sons of Anarchy and The Mentalist who is a fierce advocate for people with disabilities, ____ Grubba
12. Personal commitment
13. Military rank, abbr.
17. Contribute
21. Where you can see the Hollywood sign, abbr.
24. Broadcast
25. Finding out new things
26. Fish features
27. Prosecutor, for short
28. Montpelier's state, abbr.
30. Tuneful
31. Flower with colorful leaves
32. Rest
34. Video conferencing company
39. Life Goes On star who has Down Syndrome, Chris ____
40. Writer and champion of the 2014 ABLE Act, Sen. Bob ____
41. Fire remnant
42. "Of Mice and ___" movie
44. "How ___ supposed to know that?" (2 words)
45. A long way

Crossword Puzzle

answers on page 64

Crossword Puzzle



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