

ABILITY

JERYL
PRESCOTT

Walking Dead, Educator, Sarcoidosis

MARIA TERESA LAGO
Diversity and Inclusion UNDP

China's Yu Xiaodan
Mastectomy Bra Designer

+ Stutter, Employment and Music Advocates:

Maya Chupko & podcast
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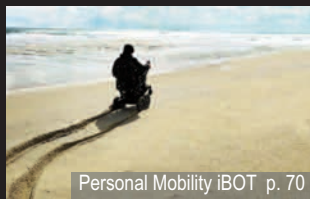




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Red Bull and FastHouse invited me to attend this years Day in the Dirt during March. It was held at the Dade City Race track in Dade City Florida. I was very excited to go but that meant I would have to load up my bike and drive for 35 hours to get there! It was a long and short trip but we all had a great time! The Day in the Dirt races are mostly just for fun for the athletes that are invited there. There are many different races and crazy kinds of races. I asked my dad to do a race with me so we did the parent/child race. You could be any age and any combination... dad/daughter, mother/son....etc. He was nervous but excited to join the race.

My family and some friends of ours all met up at Dade City on Thursday before the race. We didn't arrive until late because a tire blew on my truck and they are odd sized tires so we had to find a place to get it fixed, ugh it took forever and when we were finally back on the road we had lost about 5 hours of travel time! We were all staying in the same hotel so we met up quickly to say hi and then had to get to bed to head to the track early on Friday.

On Friday my dad and I headed to the track to finish checking in and get our bike set up. We also had a couple of practices before we headed back to the hotel to wash up and go hang with our friends and have dinner. They ran the track backwards so you really couldn't jump they didn't want anyone to get hurt since it was more about fun times then who won the races!

We woke up Saturday ready to race but the weather was not looking too promising! I had 2 races before I was going to race with my dad. Everyone had their regular gear on, but I wore a Hawaiian shirt to add to the fun, one guy had a blow up Alien strapped around his waist! Unfortunately all of my races were back to back, which I didn't really realize haha...oh well! I was getting ready to start my second race (the women's class) and it started to crazy rain! The track became a mess quickly and my dad had gone back to the truck to get me more gas because I had no time in-between races. My dad didn't make it back in time and I had to start my second race. I knew I desperately needed gas, but I had no choice but to take off! The rain was coming down really hard and a couple of little girls fell way in the back of the track. I stopped to help them pick up their bikes, they were crying.... aww poor things. The next lap around my dad

was there with the gas. I had to pull over and fuel up, what a mess haha... by the end of that race it was just a deluge and then the lighting came. They stopped the races so There was also tornado warnings so that was a little scary. They started the races back up again after about a 2 hour delay. They worked on the tack but it was still pretty muddy and slippery.

I think my dad was a little nervous but it was all just for fun! In that race we shared my bike so every lap you had to come back into the pits and change out the rider. If you had your own bike you had to swap out a wrist band before taking off! We had so much fun we were both just laughing. That was the first time I got to ride with my dad in a race like that! That was my last race of the day so we went back and got cleaned up and went out to eat. I had to come back later when all the races were done for autographs.

Once we were back to the track we decided to watch SX on the big screens they had set up. It was really cold and I brought my Smudge pot from Smudge pots direct with me. So we set that up, it is amazing it uses Diesel fuel and has this metal stack, it takes a few minutes to heat up but when it does it is so nice and toasty! No smoke and it heats up a bigger area than a fire does so glad we had it in our trailer! We all set around there for awhile and talked and drank some beers then my dad and my friend, Brenden went up to watch the qualifiers on the big screens. They came back after a bit and everyone decided it was too cold away from the Smudge Pot so we went back to the hotel. When we got there the lobby was filled with motocrossers from the Day in the Dirt race so we just stayed there and hung out with everyone and watched the races!

I had a 2 hour Iron Man race with my friend on Sunday and we swapped out after every lap like I did with my dad but we each had our own bikes. Sunday was beautiful and it was another great day of racing!

The next day we all packed up and headed home it was a long drive but definitely worth it and so much fun! Red Bull will be doing another race in November and I am looking forward to it! ■ **ABILITY**

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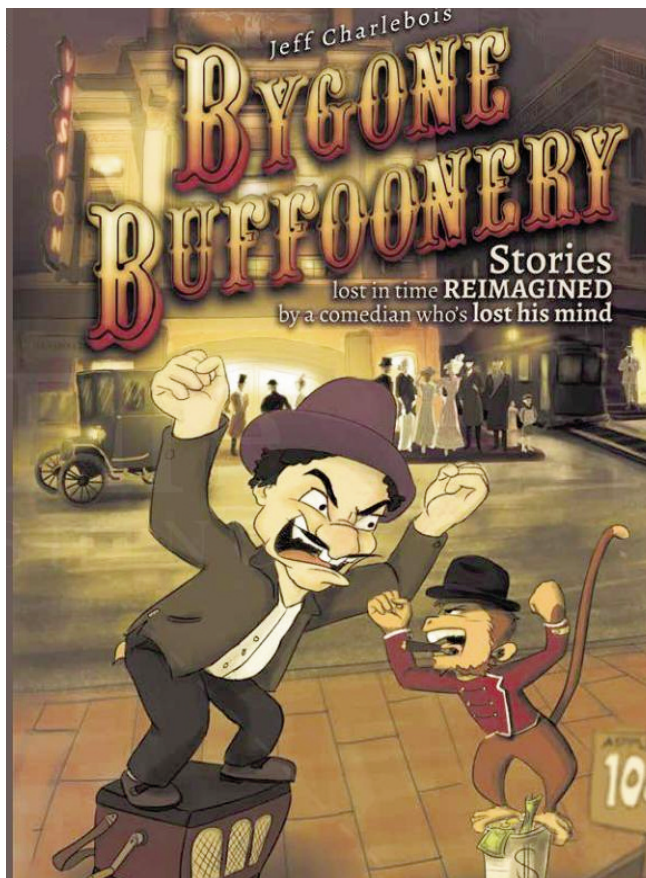
Dating Red Flags

One of our most important missions in life is to find that special someone that we want to spend the rest of our lives with. Some people spend their whole lives searching for the right person and never finding them. Some people believe they've found the right person with every date they go on only to realize that their date viewed them as the wrong person. For most of us, our goal is to settle down and get married. This can be a difficult task. It is not easy to find that certain person that we can mostly tolerate and not murder. Finding Mr. or Miss Right is a process, a job or even a chore. You must weed through the liars, bums, psychos, drunks, losers to find that perfect match or at least someone who's tolerable. So, when one is on a date, your antennas should always be up looking for red flags that will warn you that this one is going to cause me problems if I get in too deep.

You always want someone who makes an effort to look good. Girls are usually great at this. They spend hours picking out the right outfit, often changing eight to ten times before venturing out. Men, for the most part, go with their first instinct. Once our attire is on, that's it, it stays. We're too lazy to take another shot. Even if we notice our clothes are dirty, it's still not enough incentive to change. We can always put duct tape over any spots. Women can spend half a day getting ready for a date. They get their hair done then their nails, throw in a facial, a shower, the whole make-up thing, etc. It's a lot of work to impress a date but they know that's what it takes to land the typical shallow man. If a man shows up on a first date wearing a ratty Tee shirt, ripped jeans, tennis shoes and a baseball cap turned around backwards on his head. I'm sorry but it's a red flag that he's not busting his ass to impress you. He's probably thinking, "This is me, babe. Take it or leave it." I would suggest going with answer B. Leave it. He's probably wearing dirty underwear, anyway. And that's a deal breaker,

let alone utterly disgusting. Now if a woman goes on her date looking like, well, not a woman, it's also a red flag. It shows she could care less about herself so what are the chances she's going to care about you. I wouldn't roll that dice. It's also not a red flag because you probably won't be distracted by sexual thoughts. Plus, she's not going to be spending a lot of money getting dolled up. And you most likely won't be late to an event or dinner with friends as you won't be waiting too long for her to get ready.

Hygiene is an important tell. If you're around someone who stinks, it's always hard to stay around someone who stinks. You can never give your all to this person because your mind is focused on how in God's name am I gonna get away from pungent pig. Intimacy takes a backseat. Hell, it jumps in the trunk. There's also nothing as distracting as sitting across from someone with brown teeth. You can only imagine what that breath must be like – a whirlwind of hot putrid sewer air that melts your skin as it washes over your face, knocking you into a teary eye-crossing fog. Halitosis has or never will be a turn on. On top of that, no one likes to throw up after a good night kiss. Another hygiene fact, no woman wants to see long nose hair waving out of a man's nostrils. It's gross. The least you unkept men can do is take a weedwhacker to that before you head out on the town. Same goes for the ears. You never know, your date may nibble on them at some point only to freak out 'because she thinks there's a spider habituating in your ear canal. And men, you must always wear a deodorant. BO is for the gym not for a romantic dinner at Chez Louise. Cologne is always a nice touch. Something good like Manly Blue and not some cheap foul odorous dabs of Three Days in a Dumpster. This goes for women too. Men want their ladies to have a soft flowery scent and not something pungent like you just cleaned out the cat box.



Communication is vital when trying to connect with someone, but it must be the right kind. One type that is tiresome is the person who can talk an ear off a dead man. This chatter box can ramble on about all kinds of subjects and they usually don't interest you. You're lucky if you get three words in on the date then at the end of the night they say something like, "It was really great getting to know you." Then there's the one on the other end of the spectrum. The guy or girl who barely says anything. Every time you ask a question you get a quiet one-word answer. "So, whatta ya like to do?" They pause then say, "Nothing." Answers like that make table conversation a little choppy. It's never a good start when one person is already doing all the work. You need to wait 'til your married for that. Another red flag is when someone's favorite topic is themselves. They never tell you the bad things about themselves, it's always good things that are undoubtedly filthy lies. Then you tell them something about yourself and these people can take that and circle it back to them. By the end of the date, you're hoping you could unknow them and praying that your next date is the individual who gives the one-word answers.

For women, here's a quick list of red flags that don't need explaining. The man still lives with his parents. He talks about what level he's on in some video game you've never heard of. You're stuck buying the dinner and/or movie tickets. He loudly belches after meals. He doesn't have a car or, even worse, a license. He's been looking for a job for over a year but he's really not looking. You

mention some big event going on in the news and he says, "What? Really? Where's Ukraine?" If all he can talk about is sports, you know your weekends are going to be competing with football. If he's betting on the games, be prepared to be making loans to him, but before you do, make sure you pucker up and kiss that money goodbye. If he drinks a lot, like every day, this could be trouble down the line, especially if you find yourself throwing a blanket over him passed out on the floor several times a week.

For men, here are some signs that a woman may not be your cup of tea. Yes, women like to talk which isn't bad unless she continues to talk and talk and talk until your neck hurts from nodding. Also, if in all that mindless chatter you begin realizing that the main topic is criticizing you. Or, if it's constant gossiping about others because sooner or later you're going to be on her gossiping list. Another sign is, when she talks about her ex-boyfriend her eye twitches and she's unconsciously gripping her steak very tightly knife. If she gets jealous easily, like when you ask the waitress what the soup of the day is. She has no trouble finishing a nine-course meal, that's going to lead to big trouble. If you notice she flirts with everyone from the bar tender to the Uber driver to the homeless panhandler. You make a new plan, Stan and you don't need to be coy, Roy. Whenever you go out, she has a closer relationship with her iPhone than you. Nothing like sitting at a table with a dumb look on your face as she looks at her smart phone screen chuckling to herself. Thank God for the ole "I gotta go to the restroom then slip out the back, Jack" routine. An all-time favorite.

It's a jungle out there and, sadly, the chance of finding the wrong person is soooooo much higher than catching Mr. or Miss Right for me. I know what you're thinking. Why can't everyone be perfect like me? Well, you don't want to know what we would say about that. I think in our journey to find that special someone we become humble and learn to lower our expectations because we don't want to be that one who's lonely nights are spent conversing with the house cat or watching Netflix movies with your fluffy Shiatzu. Yes, look for the flags but keep an open mind. Only you can decide what you're willing to live with. The red flags are purely subjective. They're just guidelines. Some folks can put up with an uncouth pig. While others can endure an abusive lazy slob. Hey, some people can live with a serial killer as long as he's polite and thoughtful to them. "Thank you, Son of Sam for taking out the garbage. You're so sweet." We all have different limits. My best advice is pay attention to the signs and weed 'em out early or you just may be looking at turmoil and heartache down the line. Now get out there on that dating pond and hook a winner. ■ **ABILITY**

Jeff Charlebois

wheelfunnystuff.com



于晓丹 为”她” 做一件最温柔的铠甲

Yu Xiaodan: A Mastectomy Bra Designer

On April 29th, 2021, Beijing-based Yu Xiaodan Studio held its first bra fitting session for mastectomy patients. Twelve volunteers aged between 29 and 62 arrived that day.

It was around three or four o'clock in the afternoon, and the studio was filled with warm sunshine. The 62-year-old customer was the first to undress. "Let's sit here and sun bathe without our clothes on." The other participants followed suit and sat shooting the breeze in the sun. "Wouldn't it just be great if the world had no prejudices and stereotypes about us?"

There they were—women who had undergone mastectomies—sharing their experiences and concerns with each other, totally unworried by their scars or the stares they might easily have otherwise attracted.

Yu Xiaodan is their postoperative bra designer. Unlike her customers, who seemed relaxed and content, Xiaodan lived through an exhilarating and exhausting day: "I was really nervous that day. I didn't sleep much the night before, worried whether my design would really work."

During the bra fitting session, Xiaodan helped each customer put on her new bra and kept asking for feedback.

The first user took off her bra and asked Xiaodan to touch—it was all wet. Xiaodan was baffled. How could someone perspire so much in April? The woman said that it was because her sweat glands were irreversibly destroyed during the surgery. And many more breast cancer survivors would suffer from similar complications.

That day Xiaodan received words of commendation and encouragement from her customers. It also became clear to her what sort of enhancement would be needed next.

Out for truth and support

A well-known underwear designer, Xiaodan founded a brand under her English name, Emily Yu. But as well as that, she also has another identity as a writer.

In her college years, Xiaodan studied foreign language and literature at Beijing Foreign Studies College (now Beijing Foreign Studies University). After graduation, she worked as an editor of *Foreign Literature Review* in the Institute of Foreign Literature, Chinese Academy of Social Sciences. Then she pursued a Master's in British and American literature at the Graduate School of the academy.

She produced the published Chinese translations of *Lolita* and *Spring in Filata* by Russian-American novelist Vladimir Nabokov, and *What Do You Do in San Francisco* by Raymond Carver. She also authored a novel, *Beijing 1980*.

Eager to advance her career, Xiaodan flew to New York with only \$50 in her pocket in 1996 and started to do translation and other odd jobs. A year later, she was very excited to learn that the Fashion Institute of Technology was open to new student enrolment.

A detail-oriented person with a keen eye for the world around her, Xiaodan has as much of what it takes to be a fashion designer as to be a writer. It is also what she feels passionate about.

When she was only one year old, Xiaodan's hard-working parents sent her to live with one of her aunts, who knitted sweaters for a living. Learning through watching, she created quite a few pieces of needlework herself. It was also how she became interested in fashion design. As part of the application process, Xiaodan took photos of the sweaters she had knitted, unlike other candidates who submitted dress designs. Fortunately, she was awarded a place in the institute.

Xiaodan officially embarked on a career of underwear design when she graduated from the Fashion Institute of Technology in 1999. She went on to work as a full-time designer for 8 years and later as a freelancer and independent designer for more than ten years. At one stage she was employed by Komar, a leading underwear producer in New York, and at other times created underwear designs for household names such as Victoria's Secret.





At the end of 2019, an American doctor working in Beijing “blindly picked” Xiaodan to design bras for post-mastectomy wear. How could she ever be “blindly picked”? She assumed that the surgeon probably randomly selected her by digital means like a map search because her studio in Beijing was close to the hospital where he worked.

The doctor was a mastectomy specialist. He felt sad when he saw that his patients had very few options to choose from after surgery—only a cotton strap like a baby cradle. Therefore, he wanted to have purpose-designed bras.

In fact, Xiaodan knew little about this group of people. However, looking at clinical images, she was shocked to find that where a beautiful curve had been was now a surface of irregular lumps and a wriggly swarm of centipedes.

Should she do that? Xiaodan talked to a friend who, much to her surprise, said emphatically, “Do it.” Only then did she discover that the friend’s mother was a breast cancer survivor and had had a mastectomy.

“It was the first time that I had ever heard and seen real people rather than those cold, impersonal data, and I began to warm to the idea,” said Xiaodan.

The underwear designer was going to meet her supplier in July 2020, having completed her research work in May. Just as she was preparing to go through the security check at the airport, she received a message from Mi, a friend she had known for ten years: “It is happening to me and I can be your model.”

Mi had been diagnosed with breast cancer. Despite her earlier mental preparation, Xiaodan gave way to tears right on the spot, finding it hard to accept the fact. That moment made her more determined than ever to do the job well. Even if she only turned out a few comfortable pieces of underwear for her friend, it would have been worth it.

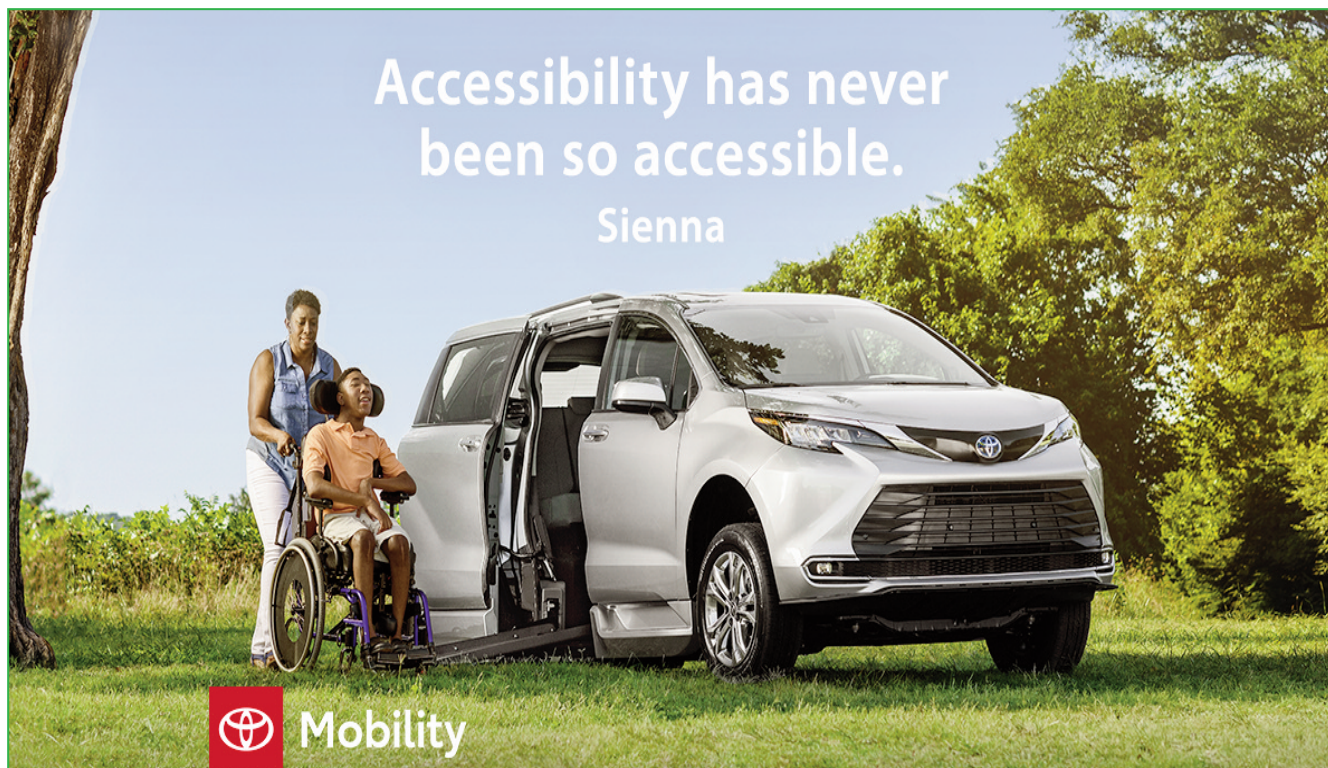
It might seem like sheer coincidence that Xiaodan was “blindly picked” for postoperative bra design, but if you think about it, it might be something that was fated to happen.

Jiang Hao: Just Good

Why do mastectomy patients need a professionally-made postoperative bra as soon as possible? If no one makes it, what can they use instead?

Some mastectomy patients need to have postoperative bras and silicone forms ready as recommended by medical staff. These solutions may look easy on paper, but in reality they’re anything but. A host of problems can follow: abrasion against the wound, imbalance between the swell and the healthy breast in the case of a unilateral mastectomy, poor permeability of silicone material, and so on.

In some cases, the intake of endocrine drugs leads to early menopause, and silicone forms can make perspiration more difficult to deal with. “Their silicone forms are often soaked in sweat,” Xiaodan said. “I’ve seen patients whose chests were all red, with skin even inflamed and showing allergic reactions.”



To combat this problem, many patients make their own pads. “I’ve seen scarves, handkerchiefs, toilet paper, and in some cases, mung beans, grass seeds, quinoa and so on being used.” Xiaodan said. What is good to use is something absorbent or granular, breathable and permeable.

Wearing an uncomfortable, ugly bra after surgery is not so much a humble option to be put up with, but more like a full-scale endurance test.

It took Xiaodan 8 months to develop her design. More than ten samples were made for maximum comfort and beauty.

“It’s essential to consider how a bra is made first, then to think about what it can be filled with, and then combine the two.” For Xiaodan, these women are not incomplete. How to make the bra needs to be addressed first because “every woman needs a good bra”.

In cases where the mastectomy involves the removal of axillary lymph nodes, a more careful choice of material, coverage and cupping is needed. Therefore, Xiaodan chose the softest high-density modal cotton, and did her best to produce a seamless design. “To avoid any foreign body sensation, no loose threads or seams will be allowed in the interiors of the bra—the side exposed to the skin, that is; even rings on the straps and the hooks in the back are kept away from the skin.”

Feedback from the trial users also opened Xiaodan’s mind about breast form design. For one thing, the problem of breathability needed to be tackled, as the memory of a wet bra was quite unforgettable for her. For another, the bra must give a sense of wholeness.

During the bra fitting session, Xiaodan replaced a breast form with a thick mold cup, but the user poked her affected breast and told the designer that it felt a little empty. Xiaodan and her staff wondered what that meant. Later, after much discussion and consultation, it was found that a weak and hollow cup could result in an awkward situation, such as one in which the user may be exposed as she pushes her way through on an overcrowded bus—enough to make her recoil with fear. A good bra needs to feel both safe and comfortable.

Finally, Xiaodan used a soft, breathable and resilient form of high-density cotton foam as a breast plate, completed with a special curvature design on the concave side.

In January 2021, Xiaodan completed her first postoperative bra design and named it *Jiang Hao*. In Chinese, the first word *jiang* means ginger, a spice traditionally believed to have healing properties and to be very beneficial to women. Moreover, *Jiang Hao* sounds the same as “Just Good” and may even be morphologically mistaken for “beautiful” if a gentleman is not being careful—to err on the side of beauty, right?

So far, Xiaodan and her team have held bra fitting sessions in Beijing, Shanghai, Taiyuan, and Wuhan, with nearly 120 participants varying in age from their 20s to 70s. The design of large-size postoperative bras is being finalized. Next will be postoperative underwear designs for different real-life scenarios, such as swimsuit and sports bras.

Bras: not a cure for all ills

In the long and tedious process of design and refine-



ment, Xiaodan repeatedly felt that she could do no more. Some of her colleagues had clearly indicated that the target market of breast cancer patients was too small, and from the market-based point of view, “there is no way to do it, and it is not worth doing it”.

According to the data of the World Health Organization’s International Agency for Research on Cancer (IARC) in 2021, there were about 420,000 new cases of breast cancer in China in 2020. A report published in the Chinese Journal of Science on December 24th, 2021, shows that there are about 2.5 million breast cancer patients in China. These two figures may seem large at the clinical level, but nevertheless suggest that the target market is relatively very small.

“It’s definitely not a way to get rich, but these people and their definite need are true and real. How can you simply turn your back on them? No way.” Since the plan was rolled out, Xiaodan and several core members have worked for more than 600 days without pay. On top of that, she scraped together tens of thousands of yuan from brand sales and family savings to fund the project. And this did not include labor costs.

But Xiaodan doesn’t intend this business to be a charitable cause. Her goal is to make professional bras. “Only when she pays for a product sold in the market, will the user tell you what she really needs, expect you to do more, or even take you to task, demanding an awesome design.”

Xiaodan also understands that her work alone can’t be a cure for all ills no matter how perfect it may be.

In addition to physiological impact, women who have their breasts surgically removed find themselves facing many hard stares in all walks of life. Some chemo

patients wear wigs when going out, worried about their husbands’ faces. While changing her underwear in the fitting session, a mother wheeled around and turned away from her 3-year-old son, who was running towards her.

They are afraid that they may frighten their loved ones, that their husbands may feel embarrassed, that they may have some exposure swimming, doing gym, or getting onto crowded buses, and that they may evoke horrified reactions from others. For them, understanding and acceptance means more than being mentally strong and confident.

In 2020, for the first time, breast cancer overtook lung cancer at the top of the global league of malignancies.

What Xiaodan can do is design a comfortable and decent bra for women after a mastectomy. An extra reward may be earned along the way if, by any chance, her efforts bring a greater awareness of this disease, draw more attention to the affected community, and help change the public view and perception.”

“Some people say that I’ve made the softest female armor. I hope so. With this bra, to say the least, they can feel warmth from outside the world, instead of hostility.” said Xiaodan. ■ **ABILITY**

by Wu Lijun

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



60+

地球一小时



垃圾分类，因好手艺而美丽。
唤醒每个人心中的环保家，从“地球一小时”开始。

2012年3月31日 星期六 20:30 至 21:30

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10 Years!

A decade may seem like a long time when you are in line for an ice cream cone or a covid test, but for me, the last ten years have flown by in a nano second. It was just ten years ago, on a long ride to my home in New Hampshire from Daytona Beach, Florida that I decided I wanted to `dedicate my motorcycle riding to raise awareness for MS. I had no idea what would become of my journey, and certainly could not have predicted some of the amazing people I have met and motorcycle milestones I have reached along the way. If someone told me I would have the opportunity to set four world records, raise over a quarter of a million dollars for charity or have a motorcycle on display in the World's Largest Museum, I probably would have laughed hysterically. In a million years I never would have seen myself as a peer advocate for newly diagnosed patients or appearing on various media platforms for disease modifying treatments including brochures and informational websites!

Today, I'm riding a motorcycle provided to me by my corporate sponsor, Yamaha Motors USA. Yamaha has stepped up and supported me in every possible way they could over the last five years, including hosting me and my bike at every national event and helping me with my travel expenses. I am also wearing top of the line riding gear provided by Aerostich Manufacturing and I haven't had to pay for any of the last 100 sets of tires I have worn out because of the support of Bridgestone USA. Many other companies have stepped up and provided me with gear and supplies along the way as well.





Fundraising events take a lot of time to create and promote, but without the support of donations to the charity, they would not be successful. Every time I ask for help for another one of my cockamamie ideas hatched over a micro-brew, my friends, followers and supporters have always pulled through. Just a few weeks ago, I put together a wacky live comedy improvisational fundraising event in Florida, where I pled my case before a crowd of long distance riders at a mock parole hearing! It was silly, but with the free beer flowing and 10 unsuspecting volunteers, we managed to raise \$3500 in about an hour. Sadly, the board voted and I was not granted parole!

Finding new and interesting fundraisers to keep folks engaged is a bit of work as well, but I still have a few more crazy ideas up my sleeve! Look for another world record this Fall and I will be speaking at a dozen national motorcycle events as well as a few live MS patient educational events this summer.

My health has had some ups and downs over the last ten years as well, a few more MS lesions in my brain have caused a few more symptoms to join the constant memory, weakness and bladder issues. I had spine, eye and nerve surgery, a few more kidney stones, a few heart stents and I have lost some hair and a few more teeth, but I'm not slowing down!

Traveling on two wheels for long stretches of time in all

kinds of weather certainly has created some issues at home, often leaving my wonderful wife to take care of the house and yard; cleaning, raking, mowing, snow blowing and caring for our sick dog all while holding down a real job! Her support of my journey has never wavered, even though I know how tough my being away has been on our relationship. My wife is the true hero of this story!

My original goal was to document riding one million miles for Multiple Sclerosis. My amazing journey has just rounded the corner I am heading for the home stretch...

I'll be home soon, sweetie! ■ **ABILITY**

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MARIA TERESA LAGO

LAYING FOUNDATIONS FOR THE NEXT GENERATION

When Maria Teresa Lago logs on to Microsoft Teams from her home in Geneva, she does so with her infant son on her lap. She's a Diversity and Inclusion Specialist with the United Nations Development Programme (UNDP), her son's not yet one year old, and she wants him to see firsthand the multitude of ways in which her colleagues communicate with one another. "See," she tells him, "this one types on the computer, and then it speaks aloud for her. That colleague's speaking even though his image isn't on the screen. This colleague talks with her hands."

Teresa's been with UNDP since 2016. In addition to leading initiatives aimed at combatting workplace racism and anti-LGBTQ+ discrimination and striving for gender parity, she's worked tirelessly to create accessible opportunities and increase inclusion of persons with disabilities. Her crowning achievement to date is the implementation of the UNDP Talent Programme for Young Professionals with Disabilities.

The initiative has two goals: deploy more persons with disabilities in key roles throughout UNDP, making decisions and implementing programs; and give young persons with disabilities opportunities to build professional connections and transferrable skills, increasing their employability across the development sector and beyond. So far, dozens of young professionals with disabilities have been recruited and deployed, and the program's still growing.

Teresa's lifelong commitment to building a more inclusive and accessible world began in childhood. "My aunt was part of the household I was raised in," she recalled, "and she had severe intellectual disabilities as well as some physical disabilities compounded by age." From a young age, Teresa gained awareness of the challenges that persons with disabilities face daily. "Society had a really hard time relating to her," she said. "There was a big gap there." Now, she's not only raising her son with that same awareness, but also showing him that once accommodations are made available and disabling attitudes and infrastructure removed, persons with disabilities can navigate and contribute to society on an equal basis with their non-disabled peers.

Motivated by her experiences with her aunt, Teresa studied psychology in college, where she developed an acute awareness of the importance of lived experience and human connection. "I discovered that I was aware of certain things," she said, "things my



peers and I weren't getting just from reading theory. Every person is different, every person with a disability is different, every disability is different, but once you spend enough time around people with disabilities, you do start to pick up on patterns. That becomes part of your intuition."

After studying clinical neuropsychology, Teresa took a job at the López-Ibor Neuropsychiatric Institute in Madrid, Spain, conducting cognitive assessments. Many of the patients had disabilities, some developmental, others resulting from accidents or violence, and still others caused by age. She worked there for three and a half years, then picked up and moved to India.

"I wanted to live in a developing country for at least a year," she said, "to open my mind. A lot of us Europeans go about our lives assuming everybody lives as we do. I didn't want to fall into that trap. I wanted to understand how people live in other parts of the world."

Based in Anantapur, Andhra Pradesh, Teresa served as the Disabilities Technical Advisor and Vocational Training Project Manager for the Vicente Ferrer Foundation. In this role, she oversaw three centers for young people with developmental disabilities. "I was training the teachers and staff," she said, "providing them with theoretical tools, and at the same time learning from them, working out how to adapt our techniques and theories to a different cultural context so we could meet these children's needs."

When young people aged out of the centers at 16 or 18 years old, Teresa observed, most returned home to live with their families. "I realized that they weren't acquiring the skills they needed to support themselves," she said. "Some of them had very severe intellectual disabili-

ties, which made developing professional skills incredibly challenging. Others didn't have such severe disabilities, but they were all thrown together in the same place, receiving the same treatment and training. We decided it would be better to take a multi-track approach. Some youths could learn a profession while others learned how to manage household chores like cooking or working in the fields. The goal was for them to leave the centers with the tools they'd need to help themselves and their families and contribute to society in meaningful ways."

"It was a beautiful project," she went on. "Everyone enjoyed working there and seeing how different people would learn and grow as long as the learning happened at their own pace, in their own way. It brought me joy to see how happy they were, especially after the holidays. They would go home for a month or so and then come back and tell us all about the things they'd cooked and what they'd done for their families. Their families were always amazed, too. As family members of persons with disabilities, we sometimes instinctively focus on protecting our loved ones, and we forget to focus on enabling our loved ones to do more. Once they saw what their children could do, the families became very supportive. It was a remarkable success, I have to say."

At the same time, this experience gave Teresa new appreciation for the state of disability movements in the West. "We still have plenty of work to do here," she said, "but in India, the way people with disabilities are treated is determined entirely by individual attitudes, which might be informed by religion or culture, or just by emotions like sympathy, pity or fear. Persons with disabilities don't have any legal protections. In the US, the negative attitudes are still there, but their impact is eroded by the power of the legal theories and the institutions. That has



a lot of advantages. It pushes people with disabilities to interact with institutions, which means participating in public life, and it means that individuals' beliefs or emotions aren't the only forces controlling what resources are available to them. Within those legal frameworks, persons with disabilities have actual rights, which forces others to respect them. Those structures aren't present in many parts of the world."

Moving to New York had never been part of the plan, but when Maria Teresa's then-boyfriend, now-husband got a job with the UN, she decided to go with him. "After three years of long-distance, we needed to be in the same place," she said, "so I moved. I found out the UN was hiring for this program, and I really wanted to contribute. They'd developed a strategy for bringing more professionals with disabilities onboard, but they didn't yet have anyone to implement it. When I proved to them that I knew the issues, they hired me."

After getting recruited, she rotated through several positions, always focusing on disability inclusion. "Change doesn't happen just because one person in one office puts some policies in place or publishes some papers," she observed. "It only happens through the effort of many--which means, of course, that it's often slow going. When you first present ideas for how to make an organization or society more inclusive, many people will come back with something like, 'That sounds nice, but unfortunately, it's just not possible.' Sometimes they have a point--maybe the exact reforms you're advocating for aren't feasible--but we have to stay focused on making things better instead of getting tripped up when one specific idea doesn't work. Everything seems impossible until it's done the first time. We have to continue believing that transformation is possible."

"Of course, there's a long way to go," she added, "but it's been wonderful to see how supportive everyone's been at UNDP, and how awareness of disability issues is increasing across UN agencies. It seems to me that more and more people are realizing that this isn't just something the UN should do for political reasons; it's actually a really good thing to do, both morally *and* pragmatically. It makes UNDP a better place to work for everyone, and it lets us do more good things in the world."

"It's been incredibly challenging at times," she acknowledged. "There's always a lack of funding, and of course it's a huge organization, working in over 170 countries, which presents certain structural challenges. It's really difficult to ensure that what we do at HQ gets properly implemented everywhere. But, little by little, change is taking hold. Interest in these issues isn't just coming out of HQ and going to the field anymore. More and more, it's moving from the field to the headquarters, too."

Since giving birth to her son, Teresa's been on maternity leave and working part-time for UNDP, but she's still a fulltime advocate for diversity and inclusion, continually educating herself and others about disability and accessibility. Though her son's not yet speaking, she's already teaching him International Sign Language as well as bringing him to virtual meetings. "I'm raising him as a citizen of the world," she said, "but not just any world. My hope is for his world to be more accessible and inclusive than the one in which I was raised, and for him to help build one that's more accessible and inclusive still." ■ **ABILITY**

Itto Outini

undp.org



A woman with long brown hair is shown in profile, facing left, wearing large black headphones and speaking into a professional black microphone. The microphone is mounted on a boom arm. In the background, there is a poster with a cartoon character and the word 'PRICED' in large red letters. The overall setting appears to be a home studio or podcasting space.

PROUD STUTTER

Maya Chupkov has been stuttering all her life and faced many challenges because of her speech disorder. However, instead of hiding her disability, she is now using her podcast Proud Stutter to shift the narrative around stuttering. *ABILITY*'s Karina Sturm speaks with Maya Chupkov in an interview for *ABILITY Magazine*'s new podcast about her work to raise awareness for people who stutter.

Stereotypes about stuttering

“Did I stutter or what?!” We all have heard this phrase from someone, haven’t we? What is used as a response to a person who hasn’t been listening attentively and misunderstood what their communication partner said is also a harmful comment framing stuttering as an undesirable trait and therefore reinforcing the common stereotypes and misconceptions around stuttering. Another example was the discussion about President Biden’s mental fitness because of his stutter not long ago, which has cast light on one of the most common stereotypes about stuttering: People who stutter might be seen as less intelligent.



Even though globally, 68 million people stutter, with more than three million in the US, which means one person in 100 people lives with this speech disability, those stereotypes prevail. Like for all disabilities, media representation of people who stutter is often either lacking or, if present, the portrayal is inaccurate or harmful. Recently, stuttering was highlighted as part of the Duke of Hastings' backstory in Netflix's *Bridgerton*, a romantic drama series set in the Regency period in England. Over the course of the first season, viewers learn that as a child, the Duke of Hastings' stuttered and was abandoned by his father as a consequence, which, in turn, led the Duke to "overcome" his speech disability - again, a typical but damaging narrative.

"Overcoming" stuttering

Maya Chupkov grew up with the exact same narrative as well. She was constantly trained not to stutter, to hide her disability. Even though she is now 29 years

old and has accepted stuttering as part of her identity, it is challenging to unlearn all those decades of conditioning. "Even speaking with you, I am very aware that I am talking a little slower, and I'm not stuttering as much. This is because deep down, I still have these natural instincts to not stutter, which makes it really hard to let go and be fully myself," Chupkov explains. While she does consider her stutter a positive part of who she is today, it's still a daily internal battle for the young woman. "I often overexert myself when I communicate with lots of people on a day full of meetings."

During the interview, Chupkov's speech disability was barely noticeable, and she says that's common for people who stutter. Chupkov can have months without any stuttering, and then all of a sudden, the stutter is back. One particular trick she uses when talking to a person that doesn't know about her disability is that she acknowledges her stutter right at the beginning because



being direct about it takes away the pressure, and this pressure could be a trigger for more stuttering.

Despite Chupkov's outgoing nature and her efforts to raise awareness, she still wasn't always met with openness. When she wanted to participate in a speech program at her college, the head of the project advised her against becoming a speech therapist because of her stutter. "He said, 'If kids hear you stutter, they might think that they'll never get rid of their stutter too.' That just crushed me. It made me feel that there are certain things that I would never be able to do," Chupkov remembers.

Becoming a Proud Stutter

As a reaction to her own negative experiences, she decided to do something about all those harmful stereotypes: Proud Stutter was born. While Chupkov could have used any other medium to raise awareness for stuttering, she chose the one that seems the most inaccessible for people living with a disability affecting their speech: podcasting. "I first didn't think it was ever possible for me to create a podcast because of my speech disability. I thought, 'Who would want to listen to someone that doesn't have a smooth voice?'" Because all podcasting is about is your voice." Chupkov had a conversation with her fiancé, who motivated her to turn podcasting around and make it specifically about stuttering. "Originally, it was only going to be myself and my co-host Cynthia Chin going back and forth, but after four episodes, we realized we needed to get some guests on the show. I didn't really think out who my guests would be; they just naturally showed up in my life."

A safe place for people who stutter

Proud Stutter released its first episode on October 22,

2021, which was Stuttering Awareness Day, and since then, Chupkov has published 13 episodes featuring people from her own mother, which she had never talked about growing up with a stutter before, a speech therapist, a journalist, a comedian - all different people, who stutter. "I recently met someone who shared his story about having a stutter while being in the army. This story has so many layers to it because there are instances where you have to communicate with someone, and if you mess up that communication, it could be a matter of life or death," Chupkov states. Ultimately, she wants Proud Stutter's listeners to understand that stuttering is simply another way of speaking and nothing that should hinder anyone from fulfilling their dreams. "The goal of Proud Stutter is to have conversations with all different types of stutters and to just bring more awareness about it, so the world becomes a better and safer place for people who stutter."

From podcasting to advocacy

Chupkov believes that her podcast isn't only educating a wide audience about stuttering but also provides healing for her guests who often haven't shared their experiences with anyone before. "I also want to use my platform on the policy and advocacy side because I have learned a lot about it while producing the podcast." Chupkov is pushing her limits every day because while she is working a full-time job in San Francisco, she still manages to produce episodes for her podcast with the second season already in planning. When she is asked what keeps her going, she says, "It gives my life a sense." ■ **ABILITY**

Karina Ulrike Sturm

proudstutter.com



Coffee and the Seeds for Disability Integration from New Zealand to Mexico, and Beyond

Robbie Francis Watene, can be thought of as a seed planter. From planting ideas about human rights in her research at the Donald Beasley Institute, to planting coffee in the hills of Mexico. She has grown an international inclusive supply chain through her formation of The Lucy Foundation (named after her prosthetic ‘Lucy Leg’). Watene’s story starts with a horrifying volunteer assignment during her PhD, which left a lasting impression. ABILITY’s Chet Cooper and Itto Outini spoke to the Aotearoa New Zealand advocate to learn more about her work.

Chet Cooper: How did the Lucy Foundation start?

Robbie Francis Watene: While I was working on my PhD I also decided to do an internship working for a disability rights organization. Part of my job was to support the organization’s efforts to monitor disability rights situations in Latin America. As part of this role, I went undercover with a team into a psychiatric institution for disabled people to document the human rights abuses. During this experience, we witnessed torturous conditions or what the UN has called “torture”.

Chet: Where was this?

Robbie: This was in Mexico City. Without going into too much detail about the horrific atrocities that we witnessed first-hand, coming away from that experience, I learned two things. One was a certainty of who I am, an educated disabled woman with support networks around me. There’s a beautiful song by Brooke Fraser, she’s a New Zealand singer, I think she lives in USA now. She sings, “Now that I have seen, I am responsible.” For me, that certainty of who I was in relation to the disability community, but also the realization that it was my





responsibility to respond to the injustice I had witnessed. That I could be an active part of the solution beyond just what I was studying in peace and conflict studies, but through my experiences as a disabled woman living in a world of opportunity, with the privileges that I have as a white disabled woman with an education. There was a sense of needing to use my privileges to advance human rights for who was now my community, my global community, the disability community.

Chet: What did you do next?

Robbie: I came back to Aotearoa New Zealand, my internship had ended. I had committed to my Ph.D. But I wanted to do more. At this time in Aotearoa, there was an article that came out in our newspaper that said Kiwis would be willing to pay more for products if they knew they had been produced in an ethical way. I started thinking, “Why is it that we have Fair Trade, all of these certifications, Organic, all of these things for the products we invest in, but as amazing as these initiatives are, how do they respond to the needs of disabled people?” From what I could tell they focused so much on the “sound-minded” and “able-bodied” person of a family and supporting them to advance their economic sustainability through ethical production and productivity. We thought, “What if we could start working on disability rights through social enterprise, through business?” This is me and my friends talking, brainstorming. We were probably only 24 at the time. Very optimistic, [laughs] maybe slightly naïve. How could we demon-

strate the value of diversity in business? We started thinking that we needed a product, having just read the newspaper article. I know it sounds so wild when I reflect back on it now, but what could we use? Kiwis love their coffee. We were students, and of course university students depend on coffee to get through their studies.

[laughter]

So we sent an email out around the world saying, “Hey, we want to work with disability empowerment and employment and education through coffee in some way, shape, or form. We think we have a market for it in Aotearoa New Zealand.” We didn’t know coffee. My focus was disability rights, not coffee, but I’ll tell you what: you can learn pretty quickly if you put your mind to it.

Chet: If you drink enough coffee!

Robbie: [laughs] If you enjoy coffee, yes! And within a week, this email has bounced around the world to several NGOs. We didn’t have our hearts set on Mexico, but we got a response from an NGO in the south of Mexico who said, “We work with disabled people, and they all come from coffee communities. We have tried several initiatives to engage the community,” but they had come to the conclusion, “until we engage the disability community with what runs through their blood, which is coffee, then we can’t progress. So we think that if you’ve got a market for it, we could get something



going here.” We were of course very excited. With no funding, we set about hosting a fundraiser and my friends and I travelled back to Mexico. We went back and forth between Aotearoa New Zealand and this coffee-farming community for the next three years. We needed to listen, to research, to understand their challenges. We learned about their coffee production, looked at the inclusion of disabled people in the community and came to understand how collaboration between us could benefit not only the disability community, but their local economy and the environment while also delivering an amazing coffee product here in Aotearoa New Zealand.

That’s how it started. Building that relationship and getting to know people. And that allowed us to work in an equal partnership with these coffee-farming families who had all been affected by disability. Then one of our team members moved over there. She’s half-Mexican, half-Kiwi. She set up a team on the ground and lived there for two years. The community is called Pluma Hidalgo. They’re a coffee-farming community high in the mountains of Oaxaca in Mexico. They’re a population of 3,000.

Chet: Who do you target?

Robbie: Initially, when we started, the target consumer was cafés. It’s not a very profitable model, because cafés buy their coffee in bulk at almost-cost price. When COVID started to take hold in Aotearoa New Zealand around 2020, more people were working from home.

We shifted our focus from cafés, we did still supply some cafés, but more to offices or small and medium enterprises. But of course, they started working from home, so there was an incentive to appeal to home drinkers, and that’s been our biggest success. It’s not just people who engage with the disability community who buy the coffee. It’s people who have never considered disability in their lives. We have a wide range of customers. And a lot of churches have been quite interested in ethical sourcing of their coffee for their congregation after church or after a service. That’s been one success area. And now we’ll be working towards securing some bigger contracts with disability agencies, for example, the new disability ministry. I would love to see our coffee supplied through them.

Itto Outini: Robbie, can you tell us a bit about your work with the Donald Beasley Institute (DBI)?

Robbie: Sure! It’s a not-for-profit organization founded in the 1970s by a group of advocates and researchers—including Donald Beasley, who was a pediatrician—who saw the deinstitutionalization movement coming to New Zealand and realized there was about to be a lot of demand for new and better support services for persons with disabilities. Families were calling for some kind of alternate support system. DBI was established to support that call.

Itto: Is DBI part of the New Zealand government?

Robbie: No, we’re not associated with any government or private business. Initially, DBI was set up to bring



contemporary thinking and research on disability rights from around the world to Aotearoa New Zealand. The idea was to host scholars, promote international education, draw researchers from overseas, that sort of thing, but it quickly became clear that we needed a framework that was relevant to our culture, our islands and our people. So, in the 1980s, DBI pivoted and started conducting its own research.

At first, the focus was on preventing infringement of the rights of people with developmental disabilities, especially as the deinstitutionalization movement got underway. DBI promoted inclusive research led by people with lived experience of developmental disabilities. That's still a big part of what we do, but recently, there's been another shift, this time toward looking at disability through the broader lens provided by the UN CRPD. I was brought onboard in 2018, right after DBI signed a contract with the Disabled People's Organization (DPO) Coalition of New Zealand to, I guess you could say, bring to life Article 33 of the CRPD.

Itto: What does that involve? What's in Article 33?

Robbie: That's the article that calls on civil society groups to monitor governments' efforts to implement the CRPD. In New Zealand, we have the Independent Monitoring Mechanism (IMM), which is comprised of the Office of the Ombudsman, the Human Rights Commission, and the DPO Coalition. Each one approaches its monitoring obligations in a different way. Our job at DBI is to conduct monitoring on behalf of the DPO Coalition. Our researchers, all of whom have disabilities themselves, run studies and work with our broader disability community to identify the gaps in the government's progressive realization of their obligations.

Itto: How is it going so far?

Robbie: This is my fourth year as project lead. We've engaged hundreds of people with disabilities throughout Aotearoa, all different ages, ethnicities, disabilities, etc., in discussions about human rights. We've also trained other people with disabilities to become researchers—basically building the capacity of researchers with disabilities. That's what gets me most excited. I feel like we're bringing together a cohort of absolutely amazing people who're getting us closer to conducting truly inclusive research. It used to be that people would do research on us. Now we're the ones setting the research agenda.

Itto: How did you first get involved with this work? Can you share a story or talk about your life experience?

Robbie: Sure. I was born with a condition called phocomelia, where the bones in the lower half of my body didn't develop properly before I was born. I actually learned to walk on a prosthetic leg, which I called a Lucy Leg because when I was a toddler, I couldn't pro-

nounce words like “prosthesis” or “artificial limb”! [laughs] So, I've always lived with Lucy Leg. I'm missing lots of bones in the other leg, too, and I've got chronic back issues, as well as all the pains and problems that come with having a slightly different body.

I've always been passionate about traveling and human rights. I grew up in a family that emphasized the importance of service, and I majored in peace and conflict studies at university and spent quite a bit of time in the Middle East, studying international conflict resolution and mediation. It took me a long time, though, to incorporate disability studies. I'd almost finished my master's in peace-building before someone from the University of Otago said to me, “Robbie, it's lovely that you want to change the world, but have you ever wondered how people like us, people with disabilities, experience war and conflict?”

At that point, I wasn't having any trouble embracing my identity. I'd even started painting my Lucy Leg; it's always got flowers on it, or some sort of colorful design! I've always been open about it. At the same time, though, I hadn't quite connected with the larger disability community. I hadn't found my people, I guess you could say. Her question really caught me off guard. I started thinking, like, “Maybe she's right,” and that made me kind of uncomfortable. I think that's something lots of people in our community go through: not just struggling to accept ourselves, but learning to accept others, too. After she said that to me, I was like, “You know what? I'm going to look into this.”

To cut a long story short, I did my PhD on the experiences of refugees and asylum seekers with disabilities. I went to Ecuador and interviewed lots of people who'd been displaced from Colombia and Venezuela, and that connected me with the international disability community. I started seeing how not everyone's had the experiences I've had—family support, a roof over my head, job security and education—and feeling that I have a responsibility to respond to these inequities.

When I finished my dissertation, I started looking for work, but even with a PhD, I had a hard time finding anyone to hire me. Eventually, though, someone whom I'd worked with at the university reached out to me. She was the Director of DBI, and she told me, “Look, we've just been offered this contract to monitor implementation of the CRPD in Aotearoa, and I'm looking for people with disabilities to work on the project. I think you'd be perfect for the role.”

I took the job without really understanding what it would mean for me, but it's opened so many incredible opportunities to advocate for people with disabilities. We're already on our third cycle of monitoring. We started with access to housing, working closely with the families of people with multiple and complex disabilities as well as the wider disability community. From



there, we moved on to health and well-being. We're now on our third cycle of monitoring supports and services as well as the establishment of New Zealand's new disability ministry.

New Zealand's considered a world leader in terms of disability rights, and I suppose we are, but we still have a lot of work to do. For example, we still don't have specific accessibility legislation, and Tāngata Whaika-ha/Whānau Hauā (Māori people with disabilities) continue to experience greater marginalization than the rest of our disability population. I'm grateful for the opportunities to travel and partner with people in other countries. It's allowing me to bring back lessons from abroad and apply them here, which I think is really important as well.

Itto: You said you interviewed asylum seekers and refugees in Ecuador for your dissertation. How did you find participants for that study?

Robbie: I contacted an organization in Quito called Asylum Access, and they put out the call for participants at the grassroots level. After that, it really just came down to building relationships, having conversations over coffee, that sort of thing. I traveled around a bit, which helped me make connections. There're very few organizations dedicated to supporting refugees and asylum seekers with disabilities, but there does seem to be a lot of interest in the work. I met lots of people who wanted

to know how to make their services more inclusive and accessible.

Since finishing my PhD, I've learned about some pretty amazing initiatives, including through the UN, and I think that's mainly because of how advocacy can resonate more broadly now, with all this technology enabling us to communicate globally instead of staying stuck in our silos. That gives me hope.

Itto: What about the pandemic? Has it hurt the disability rights movement, or has it accelerated progress?

Robbie: I can really only speak for the New Zealand context, but I think what it's done is highlight issues that were always there. We're talking about financial insecurity, lack of access to adequate healthcare, housing issues, all these areas where people with disabilities have been facing rights violations for as long as anyone can remember. We knew these things were happening, but the pandemic's brought all the atrocities to the forefront of the conversation.

When the pandemic first hit, we were at a bit of a fork in the road. COVID forced us all to ask, "How are we going to respond to this? Are we going to take a rights-based approach to addressing these issues? Or are we going to sweep them all under the rug?" I've seen some examples of both. Remote work and learning have really taken off, and those are things that



people with disabilities have been calling for, for many, many years.

At the same time, though, I've also seen people backtracking on important initiatives, saying things like, "Yep, okay, that was okay during the pandemic, but now it's time to get back to normal." I think that's an incredibly dangerous, slippery slope to be going down. I feel like, if we can advance disability rights through this terrible circumstance, then we have an obligation to maintain those gains.

Itto: What arguments do you think are most effective for convincing people—employers, for example—to stick with the new way of doing things?

Robbie: That's a tricky question. I'm not completely sure where I stand. On the one hand, I feel like it's really important to have a rights-based approach because it shouldn't matter how much we're contributing to the economy, how much accessibility costs—we have a right to be able to participate fully in society, without barriers to access, and our intrinsic value shouldn't be tied to economic value.

On the other hand, research has shown that diversity, accessibility and inclusion are good for business, and I've spoken with advocates who've found that rights-based approaches don't always resonate with people in the community all that well, and economic arguments

are more effective.

On top of that, I feel like now's just a difficult time to be having these conversations. New Zealand has been doing really well in terms of containment, but Omicron's just reached our borders, and people are frustrated, tired and scared. Business owners are really struggling, and because of that, they may be a little closed off to new ideas. Maybe I'm painting with too broad a brush—I'm sure there are some entrepreneurs who are really open-minded and flexible—but I do worry.

I guess I'm concerned that economic arguments might be effective in the short term, but we'd be setting ourselves up for long-term losses. There might come a time or an issue where improving accessibility and inclusion aren't cost-effective, but that doesn't make them any less important. We can't afford to normalize a framework that won't always serve the community's needs. At the end of the day, I think we need to make the UN CRPD the foundation of any future decision: any policy change, any legislation, any response to the pandemic, anything and everything we do as a society. Because the CRPD doesn't just benefit people with disabilities; it benefits the whole community. Everyone.

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■ ABILITY



JERYL

PRESCOTT

Walking Dead, Educator and Sarcoidosis Advocate

Jeryl Prescott shares how a well-rounded life experience led to her career as a writer, director and actor. She mined her experiences working in trucking, in college classrooms, and as a mother and wife to sink her teeth into character development in roles like "Jacqui" on "The Walking Dead." Prescott deepens her engagement with the public with "Ignore No More," a campaign to promote women's health awareness of sarcoidosis, a disorder that disproportionately affects African American women. *ABLITY Magazine's* Dr. Tom Chappell and Chet Cooper spoke with Prescott, while in LA, in between trips to Tyler Perry Studios in Atlanta and found out why the campaign is close to her heart — literally and figuratively.



Lalia resting post nerve transplant

Dr. Tom Chappell: When did you first get diagnosed with sarcoidosis?

Prescott: I was diagnosed about 17 years ago, upon the birth of my first son. I was a late-life mother, had my first son when I was 38. When he was several months old, maybe seven to nine months old, I had a very red, red eye. I thought it was just exhaustion from being a new mom and being older. But my pediatrician noticed it again, at another visit, and she was like, “Hmm, I saw that eye before. You probably should get it checked out.” I was telling her, “I’m just tired.” And then she saw it at another appointment, and she said, “I don’t know. You probably should get someone to look at it.” And when my doctors examined it, they said I had an inflamed eyeball. It had an abnormal white cell count. So, we started looking for stuff. Lupus was their first suspicion. And then we did a lung x-ray and saw scarring from previous inflammations that had come down. That was the beginning of my diagnosis.

Since then, I had nothing. A rather asymptomatic experience, until about seven or eight months ago, when my general practitioner noticed a heart murmur. That led to a series of appointments with a cardiac specialist who discovered that my heart was enlarged and functioning at 15% of what it should be and that I had cardiac sarcoidosis.

Chappell: Really!

Prescott: Yeah. I did get an implanted cardiac defibrilla-

tor about a month or so after that. I went from taking zero medications to almost 10 pills a day.

Chappell: A lung test, right?

Prescott: Yeah, all kinds of stuff. You can imagine. But I’ve been tolerating it very well. I haven’t had a lot of the troubling symptoms. I haven’t had a lot of shortens of breath. I’ve been pretty active. I feel good most of the time. Fatigue, certainly, some fatigue, but no other prominent symptoms.

Chappell: You look good, too. You look great.

Prescott: Oh, thank you. I feel good. I’ve been on the Prednisone now for a couple of months, and I haven’t noticed a lot of changes. Some gastrointestinal stuff that I think is either the Prednisone or—I’m on Methotrexate, I think it’s called. I think that might upset my stomach sometimes. I’m taking it once a week, but several extra pills that day on top of the 10. On those days I might take 16 pills or something. I feel like that day I have a lot of gastrointestinal stuff. But otherwise, I’ve been feeling really good and really fortunate to have such good care.

Chappell: How long will they keep you on the Prednisone, do you think?

Prescott: Well, we are lowering the dosage. I started, I want to say, in November on a fairly moderate dose, I think it was 30 milligrams. And I’m down to 10 now.

Chappell: Good. I’d like to see you get off of that. It does cause long-term side effects, I’m sure they told you.

Prescott: Yeah, me, too. I’d love to get off of it. I’ve been a real irritant with my doctors about reducing the Prednisone, getting me off the Prednisone as soon as possible. Also, I’m always asking questions about when we can take me off of some of the other medications. But they have convinced me that we should probably be pretty aggressive with the heart medications that we have right now because we want to improve the heart function. As I mentioned earlier, when we looked at the first ultrasounds and MRI, etc., we saw that my heart function was down to 15% of what it should be. What is it called? The ejection fraction?

Chappell: The ejection fraction, yes.

Prescott: Yeah, that it was really low, so we want to be aggressive about improving that. That’s what a lot of the medication is designed to do. So, I stopped pressing so hard to get rid of that stuff, but we are trying to get rid of some of the Prednisone.

Chet Cooper: Can you talk about the device you said you had implanted? What’s the difference between that and a pacemaker?



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Prescott: Yeah! It's a pretty cool little secret weapon I have, I feel. It is technically primarily designed to do what the external defibrillators that you see that they grab in all the medical shows and put on people's chests and give them a shot. That's its primary function. It's an internal defibrillator. So, if my heart stops, it is designed to give me a shot. But it also has a pacemaker function in that it monitors irregular heartbeat. So, if I have too many or if they persist too long, it will also try to regulate my heartbeat. I don't know if it does that with a certain kind of shot, but it monitors my heartbeat and communicates with some computer somewhere and sends data that my doctors can see. And it can do something in case I get too many irregular heartbeats in a row or I have the irregular pattern for too long. It does all of those things. Sounds amazing, right?

Cooper: And it helps start your car, which is great!

Prescott: (laughs) Which is fabulous, that's what I'm sayin', you know? It helps me get—I'm thinking, I should have one of those wonderful decals. I need a decal on my car so I can get all the great parking spaces, all that good stuff. I'm not getting the most out of it yet. (laughter) I need to do more.

Cooper: Earl Bakken invented the pacemaker, and he created the company, Medtronic. Is that a Medtronic product?

Prescott: It is. I have the Medtronic card.

Cooper: A side story: I was lucky enough to spend time with Earl Bakken, who invented it. He was in Hawaii

when I met him. The irony of it is, when he was in his 80s, he started having heart problems, and he had to have a pacemaker himself. If he hadn't invented it when he was in his 20s, he would have not been alive.

Prescott: Wow, that's amazing! You know, I'm sort of proud of my little scar. It's just the tiniest little scar here, I don't know if you can see it. It's just a little scar. When I found out that I was going to have to get it, I found out that my physician would be a female who put it on me. We were talking about where that little scar should be because on YouTube, I saw these guys who had the surgery, and it was like right here, right in the middle of their chest, their scars, and I was thinking, what's going to happen to all my cute little shirts and dresses that I want to wear, when I want to have—you know, some sexin' is happenin'? (laughter) I was like, "What can we do? I have to give up all of that, too?"

Prescott: She's brilliant. The surgery, I'm sure, the post-recovery was as comfortable as I could have imagined, and she did a great job of hiding it over here and the corner for me. It's healing very nicely. I did feel just so well cared for, I have to say. My cardiac specialist, Dr. Anousheh, who I'm going to see in a few minutes, he made sure that I was pushed up in the calendar. Because, at first, when we were checking on dates for the operation, the facilities were giving us dates months down the line. He let them know that it was very important for me to get this device as soon as possible because he feared that the worst outcome was possible. The scariest thing with cardiac sarcoidosis is sudden death from the stress on the muscle with the inflammation of the heart, which continues to be inflamed and



gets bigger and bigger and bigger. Mine was already—I think he said, like, one and a half times bigger than it should be, as well as the function being reduced so much, to 15%, which is well below the 30% standard that they usually use to define heart failure. He was really assertive about getting me a spot for an operation as soon as possible. My recovery was as great as I could have hoped for.

Cooper: Yeah, we had heard that you have a big heart, but we didn't understand the—

Prescott: Exactly, exactly, you know what I'm sayin'? I'm thrilled to represent that, absolutely.

Cooper: How has that affected your career, your workload?

Prescott: Well, I think it's still yet to be seen. I have worked since the operation. It was a great day, a couple of days that I worked in the Tyler Perry Studios on a show called "All the Queen's Men." I don't get to be the queen, but I get to be the judge. My wardrobe doesn't allow me to be sexy, so I didn't have to worry about showing off my scar this time. But maybe I'll get to do

something sexy later and I'll get to show it off a bit. It was completely uneventful regarding my health issues or health concerns. When I packed, I had to pack all my medication. That was different. I went to Atlanta—This particular show shoots in Atlanta—So, I did have to pack my medication and make sure I had enough of everything in case the schedule got moved. When we actually shot, it was a few weeks after the initial plan. That had to be changed because of COVID, but it all went well.

Cooper: Do you have any other projects lined up right now, work-wise, acting-wise?

Prescott: Nothing I'm allowed to talk about yet.

Cooper: OK, let's hear it then. (laughs)

Prescott: Not yet, not yet! But I do have a movie on Netflix right now, "Resort to Love." It's been out a couple of months. That one is fun. It's a romantic comedy starring Christina Milian, the lovely Christina from Disney and beyond. Now she's a grown woman who's a mother herself, with beautiful kids. It also stars Jay Pharoah, whom you might know from all of his multiple voices. He does all the wonderful impressions of people.

In this particular movie, we get to hear him, his own voice. He plays my son. He's getting married, and I'm not terribly thrilled at this event. It's a fun romantic comedy, and it's on Netflix. More to come, I hope, this year.

Cooper: Where do you live right now?

Prescott: I live in LA. Like I said, I was shooting "All the Queen's Men," which is a BET show, the second season. We have a season that's already streamed on BET+, and then the upcoming season also is set for BET. I have to go to Atlanta to shoot that.

Cooper: I heard Atlanta. I thought for some reason you were in some part of Georgia and you had to drive down to Atlanta.

Prescott: No, I had to fly out, yeah. I've been living here for about 15 years. Just after my diagnosis with sarcoidosis, maybe about three or four years after, I moved out to LA.

Cooper: Are you familiar with some of the different diversity issues going on beyond the standard diversity, about actors with disabilities in Hollywood?

Prescott: Well, I guess, superficially, because I have noticed, in some of the shows that I've seen, that there appear to be more actors with various other abilities working. At least from what I remember in TV. One show that I enjoy that's on Netflix is called "Raising Dion," for example, had a wonderful young character who uses a wheelchair, and she is incredible. I loved everything that I've seen her do in the show. Her presence is not the only example, it's the one that comes to mind most readily for me in recent months. But I feel like I've seen a few.

Cooper: You've now fallen into the area of hidden disability. You mentioned it, about getting a placard. You were somewhat joking, but not joking at the same time.

Prescott: Right.

Cooper: There are a lot of people with invisible or hidden disabilities who can't walk a distance, for example. There's the controversy of people seeing you with a placard saying, "Hey, you don't use a wheelchair," but they don't understand other medical conditions. Lots has been written about that—Jeff Charlobois who writes our humor section has an interesting idea of different colored placards that helps identify hidden conditions. <https://abilitymagazine.com/park-risk/>

Back to the entertainment industry, there is a movement right now for casting to try to tap into authentic actors with disabilities. Let's say you're casting something that connects to someone with a typical condition that you already have, the movement is, talk to you. Get you in

to do a casting call. It'll still be your talent that gets you the job or the gig, but the first see if there is talent out there, somebody who's an amputee, who's deaf, blind, heart disease, cancer, whatever the condition. That's something else you might look at.

Prescott: Oh, yeah, I would love to do that. And it makes sense because it has to add not only to the authenticity of the representation, but it's going to add to whatever the screenwriter is trying to do. It's going to give them another resource of reality to pull from. It only makes sense to do that. But I'll let you know, everything in LA certainly does not make sense. Everything in Hollywood doesn't make sense. But yeah, I don't see how the industry could lose in moving in that direction.

Cooper: We're actually quite involved in all of it. Just this morning we were talking with Netflix Animation. They are looking to cast a female South Asian wheelchair user for a voiceover, because the animation has a young woman who uses a wheelchair. Even in animation, they're trying to do authentic voiceover, which is great.

Prescott: Yes!

Cooper: The site is called abilityEntertainment, abilityE.com. It's a database of thousands. Of talented performers, union or non-union. We met with SAG-AFTRA, CSA, and most of the studios.

Prescott: Wow. I think it's relevant and necessary.

I do want to mention, before I forget, and we can get together again if you guys want to, I want to mention "Ignore No More" because it works so well with what we're talking about, the campaign that the Foundation for Sarcoidosis Research is promoting encourages us to stop ignoring the fact that we all have these health issues, and that African American women are even more impacted by the disease, sarcoidosis. We experience, unfortunately, a worse outcome, and that's probably because we get diagnosed later. We need the health-care industry to be aware of this so that they can help be advocates and pay attention to the potential for this disease among African American women. And we need African American women ourselves to be more proactive and be advocates for ourselves and for each other. That's what "Ignore No More" is designed to promote, to remind us to pay attention, to share our stories and talk about it so that we can remove stigma, both inside and away from the workplace. I think that, too, is an issue among actors. Everyone wants to seem invincible. "Yes, I can jump out of that plane. Of course, I can do whatever you need me to do. I have no limitations."

We need to talk to each other and share our vulnerabilities as well as our abilities. I think it'll help all of us, help our work and our lives. So "Ignore No More," the



Foundation for Sarcoidosis Research has a lot more information than you'll find most places. I know when I first found out I had sarcoidosis, I had a hard time finding information about it. The foundation is working on being a resource for people who want to be educated and for people who have been diagnosed. I didn't want to forget to say those things.

Cooper: I'm glad you did. What got you into acting?

Prescott: Oh! OK! Let's see. That was so long ago. I could say I kind of stumbled into acting, I guess. Some people do that. It's not something that I studied a lot at first. I started studying really after I started booking, I started studying more. But I did some theater first, before doing any television and film.

Cooper: Is this high school? College? What age was that?

Prescott: That would have been college. I did one theatrical presentation in high school, one, when I was a senior, and then in college I did a couple. And then I started to do community theater in the summers, like, every summer, wherever I was living, I would do community theater in the summer. And in that way, I found some wonderful mentors and ended up spending a lot of time with Larry Leon Hamlin, who was the founder of the National Black Theater Festival that happens every year. It switches from North Carolina to Georgia every

year, on alternating years. He was wonderful, he helped me a lot. And I also met and began working with a couple of other directors in the North Carolina area who were teaching at the North Carolina School of the Arts, which has given birth to quite a number of people in the industry, actors as well as directors who have done really well.

They were on faculty there, but they were, in the summers, sometimes working on independent projects or on theater projects, and I was able to really begin some training with them. That was really valuable for me. And then I met the father of my boys, my first husband. At the time, he was working for Spike Lee. He was an editor, and he had worked on about eight of Spike's films.

Cooper: Nice.

Prescott: And I invited him to a play that I was doing. He came to my play, and he's the one who said, "You know you're pretty good. You should take it more seriously and get an agent, take some more classes and things like that." I was like, "Oh!" Because I had thought of it as a hobby, something I was doing for fun. I loved the people I would meet, always in theater, just wonderful people. It attracts such great people. After he said that, I enrolled in a class with one of the professors who was teaching at the School of the Arts. I got an agent, and things started to happen. So yeah,

that's sort of how it happened.

Cooper: What were you taking in school before you started dabbling in—what was your major?

Prescott: Oh, Lord! I don't know if you want to reach that far back. I consider this my third life as an actor. I have a B.S. in industrial management. I worked in the trucking industry for a couple of years for the now-defunct Roadway Trucking, do you remember them?

Cooper: I remember that banner on the sides of those rigs, sure.

Prescott: Yeah, those big orange trucks. I think Roadway Trucking merged and no longer exists. That was my first job out of my undergraduate program at Clemson.

Cooper: That got you on the road!

Prescott: (laughs) Yeah! That put me on the road! That was cool. But then I decided I was bored after a couple of years doing trucking and that I needed to go to graduate school. So, when I went to graduate school, I studied African American literature, women's literature, and I ended up doing a lot of studying and got a PhD. in American Literature, early American literature before 1900.

Cooper: Wow! That's great background for writing.

Prescott: And then I taught, I was teaching for about 10 years on the college level. I did some adjunct teaching when I first came to California, and then I started to act more. I was doing the teaching while I was looking for acting jobs. It was my little side gig, teaching a couple of courses in writing, seminars in literature, things like that.

Cooper: When you say "writing," what type of format in writing were you teaching?

Prescott: Mostly critical writing, critical analysis, essay writing, teaching the kids how to write good essays and how to do good critical analysis of texts, which I think is what has helped me as an actor. Because when I get hold of a script, it's my Bible, of course. And yeah, I can see all the themes and subthemes and all the character details, all the hints about the things that the character cares about, all of that good stuff. So that was very meaty for me, and it's really helped me with character development, having that background.

Cooper: What about writing yourself? Have you written things?

Prescott: Yeah, I wrote a film called "Stand Down, Soldier." I was able to produce that. That was quite an experience. I need to write more. I'm always thinking

about writing more. I have fragments of scripts all over the place. It's something I need to do more. That's how it all came to be. So then eventually, the acting took over the teaching, probably when I got "Walking Dead." I was teaching at that time at the Art Institute of Hollywood, teaching probably three classes in critical writing, two in critical creating and one in technical writing. I believe that particular first summer term ended at the time that I was supposed to go to Georgia for a couple of months. So, I left LA and went to Georgia to shoot "Walking Dead." I don't think I took another teaching job after that.

Cooper: What do you see yourself doing now between acting gigs? Go back to teaching? Focusing on writing?

Prescott: Yeah, I need to do both. These days, the world is so upside-down, it's hard to look at life the same. These days, I yearn to be back in the classroom, honestly. I want to teach. I want to find out what's on the minds of young people. I'm curious about what they're thinking about, what they would want to write about, what they want to read these days, and how they interpret what they read, what's going on around them, in their world, what are they thinking? And it might be my age, too. I don't know. My children—I'm soon to be empty nest.—I have two boys, and one just went to college. He's finishing his first year at Arizona State. And I have a second who is 16. So, he'll be off in the couple of years. I sort of want to follow them around, maybe teach wherever they are, that would be fun.

Cooper: (laughs) They would love that. "Mom's the teacher!"

Prescott: (laughs) Right? It would be fun for me. So yeah, I really would love to do that. I was bugging my agents because I've never—I did a couple of episodes of "One Tree Hill" back in the day, before "Walking Dead." But other than that, I don't think I've ever been in any of these shows that are set in a school, on a university campus or anything like that. And there are several of these shows, and I'm like, I should be on those, and I should book those jobs. It's just one of those things I've been thinking about a lot lately, getting back to the classroom in some way. ■ **ABILITY**

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Interview with **Hannah Orban**

“I’m committed to policymaking that improves the lives of people with disabilities,” says Hannah Orban, an advocate, public policy specialist, and Fulbright scholar from Sydney, Australia. “We have to redouble our efforts to dismantle disabling attitudes. People with disabilities have been fighting tooth and nail for far too long.” For Hannah, these issues are personal: two of her brothers have Fragile X Syndrome, and she grew up watching their exclusion from mainstream society. Today, she’s a master’s student at the University of Michigan, but still makes time to volunteer with the local Best Buddies program and mentoring community members with developmental disabilities.

Itto Outini: Where does your passion for your work come from?

Hannah Orban: My eldest and youngest brothers were born with Fragile X syndrome, a genetic condition that causes cognitive impairments and developmental disabilities. My eldest brother has a more severe case. My youngest brother’s is milder. My older brother, Joshua, and I don’t have it at all. Joshua is a political science PhD student at the University of Michigan, and he’s dedicated to research in disability studies as well. His research looks at public attitudes toward people with disabilities and how people with disabilities engage with politics. Just witnessing that variation within my own family taught me from a very young age that opportunities aren’t fairly distributed and life is decidedly unequal.

Itto: Are you close with your brothers?

Hannah: Of course! They’re my best friends. They’re the light of my eyes. We’ve always had that unique sibling bond of shared experience and understanding.

Itto: When you were a kid, how did their disabilities impact your life and the dynamics within your family?

Hannah: I got to see firsthand what it’s like to live on the outskirts of society. I witnessed how they were misunderstood and bullied at school and at times prevented from joining the social circles they wanted to join. Basically, they were informally segregated. Once, for example, when I was in primary school and my younger brother was in a mainstream class, I went to pick him up, and one of his classmates came out to tell me all the things he’d done wrong that day and how embarrassing he’d been. I remember feeling trapped, and mortified, and really, really sad, but also furious on my brother’s behalf because this person, who was only a child himself, was judging him, and that contributed to my brother’s feeling of alienation at school.



degree. He lives with my family in Sydney. He works as a receptionist, and he's taking classes at a community college, and he also loves cooking. We have a couple of social workers whom he really likes, and sometimes they all go to the gym together.

Itto: What about their relationships with your parents?

Hannah: My parents love all of us equally. They've always been clear and consistent about that. Sometimes, it causes them grief to know that Tom and Hamish—those are my brothers with Fragile X—face so many difficulties and limitations. But they're also hopeful for the future. In Australia, there's a new program called the National Disability Insurance Scheme (NDIS), which supports people with lifelong disabilities who want to live independently and pursue

Itto: Did it impact your social life, too?

Hannah: Yes and no. When I was very young, I worried about needing to explain my brothers to my friends. I felt like I needed to stand between my brothers and the world. Any threat of alienation or difference is scary to children, so this made me nervous sometimes. I worried that my friends wouldn't understand them, or they would think we were strange. But as I grew older, I realized I'm not standing in front of my brothers, trying to shelter them from the world. I'm shoulder-to-shoulder with them. Also, I decided I didn't really care if people formed negative opinions of them because they have disabilities. That's an absurd reason to form a negative opinion of anyone.

Itto: What about now? Have things gotten any better? Can you describe your brothers' daily lives?

Hannah: Yes, things have definitely gotten better. My eldest brother lives in a group home with two other flatmates who also have intellectual disabilities. He loves it there: being independent, and having his own space, and how it makes coming home to visit the family more special. He swims and plays sports and goes to the gym. My youngest brother also has fragile X, but to a lesser

their own interests and professions. It's had a really positive impact on our family. For 30 years, my parents couldn't leave the house together. One of them always had to be there with my brothers. Now, thanks to that program, they can go on dates again and do things with each other, and my brothers get to live independently. It's transformed all of our lives.

Itto: What do you think family members can do to support and advocate for persons with disabilities?

Hannah: We're in a unique position because we know how important our loved ones are, and what they're capable of, and all the joy and value they can bring to the world if only they can access opportunities. I guess you can say we're the ones who are motivated. We can advocate for them, and maybe more importantly, we can listen to them. Honestly, though, it's not just our responsibility. It's everyone's.

Itto: I agree! Especially since there are people like me, with disabilities and no families to support us. Society has to play a role, too.

Hannah: Exactly. Disability is something we all interact with at some point, directly or indirectly. It's a category

that encapsulates a huge cohort of society, and one that's constantly changing. It might not happen to everyone, but it *can* happen to anyone. It can be visible or invisible. The social model really underscores that there's a difference between an impairment and a disability, and that a disability is largely something society or the environment imposes on people, not something internal. So, within that framework, it's the responsibility of society as a whole to dismantle those disabling attitudes and create environments and systems that are more inclusive for everyone. Policy is a cornerstone, but in a free society, it's beholden on all of us to live inclusively.

Itto: Would you apply that to the media, too?

Hannah: Absolutely. I think people in the media are finally starting to recognize some of the mistakes they've made, how they've been promoting disabling stereotypes and stigmatizing or omitting people with disabilities entirely. There also seems to be a broader cultural effort underway to promote better media representations. But of course, there's a long way to go.

Itto: That's a good segue into your work in public policy. Can you talk about the work you did in Australia?

Hannah: Of course. Like I said, growing up with Tom and Hamish taught me that opportunities aren't distributed equally, and that motivated me to embrace whatever opportunities came my way and make the most of them. I studied philosophy as an undergrad and loved it because it taught me to listen carefully and think critically, but after that, I wanted to do something less abstract and more applied. I went into public service in New South Wales and joined the Department of Education's disability strategy team, and we worked on all sorts of programs for students with disabilities in public schools. I redesigned a survey to help teachers recognize their students' capabilities. I also designed a pilot program to train teachers to better support students with disabilities, and to connect those teachers with their fellow educators in different types of educational settings. This work really emphasized to me the impact that public policy has on people's lives. Eventually, I decided to go back to school so I could become a better policymaker and a better public servant.

Itto: You're studying on a Fulbright scholarship, right? Do you think there are opportunities within the Fulbright Program for persons with disabilities?

Hannah: The Fulbright Program's all about leadership, diversity and mutual understanding, so yes, I think it represents a wonderful opportunity for people to reshape societies and transform their own lives. I'm excited to be part of the community, and I want to promote it more among people with disabilities. I think Fulbright is committed to an equitable and inclusive future.

Itto: Can you talk a little more about the current policies in Australia and the US, and how they affect persons with disabilities?

Hannah: The current policies are many and varied. Part of my research is to identify what works and what doesn't through comparative studies. In the US, there's the ADA, which has been a really successful piece of legislation, but hasn't achieved much in terms of helping people with disabilities find jobs and stay employed.

Itto: Can you elaborate on that?

Hannah: The literature seems to suggest that the ADA's anti-discrimination approach has been too narrow to effect the change we need for people with disabilities to enjoy the whole and unencumbered equality they deserve. In the case of employment accommodations, the ADA's antidiscrimination model calls for the righting of wrongful discrimination, but it doesn't stipulate that employers are obliged to provide employees with disabilities with all the tools and resources they need to fully participate in the workplace. For example, it's not the employer's responsibility to make sure their employees can get to work on time, regardless of the obstacles they're facing. The way the ADA's interpreted, no one really has that obligation, so quite often no one does it.

Itto: How would you compare the ADA to other approaches?

Hannah: That's another big part of my research: looking at comparable models in Australia. The NDIS adopts a bio-psycho-social model of disability, which synthesizes the medical and social models, so it's a little different from the ADA. I'm really interested to see how it's going to work. I also want to identify for whom and under what circumstances the antidiscrimination approach works well, and when alternative approaches will gain better outcomes. These issues are complex, and so is the legislation, and there are lots of little moving parts and pieces that might not seem all that important at first glance, but they end up having a huge impact on the outcomes. The NDIS is still quite recent, so we're all waiting with bated breath to find out whether it really helps people with disabilities achieve what they want to achieve.

Itto: What's your focus as a policymaker? What do you personally want to achieve?

Hannah: I'm focused on the social side of disability policy, rather than the health side. I'm interested in how we can improve education and employment for people with disabilities so they can fully participate in society and become economically independent and socially equal. My long-term goal is to work alongside people with disabilities to produce excellent public policies that help them access all the opportunities they deserve and achieve what they want to achieve.

Itto: That's beautiful, Hannah.

Hannah: Thank you. ■ **ABILITY**



Lalia Susini

Acting, Clothing, School, Sports and Life After a Traumatic Brain Injury

You may have seen Lalia Susini after she landed her first big role on ABC's hit TV show, "Station 19". Lalia, a sweet-natured young lady was quite poised as she recalled a horrible accident that happened to her at just 11 years old. "My grandfather was pushing me on the swing," an ordinary day, a grandfather and granddaughter having a pleasant time on a porch swing. When unexpectedly, the swing hanger unbolts and hits the back of Lalia's head. She's thrust forward, and apart from dream-like visions, she doesn't remember what happened after that. On a lovely, rainy Los Angeles afternoon, Lalia connected with *ABILITY*'s Lia Martirosyan and medical editor Dr. Tom Chappell to share her story and what she's looking forward to.





Lalia resting post nerve transplant

Lia Martirosyan: Lalia, how is your day going?

Lalia Susini: Good. Today I went to OT (Occupational Therapy) and physical therapy for the first time after my surgery for my arm.

Martirosyan: Two therapy sessions already, what was the surgery for?

Susini: Yeah. I've had three surgeries so far, and I'm sure I have a lot more left. But I had surgery for my arm to help get my fingers and my wrist fully working again because I had nerve damage from the stroke, so I got a nerve replacement.

Martirosyan: Oh! How recently did you have the surgery?

Susini: March 2nd, so about four weeks ago.

Martirosyan: Are you feeling good?

Susini: Yeah!

Martirosyan: Good! Would you like to share how this all began?

Susini: All right. So, I was on a swing on October 22nd of 2020. It was a swing—I don't know how to explain it, it was like an O-ring, kind of, but it was nailed into a circle at the end. There was a little swing attached to it. I was swinging with my grandpa, and he pushed me, and

I felt—the swing came out of the ceiling and right into the back of my head. Yeah. Then I fell forward. I would say a minute later maybe I had a stroke. A couple minutes after that, station 97 showed up and they got me to the hospital and started brain surgery.

Martirosyan: Wow! How old were you?

Susini: I was 11.

Martirosyan: Were you cognizant of what was happening?

Susini: Well, I think my body went into shock. I was aware of what was happening, but when I first—I don't really remember it going into my head and falling. I remember being on the ground. I was a little confused at first, but I kind of had an idea of what was going on.

Martirosyan: When you came to the realization of what happened, what were you thinking?

Susini: Well, I think I didn't realize what had fully happened until I woke up from surgery later that night. I had thought something else had fallen on my head. My mom explained to me what had happened and I kind of got an idea of what happened. I was like, "Wow! This is going to be a long road!" I don't know. I think I was kind of in shock.

Martirosyan: Understandably so. Was your first acting role on *Station 19*?

Susini: Yes. I think in 2019.

Martirosyan: 2019 on Station 19.

Susini: (laughs) Yes.

Martirosyan: I'm sure that was exciting?

Susini: Yeah. (laughs) I was so excited! I think it was the beginning of season four when I had my accident. Maybe two episodes and then I had the accident. I returned for one episode that season, and I haven't returned for the next season because of my surgery.

Martirosyan: Had you ever thought about traumatic brain injury (TBI) or what it meant?

Susini: You know, I feel like I never had—I never knew anybody who went through that and I didn't have an idea of what it was like until it happened to me.

Someone at Station 19, also had a TBI. When I first got back to the set, my first time after the accident, he was there and he welcomed me back. It was so cool. I never knew he had a TBI, and it was just so cool to hear other people's stories. I would have never known that anything had happened to him if it hadn't happened to me. It's so cool how many people you meet and you don't know their stories until it happens to you.

Martirosyan: Absolutely! Are you involved in getting to know other people's stories who have gone through similar experiences?

Susini: I love hearing other people's stories. it's like—I don't know how to explain, but it's so crazy to hear other people's stories, too. I have so many friends in hospitals where terrible things happened to them, and they're all incredible. That's why I named some of my clothes after Ethan and Jack. I've met some really cool people who have amazing stories.

Martirosyan: Let's talk about your adaptive clothing?

Susini: I have some of my clothes. These [shows clothing] aren't the adaptive ones, these are just the regular ones. I'm wearing one of the Valentine's Day t-shirts right now. We do have adaptive clothing, and I've been having to wear—I had a cast on my arm and I just got it off and got this [points to splinter] put on, but before that, I couldn't fit into any sweatshirts, anything. I was wearing my stuff because I needed adaptive clothing. We made adaptive clothing because when I was in the hospital, I remember that it was so hard to get anything over my head. I had a cast when I was in the hospital, PICC lines and IVs, and it was hard to get anything over that. I had a lot of friends with g-tubes and catheters. It was really hard. We had to wear hospital gowns, and when you're in a hospital, you don't want to be in a hospital gown, lying in your bed all day. I would like to be



Dr. Melo (Cedars trauma first to see Lalia in ER)

in something cute and comfortable. So that's why.

Martirosyan: That's where you started your clothing line idea?

Susini: Yeah.

Martirosyan: Now you've expanded I see.

Susini: Yes. I'm going to hold these up. We have the shorts right here. As you can see, this is the CHLA (Children's Hospital Los Angeles) logo.

Martirosyan: Are you collaborating with them?

Susini: It's the CHLA logo because I was there for rehab and they helped me walk again and also helped me with my left arm. Some of our proceeds go back to Children's Hospital and we bring some of our adaptive clothing there.

Martirosyan: You seem passionate about it. Will you continue to pursue the clothing line?

Susini: I hope so. I've always wanted to be a clothing designer. Now I kind of want to be a brain surgeon after everything I went through. Maybe I could do both.

Martirosyan: Maybe! You're in school now? Being a brain surgeon requires plenty of study!

Susini: Yeah a lot of school! I just started in-person



Chla therapy dog

school at the beginning of the semester. I was at the school with the hospital.

Martirosyan: How does it feel to be back in school after the pandemic and this journey you've been on?

Susini: It felt really different. I haven't been to school since, like, fifth grade, in-person grade school! But it's really fun. I didn't think I'd ever say that about school, but I really like it.

Martirosyan: How old are you now?

Susini: 13.

Martirosyan: Building fun memories. How are you spending your time outside of school?

Susini: Getting back into sports. I've recently gone into basketball, and I've been doing basketball with my left hand and it's in good condition. I've been getting back to track, trying to ease my way back into sports.

Martirosyan: You quite enjoy being active it seems.

Susini: I have three brothers, so our house was super-competitive. It was always like, "I'm better at basketball. I'm faster on this and that." It was always a competition.

Martirosyan: I can only imagine. That's a lot of boys!

Susini: It's a lot of boys! (laughs)

Martirosyan: Did you expect to have more surgeries?

Susini: I think I was always going to have to have one for my hand, because I had nerve damage. But for my foot, my left foot, I got really good news the other day. My doctor had said, "You're going to have that surgery for your foot." And now he's saying that I might not have to have surgery, that my foot's getting a lot better.

Martirosyan: That's wonderful news! So a lot of physical therapy, and training.

Susini: My therapy has gotten me so much better. I'm walking and running again. I play basketball. I just think you should stay happy about it and know that you're putting in all this hard work and good things will come from putting in the hard work.

Martirosyan: Absolutely. How has your experience been with friends along this journey?

Susini: I have really good friends. They've all been super-supportive of me. I love my friends.

Martirosyan: How are you feeling in this moment?

Susini: I'm super-excited for this process to be almost over and my hand be fully working again and being back to basketball and maybe soccer, too.

Martirosyan: I'm excited for you! Do you have a lot of tingling? Has your sensation returned?

Susini: In my hand right now since I got the surgery for the nerve, I'm getting feeling, I felt it right after the surgery, I'm getting most of the feeling back. It's not that bad.

Martirosyan: Was it mainly your left side that was affected?

Susini: Yeah, it was just my left side.

Martirosyan: And that was from the stroke?

Susini: After my surgery, I remember I was waking up and I had a thing around my head because I just got brain surgery. And a couple weeks later they took it off and I was feeling the back of my head and I look at my mom and I go, "Did they shave my hair?" She didn't want me to be upset, and she was like, "I don't think so, just a little part." And then I got my phone back and I



Lalia modeling some of her clothing line

looked at the side of my head, and I remember I was so mad at my doctor. I called him “Dr. Dinosaur.” I was like, “Why would you shave my hair?” He was like, “We had to do that.” I remember I was so mad.

Martirosyan: That took some getting used to, I’m sure.

Susini: It did.

Martirosyan: Do you know what they did surgically as far as—

Susini: It was 4 1/2 by 2 1/2 inches, so almost half my head. The nail just went in and shattered it. I think they tried to piece most of it back together. I remember I had brain surgery August 30th of 2021. They put—I think it’s a PEEK implant or a metal mesh, I don’t remember which one exactly. They put it in my head to have something protecting it, at least. I think when I’m 18, they’ll have to put another plate in my head, for good, though.

Martirosyan: Is it soft to the touch now?

Susini: It’s still pretty delicate. But I have gone back into sports. One of my doctors said that the plate would grow into my head and I’ll be able to do more sports and stuff.



Martirosyan: Wonderful. Are you going on auditions now?

Susini: Some of them, but not too much. I’ve been mostly focusing on sports and getting better.

Martirosyan: It seems like you’ve come a long way in a very short amount of time.

Are you working with someone in designing and producing your clothing?

Susini: Me and my best friend, we come up with the designs, all the colors how we want it, and then we have someone actually design it for us.

Martirosyan: How did you come up with the name?

Susini: It’s like Lalia and Cate matched together, Lalia and then Cate, LATE. We have the “Love” tank top here because they were like, “You’re probably going to walk again, you’re probably not going to do this again.” I was like, “Nope, nope, nope. I will do that again.” We pick out the designs. That one right there, that’s one of my favorites. I love that one.

Martirosyan: That’s pretty.



Jania Ortez, Lalia and Patricia de Leon on the set of *Station 19*

Susini: Thank you. It's all different basketball players' hands, about love.

Martirosyan: A lot of work, to start a business! Are you making them in different sizes?

Susini: It ranges from extra-small to extra-large. It's kind of for teens, but my brother, who's six foot tall and plays football, all of his friends love the sweat pants. Everyone at his school wears the sweat pants. We have a bunch of different colors and sizes.

Martirosyan: Supportive of him. Are you hoping to bring it into retail, how are you selling it?

Susini: It's online right now, we've done pop-ups like in the Village, but we're mostly just doing it online.

[Dr. Chappell connects]

Martirosyan: Dr. Chappell, Lalia said she wants to be a brain surgeon. Do you have any advice, being that you

took that route?

Dr. Tom Chappell: Study hard!

(laughter)

Generally it's relatively straightforward, but pretty competitive to do well in school, when you get a science background there are certain prerequisites to get into medical school. You don't have to necessarily major in science, interestingly enough, but you do have to meet certain prerequisites to get in. That's pretty tough, just because it's competitive. And once you've completed that, you have to do pretty well there, because it's competitive to get into a neurosurgery residency. I don't remember now, but there are only, I think, 110 training spots in the whole country. You, of course, could get citizenship in another country, but 110 training spots. Usually several thousand people apply for them. It's fairly competitive.

Susini: Wow, that's crazy!

Martirosyan: After Lalia's accident, she had to get a PEEK implant.

Chappell: So it was made of PEEK. That's relatively new. Back in the old days, we really did—this was before my time, even, put just a solid metal plate in. We haven't done that in many, many years. There are different products we can use.

Susini: What material is PEEK?

Chappell: It's "polyether ether ketone", that's what PEEK stands for. If I handed it to you, you'd say, "Oh, it's like plastic".

Martirosyan: And that's just a one-time surgery, or do you have to keep going back to maintain it?

Chappell: It's a permanent implant. It's kind of interesting the technology that's used now. When they did it for her, they took a scan of her head and used a computer to carve the implant out of the material PEEK based on the opposite side of her skull, the normal side, and then it also cuts the piece to fit the actual defect. I read about your accident. I've seen all kinds of accidents, and I have to say, that was a pretty unique one. I'm really sorry.

Susini: Thank you.

Martirosyan: She also experienced a stroke, on her left side—

Susini: The left side, yeah.

Chappell: It looks like what happened was that section of the brain was damaged. If the object penetrates the skull and damages the part of the brain that controls the opposite side of the body, that's the effect you'll get. It can look a lot like a stroke.

Martirosyan: Are you left-handed or right-handed?

Susini: I am right-handed.

Chappell: Pretty lucky. If anything is good here, that's better than it might have been. It could have affected your speech, too.

Martirosyan: With rehab she's at a point now where she's not only walking well, but she's running, and started to play basketball again. Not on the competitive level, she's not a pro, yet.

(laughter)

Chappell: Maybe Stanford and girls' basketball, they're doing pretty well.

Susini: Maybe! (laughs)

Susini: I just had a nerve transfer in my hand, and my doctor thought he would have to do one in my foot, too, but a week ago, he said that my foot was getting a lot better and a lot stronger and he doesn't think he'll have to do it any more.

Chappell: That's good to hear. Those are all maneuvers to try to improve the function in the extremities, which we call peripherally, out in the extremity itself. Those are orthopedic doctors who do that, usually.

Martirosyan: How does that work, and recover?

Chappell: Of course, I can't speak to the surgeon, nor am I an orthopedic expert, but more than likely what they're saying about the leg is that it's good enough that they can't improve upon it. That's probably more what they're saying, that it's recovered significantly so that anything that they might do would not greatly improve upon what she's already been able to recover on her own.

Martirosyan: Is it also good that she's young and still in a growing phase?

Chappell: You're much better off to be younger and have something like that happen. Had it happened to me, I'd be in big trouble, for sure.

Martirosyan: It doesn't seem like your speech was affected, or noticeable.

Susini: Thank you. Right after my accident, my mouth dropped so much when I talked. I still have a little bit of a mouth-drop, but when I talked, it was really noticeable.

Martirosyan: How did your family get into acting?

Susini: We lived in Dallas before we moved to LA. I think one of my mom's friends was a casting agent, and my older brother started acting first, and then I wanted to get into it, and then all my other brothers started wanting to get into it, too.

Martirosyan: Susini, is that French?

Susini: Yeah, it's French. My dad's French. It's French and Corsican. That's where he grew up.

Martirosyan: Do you speak French in the house?

Susini: We try to speak French. My older brother and my dad and my mom, my dad's fluent still, and my brother can barely speak French any more, but they're all fluent. We try to speak French, because we go there every summer.



Martirosyan: What part of France?

Susini: Paris.

Martirosyan: Lovely. Do you enjoy being there?

Susini: Yeah. It sort of reminds me of LA, I really like it. That's where all our family is.

Martirosyan: What's your favorite part about being in Paris?

Susini: My grandparents live in a small, little part of Paris, and I love being able to walk everywhere. It's so pretty. I love shopping with my grandparents. I love it there.

Martirosyan: Très bien! I see a picture behind you is that you holding a surf board?

Susini: Oh, yeah. This picture there? I really want to get into long boarding. This was two weeks before my accident. That's [holding the picture] one of my best friends.

Martirosyan: I see trophies. Did you win a contest?

Susini: I did junior lifeguard, and we had a surf competition with all the beaches, and I got eighth place for girls 7 to 15 years old. I was 9.

Martirosyan: Impressive. I surfed once, and it was in Israel, did you know people surf in Israel?

Susini: I didn't. (laughs)

Martirosyan: Most people don't know that. Tel Aviv is on the shores of the Mediterranean sea. Where do you surf?

Susini: Near Malibu, and Huntington Beach.

Martirosyan: Those are two very different places.

Susini: I like Huntington Beach, but it's always super-crowded. There's a place in Malibu called Sunset and I like it there because the waves are perfect, the perfect size, and they don't go too fast and they don't break too quickly.

Martirosyan: Have you surfed on the north side of the pier at Malibu?

Susini: I have, like, one time. It's always super-super-crowded.

Martirosyan: Do you know an actor named John C. McKinley? He did the TV show "Scrubs." That's before your time.

Chappell: Everything was before her time.

(laughter)

Martirosyan: He's an actor who lives in Malibu. There is private access into the area called Dunes, so no crowds.

Susini: That's really cool.

Martirosyan: Will you surf when you get your arm—

Susini: Once I get all of this healed, I really want to get back to surfing.

Martirosyan: Will you try a long board then? Dr. Chappell does paddle-boarding.

Susini: Yeah, I want to try long boarding, because on a short board you go so fast, and I want to go long. I think I want to start again on a long board.

Chappell: I was thinking you might try stand-up. That'll be a long board and you'll already be standing up. All you've got to do is paddle and catch the waves standing up. You don't have to worry about your leg coming up when you need for it to, if it's not doing that right away. Might be fun to try.

Susini: I haven't thought about that. It's been so long.

Martirosyan: Have you seen people surfing with the stand-ups?

Susini: I have. It's really cool.

Martirosyan: The boards are getting more and more versatile, I guess, I don't know how to describe it. Dr. Chappell could.

Susini: Yeah. I was going to do it this past summer, but then I got brain surgery.

Martirosyan: We might be writing an article about accessible surfing in Huntington Beach in the near future. Once it's all sorted, we'll let you and see if you want to come out.

Susini: You know, that sounds really cool.

Martirosyan: We wish you all the best in your healing. Keep doing what you love to do.

Susini: Thank you. ■ ABILITY

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Celebrating Scrupulosity

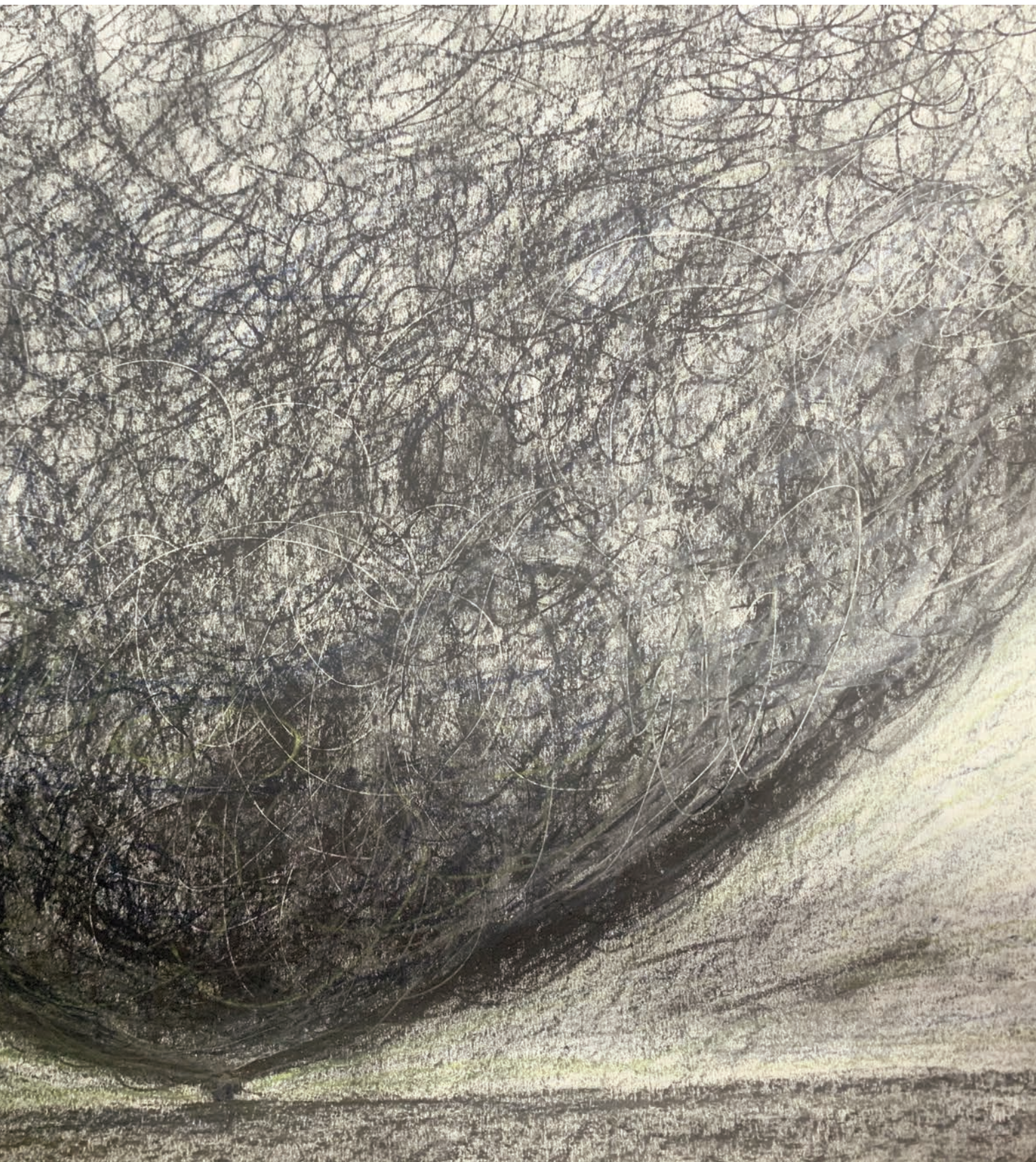
From sunup to sundown, starting in my 11th year, I found myself beset by constant, overwhelming fear. I'd been raised Catholic, and thoughts of sin, confession and guilt relentlessly plagued my mind. Years later, I would learn that I'd developed the religiously inflected version of obsessive-compulsive disorder (OCD) known as "scrupulosity," but at the time, all I knew was the excruciating psychic pain. My mother found out one day when she saw me uneasily pacing my room. After exhausting both of us with her attempts to reason my concerns away, she finally told me firmly, "Stop it."

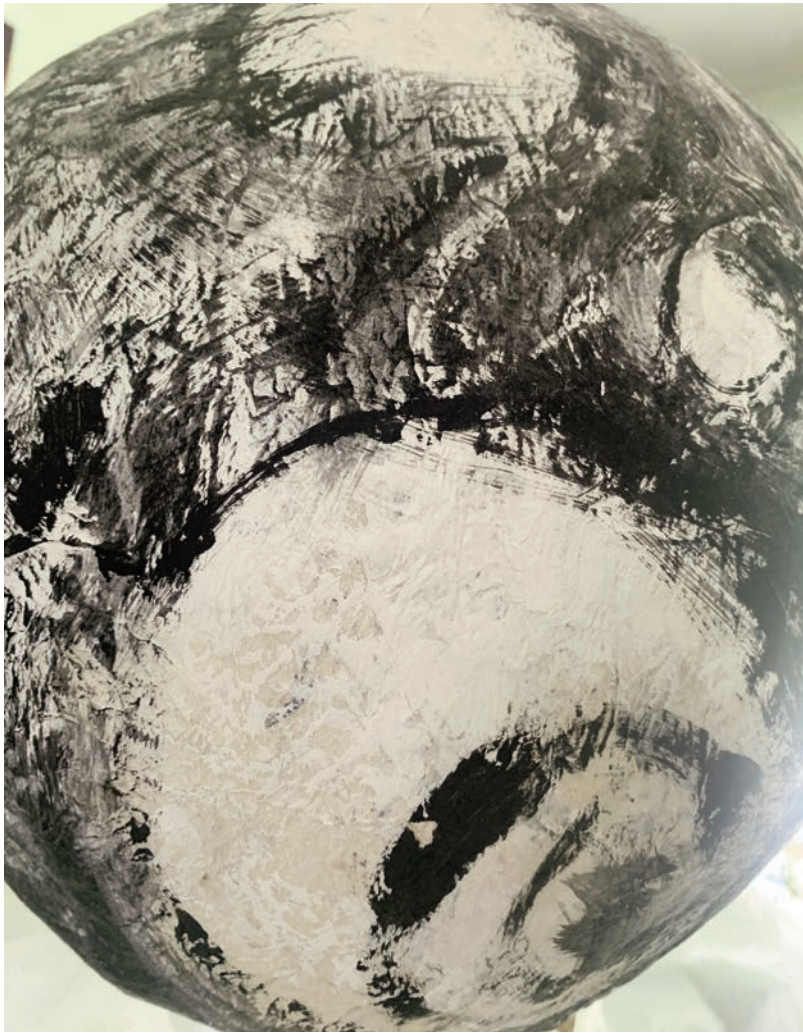
As far as she was concerned, that put the matter to rest. If only it had been so easy.

I managed to suppress these urges during my 12th year, but they came back with a fury when I was 13, before gradually subsiding again during my later teenage years. During the acute phase, I was extremely embarrassed about it and didn't want a soul to know. I felt like I was the only one in the world like this; I thought I was a "freak." However, as I grew older, I discovered that mental illness and drug and alcohol addiction run in my family, as in so many others.

The most shocking event of my entire life happened when I was 20. One week after I returned to college, on September 3rd, I received a shattering phone call from my father, telling me that my brother had died from suicide. There'd been no outward indication that he'd any problems whatsoever that summer. He was 18 and had done well in college the previous year. That summer,







he'd been playing a lot of baseball and had many friends. Over the years, I've come to understand that he must've been extremely depressed. I've read that depression actually changes the anatomy of the brain, as well as the chemicals that regulate moods. As we searched for answers as to why this happened, my family members and I wondered if something we'd done, or not done, had caused this to happen--and also what we could've done to help him.

I've since realized the truth: the fault lies not with any individual, but with society as a whole. The stigma surrounding invisible disabilities is pervasive, and people are understandably hesitant to share their suffering with anyone. This seems to be changing, but we still have a long way to go. Early on, I found relief in going to groups like Adult Children of Alcoholics, where participants share their life stories without and receive neither feedback nor criticism. Mutual self-help groups finally gave me the freedom to discuss the problems I was having openly, free from the threat of judgment. However, it's one thing to share with strangers and quite another to share with family and friends. When I've tried to share my story, I've met with responses like, "You just need to toughen up," or "We all have our cross to bear." Because I'm a white woman, many assume that

my racial privilege insulates me against all forms of suffering. Since I supposedly have it so easy, I have no right, evidently, to "complain." The message, whether explicit or insinuated, boils down to "Just shut up."

According to the International OCD Foundation,

OCD affects men, women, and children of all races, ethnicities, and backgrounds. It can start at any time from preschool to adulthood, but there are generally two age ranges when it tends to first appear: between the ages 8 and 12, and between the late years and early adulthood. The best estimates are that about 1 in 100 adults--or between 2 to 3 million adults in the United States--currently have OCD. There are at least 1 in 200--or 500,000--kids and teens that have OCD. This is about the same number of kids who have diabetes. That means four or five kids with OCD are likely to be enrolled in any average size elementary school. In a medium to large high school, there could be 20 students struggling with the challenges caused by OCD.

Some movies made in recent decades have helped chip away at the silence and stigma surrounding OCD, raising some measure of awareness around OCD's existence and some of its symptoms. One such film, *As Good As It Gets* (1997), features Jack

Nicholson as an author with OCD who writes romantic fiction and is rude to everyone he meets. And yet, even as they've helped increase the visibility of OCD, such films have resoundingly failed to convey the serious suffering and pain involved. They often trivialize the disorder or render it comically without ever acknowledging that those of us with OCD are fully aware of how irrational our thoughts and actions are, but still unable to change. It's out of our control. Often, even with the benefit of treatment, OCD persists. Though there are ways to manage symptoms, there's no cure. Those of us with OCD are frequently tormented by intrusive thoughts and feel compelled to engage in repetitive actions to counteract or neutralize these thoughts. Some people who check things over and over, confirming that the stove is off or that they locked the door. Others must arrange the objects in their homes in perfect order, count things repeatedly, or wash their hands until they bleed.

The effects of my early bout of perfectionism and OCD have lasted a lifetime, I believe. I've struggled with anxiety and depression, hoarding and procrastination. My relationships with men have been affected, as I've sought comfort, reassurance and relief from worrying

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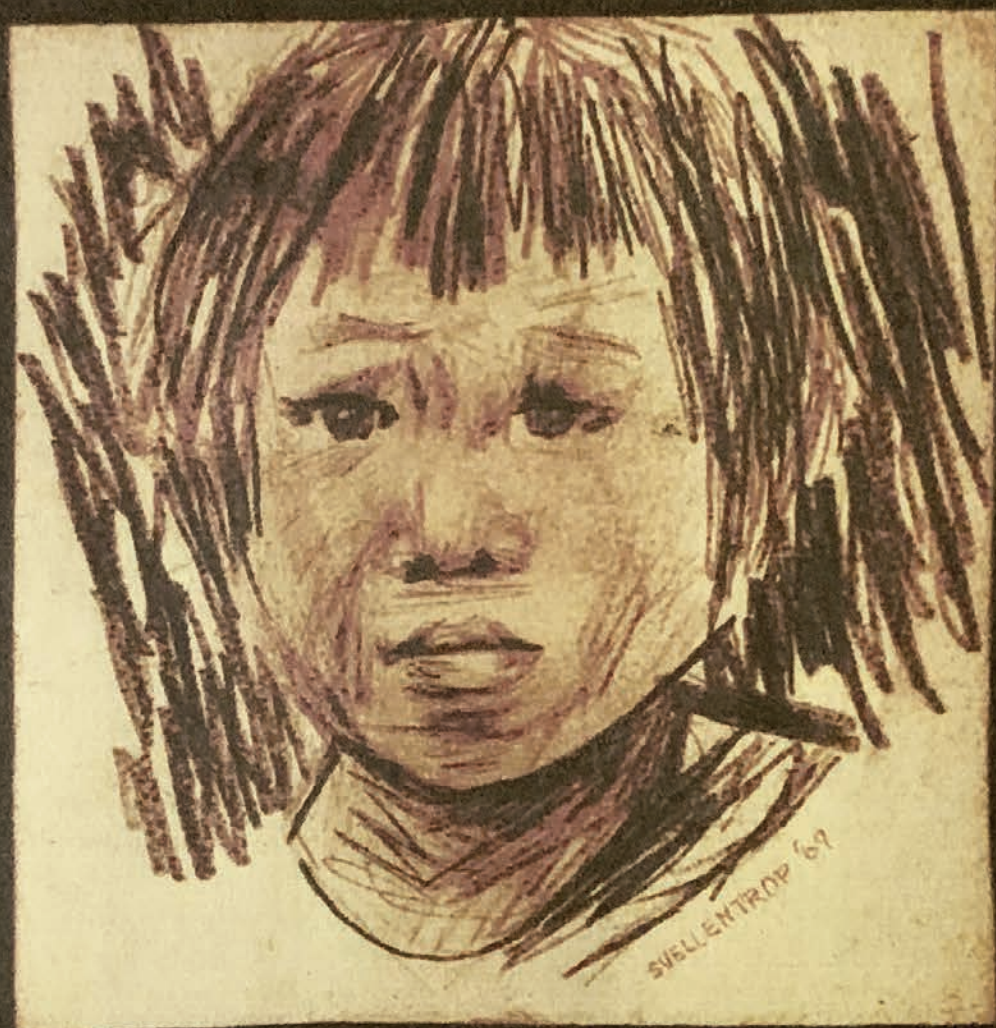
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and low self-esteem. Time and again, these relationships, and the limited succor they offered, proved temporary and only traumatized me further.

As an adult, I started seeking help and fighting back. I've tried many types of therapy and medications and found self-care practices that have greatly helped me, such as meditation, exercise, healthy eating, and finding supportive friends. I've developed a healthy spirituality over time. Although self-doubt waged a constant war against me in my own mind, I've finally come to recognize that nothing and no one is perfect. Lately, I've begun to study Gospel nonviolence and come to the realization that perfectionism is essentially an act of violence against oneself. I turned my anger on my inner bully and stopped paying attention to the negative thoughts it was sending me, recognizing them as passing thoughts that warranted neither my belief nor my attention. Slowly but surely, I've been learning to make peace with all parts of myself.

Despite the suffering it's caused me, I've found reasons to celebrate my OCD, too. I believe it's made me more sensitive to the suffering of others, especially children, and attuned me to the possible reasons behind others' behaviors. I could never stand to see classmates bullied and would often speak up to defend them. As a result, I've become a compassionate and intuitive person, traits that have served me well in my chosen career. As a master's-prepared pediatric nurse, I've worked for more than 45 years in public health, newborn ICUs, pediatric hospital units and mother-baby units. Though I've struggled with self-doubt and guilty feelings at work, too, I've found it deeply fulfilling to offer sensitive care to children and their families.

During the 1990s, an influx of migrants from Mexico and Central America brought days at the hospital when all the patients and their families spoke only Spanish. There were no interpreters available, despite the Americans with Disabilities Act having passed in 1990. I realized this was a dangerous situation, and since I'd studied Spanish in high school and college, I thought I might be able to help. I returned to college and took some classes in conversational Spanish and grammar, then became a certified medical interpreter and began interpreting at the hospital. By chance, I met a young medical doctor from Mexico who was here learning English. I successfully advocated for him hired to be hired as a night-shift translator. Helping in this way proved deeply gratifying, and I still attribute my capacity to do so, in part, to the compassion fostered by my OCD.

I believe, too, that OCD's helped make me independent-minded, not easily moved by group opinions different than my own. In recent years, my passion for human rights and social justice has turned me toward working for the abolishment of nuclear weapons. As long as nuclear weapons capable of wiping out all life on Earth exist, I realized, we're all on death row. Vladimir Putin's



invasion of Ukraine is once more raising the threat of all-out nuclear war. Kansas City, where I've lived for my entire adult life, is home to a plant that produces parts for nuclear weapons, called the National Security Campus. It makes or procures "85 percent of non-nuclear components that go into the [American] nuclear stockpile." In 2008, I joined a local group called PeaceWorks and two national groups, the Alliance for Nuclear Accountability (ANA) and Physicians for Social Responsibility (PSR). Informed by ANA's annual spring meetings to lobby in DC and its annual fall tours of nuclear weapons facilities across the country, I embarked upon a steep learning curve, educating myself about nuclear arms history, current data and the overwhelming environmental damage that nuclear weapons, whether detonated or not, have done. PeaceWorks began protesting at the KC Plant, and to date, we've incurred over 160 arrests for trespassing in civil disobedience actions.

Finally, art and music have offered additional positive outlets for perfectionism and OCD. Since childhood, I've loved painting and drawing, as well as playing the piano and saxophone. As an adult, I attended the Kansas City Art Institute and immensely enjoyed every minute of my photography and video major. I now sing in an African American choir, which I find deeply freeing and healing. I recently played a sax duet with a flautist in my church, and seeing the congregation's excitement put me in a state of bliss.

I believe there's power in my journey. I've learned to be persistent and to trust myself and depend on my own common sense, even when beset by irrational impulses. I had to be patient and carefully practice self-acceptance and self-love, and in so doing, I've learned to show that same kindness to others. I now understand that while it's necessary to question things in life, there's not always a completely satisfying answer. In learning to live with uncertainty, I've become a stronger person. Perhaps most importantly, I've come to appreciate my strengths and to value the many friends who've loved and encouraged me over the years. ■ **ABILITY**

Ann Suellentrop

IT'S ABOUT T.I.M.E. MUSIC FOR ALL

It's about time for music to be inclusive. It's about time for bands to be made up of people with disabilities. It's about time that music is for all. It's about time for T.I.M.E. a UK-based charity on a mission to bring music to everyone! *ABILITY Magazine's* Karina Sturm spoke with co-founder Rob Fillary and musician and T.I.M.E. participant Gary Walkers about the charity and their different programs.

Together in Musical Expression

T.I.M.E. stands for "Together in Musical Expression" and, as the name states, is an organization with the mission of enabling every person to express themselves through music - no matter their age, background or ability. T.I.M.E. offers music-based workshops, therapeutic and sensory-based relaxation sessions,





CAGED ARTS





songwriting workshops, instrument tuition and much more. It was founded by Marc Barnacle, Mike Barnes, and Rob Fillary and just received charity status right when the COVID-19 pandemic hit the world, so the organization had a very challenging first two years.

“Over lockdown, it was quite difficult to really do anything because of the nature of our job. We work with very vulnerable people; we go into care home settings; we go to disability day centers, and obviously, a lot of them were closed,” says Fillary, who is a passionate bearded young man with a bald head and a delightful British accent. “We did do some Zoom sessions for dementia homes, which is something that we’re really passionate about. Music for people with dementia is absolutely fantastic and quite effective, actually.”

According to Fillary, music is like medicine for people with dementia. “When we go into the homes, people put aside their walkers and walking sticks, and they’re up



dancing. After the first couple of songs, you got the old women floating with us, shining a bit of leg,” Fillary laughs, his face radiating joy. “It’s incredible.”

All founders have a music and community outreach background, and their programs have brought smiles to people in nursing homes, drug and alcohol rehabilitation facilities and mental health institutions. But what makes T.I.M.E. so unique isn’t the competence of the team behind it, but their philosophy that really everyone should be enabled and empowered to create and make music.

For example, they work a lot with people who are non-verbal by using different musical exercises to cause a response. “If we play an instrument to them, they’ll play it back. So essentially, we’re starting to communicate through music.” The instructors are trained in noticing the slightest change of body language to see if the participant is reacting to the music. Additionally, they are using varying adaptive instruments, like wrist bells and egg shakers, for people with limited motor skills, and in the future, T.I.M.E. wants to find more instruments or musical tech equipment to break down communication barriers using music.

Caged Arts

One of the people who found their voice through T.I.M.E.’s music program is Gary Walker. Walker is on the autism spectrum and has been involved with T.I.M.E. over the past seven years. He says when he interacts with the world around him, he often doesn’t understand what people say or mean. However, when he is making music, it’s different. “I didn’t use to commu-

“It allows me to be a part of the conversation – at eye level.”

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nicate. I was quite non-verbal years ago. But then I started to make music, and now I talk to nearly anyone,” Walker says.

The young man with the beard, who is always wearing stylish hats, and the Foo Fighters poster in the background refers to his band called Caged Arts, which exclusively has autistic members. The band formed at one of T.I.M.E.’s drop-in sessions. In the beginning, Rob and his colleagues assisted Caged Arts with song-writing; however, these days, the band writes songs, organizes gigs and records music videos independently from T.I.M.E.

Song Lyrics: The Artist by Caged Arts

*I don’t want to,
Trouble your mind,
With thoughts that I drew,
Gonna bring the page to life*

*The artist puts all their time,
Those hours that pass on by*

*What was blank then,
Has taken form now,
The canvas shows all,
Put yourself in the picture*

All these sleepless nights,

*Rest your eyes,
Before the morning arrives*

So far, the band has released three singles, with “The Artist” being the latest song written by Walker, who is also the lead singer and plays the bass guitar. He writes about “really, whatever comes to mind. I put my feelings down on paper.” Most recently, the band took part in Autism Got Talent in London’s Mermaid theatre - the biggest gig they ever played. Singing in front of such a large audience would be challenging for people with or without autism, but not so much for Walker. “That’s the one strange thing. I might get nervous after I finished, but I’m okay with all that sort of stuff.”

Besides being a songwriter and guitar player, Walker is also an artist. He has created all the cover art for the band, and some of his pieces are tattooed on his body as a reminder of how far he has come. What he likes most about T.I.M.E. is their Monday evening event, “INVOLVE Disability Nightclub,” a meet-up of people with and without disabilities to sing and dance together. It offers karaoke and live music, with the latter being Walker’s responsibility. “You get about 50 or 60 people in one room, and they feel safe. Normally, in public, you probably wouldn’t see the same people. There would just be that one person doing karaoke in a pub where they’re maybe not as safe as here,” Walker explains.

T.I.M.E.’s projects



Walker has additionally been part of another big project T.I.M.E. just released: The Basildon Audio Visual Music Machine (Open Labs 2021). Together with audio-visual artists Strange Pill, T.I.M.E. created an anthem, featuring a group of diverse musicians who all independently recorded music loops - a short segment of music that is continuously repeated in a loop - which later were fused and edited to become a 7-minute song with earworm potential, encompassing several different styles and genres of music. "We converted this old shop space into - I guess you could call it - a music hub. And people of all ages and all abilities came in to make music. Everyone was brought together through music, and it was really beautiful," Fillary explains. The project was a celebration of the diversity of the local music scene. "People just came in off the street and made music. They would say, 'I can't make music.' But by the end of it, they were recording loops, and they were singing or playing some drums. It was the perfect project for people that had never done music before or lacked confidence. At the end, they were transformed into musicians," Fillary states.

T.I.M.E. also recently finished a songwriting workshop with the Stroke Association where they tried to encourage movement and promote confidence and self-esteem to people who had had a stroke. "Over the years of doing this, I found that music is therapy, and there is no right or wrong of 'this is music therapy' and 'this isn't music therapy.' If it works for someone and it's benefiting them in a positive way, then, yeah, that's sort of therapy in itself, really. So I guess the approach we take is very flexible and versatile, which allows us to be quite free and experimental with music," Fillary states.

And they have written many interesting songs, whether those were about buses, Harry Potter, or a new sensory garden the participant built.

In the future, T.I.M.E. wants to focus more on people with dementia overall. "We've found from our experience with regards to that sector, there is a real lack of finances for external activities for things like music to take place in these homes," Fillary says. "In the past, some homes that we've been to have had to do fundraisers to raise money to pay for our services, and it shouldn't be that way. But our new charity status allows us to receive donations, which enables us to do sessions in dementia homes at no cost."

T.I.M.E. is giving a voice to all people, regardless of how they choose to communicate. Their organization is growing, and so are all their program's participants. But to end this article with Fillary's words: "We don't only have a work relationship, but we are also developing friendships." Because for the team at T.I.M.E., we are all the same: musicians.

If you want to support T.I.M.E.'s mission or become a participant yourself, you should. ■ **ABILITY**

Karina Ulrike Sturm

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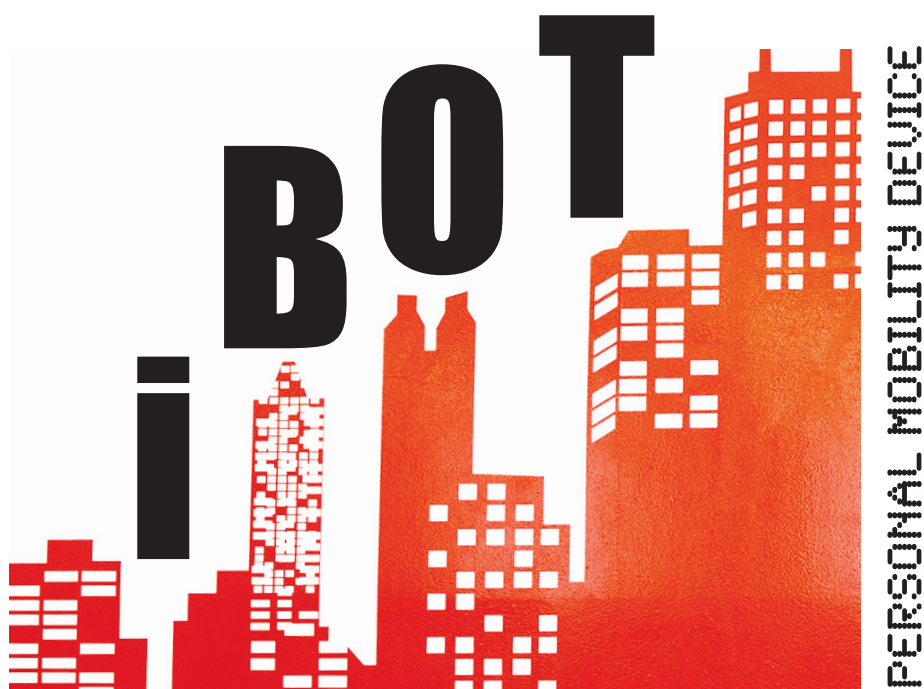
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Mobius Mobility team members Dawn Hameline and Megan Yeigh sat down with *ABILITY*'s Sabrina Bertucci and Denise Miller to discuss the improved design of the innovative iBOT. The personal mobility device utilizes advanced electronics, sensors, battery technology, and software so you can go where you want to go. Barriers to accessibility are too common out in the world. So curbs and stairs be aware—iBOT can roll up or down you!

Denise Miller: What are your roles at Mobius Mobility?

Dawn Hameline: I am an occupational therapist and an Assistive Technology Professional (ATP). I started with Mobius Mobility about four years ago. I'd always worked in a hospital, but I took my clinical skills to the manufacturing service side of things. What I do here is a lot of the education about the iBOT. I work with both users and clinicians. Both groups are required to be trained on the equipment. With the clinicians, I help them understand how the device operates in order to answer questions for their potential clients or patients. Also I explain other things about the device—who it might be appropriate for, who it might not be appropriate for, and what the different ways to use it at home are and in the community.

Megan Yeigh: I am not as fancy as Dawn. (laughs) I'm an engineer by background, by training, but I'm program manager for Mobius, so I'm running daily operations, getting iBOT out the door. That's my main role, and also making sure that iBOTs stay in the field and in service—the post-sale side. The other hat I wear is why we're here with you today: how do we raise awareness? How do we let people know that this is a technology that is available and is ready to be out in the world? How do we make it more affordable for people?

Miller: My husband is mobility limited and I was showing him the website. He said, "I don't believe it!"

Hameline: (laughs) Believe it!

Sabrina Bertucci: Could you give us a little background about iBot. What was the idea that launched it?







iBOT assisted climbing

Yeigh: The inventor of the iBOT is Dean Kamen, as you may know. He was in a grocery store parking lot and he noticed a gentleman in a wheelchair unable to find a curb cut, unable to get up the curb, or maybe it was down the curb, I forget which one.

Bertucci: Either way, it's hard!

Yeigh: For sure. Dean was walking right by him and saw that the man was unable to get to where he was going. That was the genesis of the iBOT. Dean said, "This is a problem I can solve. There's no reason that a person shouldn't have the ability to get to where they need to go in this world." That's what kicked off the iBOT program. Funnily enough, people would say that the Segway was the older brother of the iBOT, but it's actually the reverse.

The FDA regulations for medical devices are so long and stringent that in the process of developing the iBOT, Dean said, "OK, we can use the same balancing technology, take the seat off, take the rehab side out of it, and let's just put a little go-stick on it and call it a Segway." He sold that company off while the iBOT was still being developed and going through the FDA process.

Miller: So that is how the Segway came to be. So it validated the engineering of it?

Yeigh: Absolutely. The safety was there, obviously, because to put a people mover product on the market,

you still have to show that your safety has met certain ISO standards. The iBOT was launched in the early 2000s under a company called Independence Technology, which is owned by Johnson & Johnson. It was on the market for several years, but ultimately Johnson & Johnson pulled it from the market for a lot of reasons. One reason was that the product was really expensive and it wasn't a fit for a lot of people. So Dean was able to buy back the technology and the licensing from Johnson & Johnson. The engineering team got to work again and redesigned it, taking into account all of previous customers experiences and input.

What Mobuis sells now is the iBOT Personal Mobility Device—completely redesigned PMD, with the core technology still inherent. It still has all the same operating modes, standard mode for indoor ADA surface-type use, four-wheel mode, which is all-terrain, grass, gravel, sand, rock, snow. We have balance mode, which is the real eye-catcher—where you're elevating up on two wheels at eye level. The stair mode allows the user to climb stairs with or without the help of an assistant. All that technology is still there, but we've redesigned the battery life, the weight, and the transportability. The biggest change is adding the rehab seat to it, so now it is appropriate for a vast majority of the population of people who need a mobility device.

Bertucci: I have a question. It's about who the product would be appropriate for and not appropriate for.

Hameline: You guys are in this business, so you understand that it's not cut and dried. We do have some things

that definitely we use to direct who might be appropriate and who might not. There are a few things. A person needs to weigh between 50 and 300 pounds. That a rather wide range.

Bertucci: Right! That's great!

Hameline: Right now we are not able to accommodate a ventilator, so a person cannot use a ventilator. Because the iBOT is a multi-modal device, meaning it's like five devices in one, a person needs to be able to attend to the learning and go through the training process. They also need to be able to demonstrate some good visual-special skills, meaning, the device has the ability to be used to go over a five-inch obstacle. So if you came up to a curb and it was this high, let's say this is five inches, a person looks at that and they can see that it's five inches, that's great. If they look at something that's 12 inches and think that it's five inches that's a problem. Visual-special skills are about a person's ability to evaluate their environment and be able to make some of those estimates so that they can safely use the equipment to its ability. We look for somebody to have good special awareness. We have folks using the device who have lower extremity or upper extremity amputations. We have people with a lot of different neurologic conditions, like MS or cerebral palsy or spinal cord injuries. It's a wide range of potential users

The iBOT currently is not able to accept specialty controls, so if somebody uses their head or a sip-and-puff to drive to operate their wheelchair, currently we're not able to accept those types of controls. We look at all of those abilities. We try to manage those types of expectations in advance of somebody getting too far along in the process. Those are some of the things that we discuss with people.

The one other area where we spend time and make sure that people are on the same page about is when it comes to stair climbing. The iBOT can be used to go up and down stairs. It in and of itself does not climb the stairs, meaning you don't push the joystick and it doesn't go up and down the stairs. It takes some physical exertion or support to shift a person up and down the stairs.

Bertucci: Can every iBOT use this feature?

Hameline: First, if a person has no hand movement at all, they still can use the device to go over to go over the curbs, through the grass, go to the beach, and do all of the things the iBOT offers, balance mode, four-wheel mode.

But if they can't grasp a handrail, it only means that they cannot do stairs by themselves. The alternative is a trained assistant is able to help them go up and down the stairs.

Miller: Is the user pulling themselves and the chair up the steps?

Hameline: The best example I can give is this one. If you are in a standard kitchen chair and you tip backwards on those back two legs, we've all tried that, right? You can kind of balance there. If you imagine holding on to something and going back and coming forward and tipping back again, that's the motion, that's the movement that you're doing to help the device to climb up and down the stairs. It's more tipping backwards. It's not necessarily pulling yourself up the stairs.

Miller: That's a good analogy.

Bertucci: Yeah, that's interesting. May I ask a question?

Hameline: You keep going, Sabrina! (laughs)

Bertucci: (laughs) I was wondering, because I've always wanted to go on the sand. I have a wheelchair, I'm sure you guessed that. It seems that the iBOT can go on any surface, right? Sand, rocks, and that's great. My brother has a cobblestone driveway. It would be really helpful to go down that. In terms of slick surfaces, such as rain, I did see it on the website, but I was wondering if it's hailing or storming, that would be inconvenient, right?

Hameline: Sabrina, I love the questions that come from people who use wheelchairs, because you've run into other problems. I know exactly where you're going when you started talking about where it can go. It's more about, you're really wondering where can it not go, you know?

Bertucci: Exactly! (laughs)

Hameline: I think that—we always like to highlight where it can go. The device is designed to go over five-inch obstacles. It's essentially the full height of the palm of your hand. We're talking up and down curves, on the trails through the woods, where you'll have tree roots and rocks and dirt and all of that. All of this you would do with the device in four-wheel mode. Four-wheel is our all-terrain vehicle mode. You've got four drive wheels actively working that are able to push you through all these different obstacles.

The other reason it works so well is that when you're in four-wheel mode, the seat itself is a little bit higher, so your foot plate is higher off the ground. You won't get that foot plate stuck in anything, and those little casters on the front of the chair are up off the ground. So those don't get stuck. You have four big drive wheels pushing your through. That's what allows you to get through things without getting stuck.

You asked about slippery wet surfaces. When the iBOT is in balance mode the wheels need to maintain contact and have some traction with the ground below them. If traversing something slippery like wet grass or ice The device could slip just like you or I. If we slip, we may lower our center of gravity and maybe take a step for-



ward or back, to avoid a fall. The iBOT has a similar built-in safety system. If it senses instability or "slips" when in balance mode the device will automatically transition to put four wheels on the ground seeking stability.

Bertucci: I get it.

Miller: I have two questions. First of all, how do you clean the iBOT if you go into the sand and the mud? My husband's driven into mud with his power chair, and it's like, "Oh, man, why did you do that?" (laughs)

Hameline: And then he drives it into the house, right?

Miller: Right, right!

Hameline: I have to say, this is one of my favorite things about the iBOT. I have a lot of friends who use wheelchairs, and if I go to their house, there's usually a series of towels that they have to roll over before they get into the house so that they can clean the wheels, the base, and whatever got wet or dirty before they go back in the house. The iBOT itself, the power base, is a closed design, meaning all the electronics are totally sealed in there. You can just take a garden hose and just run water over the whole base, rinse it all off, and then drive right into the house.

Miller: Wow! You sold me!

Bertucci: I want one!

Miller: Next question: How do the majority of the users use it? Four wheels on the ground? Two wheels?

Hameline: Gosh, everybody's different. One of the biggest things is the fact that a lot of people find that this one chair meets many needs. Instead of having an indoor chair, an outdoor chair and a recreation chair, they can do all that and more in one chair. It makes things easier. I am an occupational therapist, so I look at function. What it is that people typically need to do in their day? What is accessibility like? From that standpoint, people who are out in their community, four-wheel drive, four-wheel mode is one of their favorites, because they can get all over town without problems.

The other one is balance mode. People who are so tired of looking at somebody's belly button all day want to be up at eye level. They want to be received in a different fashion. It's a feeling that you get and how you feel about yourself, how you feel you're perceived. That's something different. Balance mode is another one for people who are again out and about, working in their community, communicating with peers and workers out there. That's typically the modes we see when people are out in their community.

Then going back into the house, you go into standard mode, and it's like your typical wheelchair. You can be in your house to do what you need to do there. I think stairs are good, but they're kind of that little added bonus, but that's not what the iBOT is totally about. A

lot of people can function in a whole new way using balance and four-wheel mode and never use stairs. That's an added bonus. Some people love it and it works great. Other people find it's not something they need to have and it doesn't change their ability to access the community in the way they want to.

Bertucci: What about narrow places like bathrooms or hallways?

Hameline: It's all about the turning radius. Depending on what mode you're in, whether it's standard mode, four-wheel mode, balance mode, they all have a different turning radius. In standard mode you have two wheels on the ground and two casters on the ground. In this point you have your largest turning radius, because we're using the majority of that space, and the device drives like a rear-wheel drive wheelchair.

If you're in four-wheel mode, we have four wheels on the ground and the tires are all working at the same time. It's a lot like scrub turning, so you have a really tight turning radius. From there, if you're in balance mode, it is like turning on a dime, because you only have those two wheels. Literally, it's like a little ballet pirouette. You are so tight. It kind of depends what mode you're in.

Miller: Do you do road shows or anything like that? The pandemic probably stopped any type of marketing effort that way.

Hameline: We've barely been to any in-person events. They're just not happening.

Miller: How do people find out about you?

Yeigh: It's a great question. It's part of the reason we're doing this interview. For the first time, we've felt comfortable spending some money on advertising. Our philosophy has been, keep it super-small-scale, and keep that grassroots feeling of letting iBOT users tell other people. Because if we went out blazing with a sales course and huge branding and huge shows, we would just be jacking up the price of the iBOT for the people for whom it's already expensive. I think the thing to know is that what you're paying for now is purely the technology. We are not using any distributors for the same reason of not having another mark up tin price for the iBOT. You're paying for the technology, for the quality of the product as it is. This is the first year where we've put aside a small budget for some marketing and advertising, but as you can tell, we're still doing it all ourselves internally. We haven't hired marketing or sales. We're just—Dawn and I are—

Hameline: You're lookin' at it! (laughs)

Yeigh: We're very sensitive to the affordability piece. We feel that—medical equipment is outrageous for populations that are already strapped in so many ways.

We're working really hard to try to keep that costs down and more manageable. We've got this small team. We're trying to do it all. We do a lot of virtual support for people virtually, as that helps to keep the cost down.

Another example is we have new users who can't travel to us and they need to have a trainer, like Dawn, go to their home. I spent almost six hours the other week figuring out how to get more affordable rental cars for us to go to their homes, and we're spending \$1,000 on the rental car. Rental car prices are absurd right now.

Miller: Oh, they've gone through the roof!

Yeigh: And I'm on the phone with rental car companies saying, "Can you help us out here?"

There are some things we've been doing that I'd love to highlight. First of all, we have two national credit unions who have offered financing for iBOTs at rates that are almost as low as car payments right now. That's been enormous for us. That means that someone even on a fixed income can find, maybe with some nonprofit help as well for a down payment, an affordable rate that they can pay for getting a device that's better than whatever insurance will cover for them. We also work with non-profits and fundraising organizations. And many VA facilities have covered the iBOT for Veterans—we encourage Vets to go to their local VA and inquire about the iBOT and schedule a seating assessment.

Miller: I'm going to raise my hand here. The elephant in the room: does Medicare or normal insurance cover it?

Yeigh: Some insurances do cover it, private insurances. Medicare and Medicaid to date have not. That's an issue we would like to work on. It takes almost an act of Congress to make it happen. It's something we're committed to, but I don't see it as a short-term goal, which is why we have these financing options in place and why we work with nonprofits, to help make it affordable. Private insurances are covering it. We are seeing that once one insurance covers it, the others start to follow on. We are seeing that to a certain extent. "OK, Blue Cross/Blue Shield of Massachusetts signed up, and now Blue Cross/Blue Shield of New Hampshire is coming on board." So we are seeing that to a certain extent.

But even once Medicare and Medicaid are covering it, there will still be a huge cost share. You're aware that there's a huge cost-sharing component with Durable Medical Equipment (DME)—that is the ugly truth of public insurances. We will still need affordable options once we have that as well. Because if you have a 20% co-insurance, that's expensive.

Miller: Please tell us how much it costs.

Yeigh: The base price is around \$32,000, and that gets you an entire unit. What drives the cost up from that is



if you need a special seating component. That would be special—

Hameline: Like lateral supports or thigh guides. Those would be additional. But we're talking about a back, a seat, arm rests, leg rests, tie-downs, securement points, all things like that.

Yeigh: Unlike other wheelchair manufacturers, we don't start the price at \$5,000 and then charge for each individual thing on top of that.

Hameline: The other thing to know with that is, the base itself comes with all those different modes we talked about already built in. If you don't want to do stairs, we can go into the computer and turn it off. But it's there. So if in a year or so you decide, "I've moved, I now lived where there are stairs everywhere, and I want to do that," we can go back in and turn it on. The same thing with balance. You can turn it on or turn it off, so everything is already there. You don't have to add a motor or switch to a whole new thing.

We use Motion Concept's ultra-low-Max seating. With that, you have a lot of customization, meaning that we can make the seat wider or longer, we can put on different styles of arm rests. Some of those things can evolve as they need to, but you can still keep that power base as it.

Miller: I'll bring Sabrina and my husband in for a fitting! Do you customize it that way?

Hameline: There's yes and kind of yes. If Sabrina came to visit us here in Manchester or we were in your area, we would try to make some adjustments to make it fit good enough so that you were good and stable in the iBOT for a demonstration. But then we might look it, if you're going to use this long-term, we should consider a back with more contour. Or maybe you need arm rests that are shorter because you're always at a desk. We would go into that kind of configurability. There's that fit in terms of what fits your body well.

The other fit is something we call "center-of-gravity fit" or CG fit. This is a unique thing to the iBOT. The device, as you go through the CG fit process, moves you while you're sitting in it in about five or six different positions. While it does that, it calculates where your center of gravity. Yours will be different from mine and from the guy across the hall who's six foot two versus the guy who's got huge shoulders. Where our center of gravity is is different based on how our bodies are built or configured. The device collaborates specific for you. That is what lets the device operate optimally outside, going over rough terrain, when you're using it to go up and down the stairs, because it's a perfect fit for you. Once we have done that fit, somebody else can't hop in the chair and use it as effectively because it's won't fit well.

Miller: That is similar to how cars work today...the computers remember your braking habits, and so on.

Hameline: And it's uniquely fit for you. There's no other chair out here that does that. I think that also

shows how you can optimize your ability to use it in a lot of different situations because of that.

Bertucci: I have a really bad tremor. Is there a different type of mode for that? Is it customized so that I—could you explain that?

Hameline: Is your tremor mostly in your hands?

Bertucci: Yes.

Hameline: One of the things we can do is through the joystick control. We have something called a dead band or like a tremor dampening—the joystick is proportional, so we can adjust it so that if you have a little bit of a shake, we can have it do nothing, it will be unresponsive. You have to get outside, you have to do a bigger movement for it to react. That is something we can do to control from a driving perspective. In terms of the center-of-gravity fit, when it tries to customize to your body, you would just be sitting there, and as long as your legs aren't kicking out, your arms aren't doing giant movements, it will be able to collaborate to you. Some of your small movements within that zone will end up integrating just fine.

Think about somebody having a seizure, where they have really big movements that would change their center of gravity that could be something that could influence how the device operates, particularly when it is in balance mode. That would be something we would have to look at and talk about how your body might respond. If you're going over the grass to watch your friends at a soccer game or something like that and you're bouncing around, if that tends to trigger a lot of spasticity, we might look to see what your response is and how that works for you.

Bertucci: It's pretty impressive! It looks pretty large, but given the things it can do, that would only be appropriate. Is there any way it can be put in a car? It's a hard question.

Hameline: It's not hard! It's a good one!

Yeigh: It looks big, but the footprint is actually smaller than most power wheelchairs. Power positioning wheelchairs have a much bigger base of support because you have that whole tilting action happening. The iBOT doesn't have that length and it doesn't need the stability of that base of support. It has a very small base of support because it's dynamically stabilized. It's much smaller footprint-wise than the average power wheelchair. And yes, it can go in a car. It fits in my Subaru Outback.

Bertucci: I love it! I want to have one! (laughter)

Yeigh: And it sits in the Subaru by the backrest is on a single post and it folds right down, and I then lower the

arm rests all the way down into their little joints. I fold the back rest down, take the cushion off and it folds down even further. We have what's called a remote mode, which we haven't talked about. When the device is unoccupied, you can use remote mode and drive from the joystick away from the device. There's a little extension cable that goes to the device, and it goes to a 20-degree slope, which is pretty steep. I use small four-foot ramps to go up into my Outback and it just drives right on up there like a little crab.

Bertucci: (laughs) That's great!

Hameline: It works great, because you do not need a modified vehicle, and if you travel, you don't have to deal with waiting for that one adaptive rental vehicle that somebody else might have out. It allows you to access a lot more vehicles. You do need somebody else to set up the ramps and drive it in, in most cases. The device has got to be unoccupied. But it drives up and it's more stored like cargo. Then you drive it back down to get it out. If we go to clients or clinicians in our area, that's what we do. We've been loading in it all of our different vehicles to take it places.

Yeigh: In August 2021, we received approval from the U.S. Food & Drug Administration to use the iBOT as secured Occupied Transport device in a vehicle. We have two methods for people to drive from their iBOT if they do want to have an adaptive vehicle or already have one. You can use either a four-tie-down system, just using tie-down hooks you're probably familiar with, or we have an easy-lock system that is customized for the iBOT. You can have that installed in your van or truck, your vehicle.

Bertucci: I just want to make sure I have all the points here. You can take the parts apart? I'm just wondering. I live in New York, and it's such a pain if I go in an Uber. Are you saying you take these different parts and then you go up the ramp into your car?

Yeigh: If you're going to take it like cargo in the trunk of your car, all you have to do is fold the back rest down and then it will use remote load to drive up. Remote mode is just like any other modes, you access it through the joystick and you can have whoever, the Uber driver, drive it up like in a video game into the back of their ride, if they have ramps. It also only takes two medium-sized people to be able to lift it, so if you don't have ramps, someone can lift it into your trunk. Dawn and I can lift it. It's not a heavy device.

Hameline: The average weight is 250, 260 pounds. I use a ramp to load the device in my Jeep. The back needs to be folded down, and that's the only thing needed to do to get it up into the back of the Jeep.

Bertucci: That's great!



Hameline: The other thing I love about travel is for people who travel on planes, I think we all know that that's a big area of interest right now for the disabled commu-

nity, because equipment gets damaged so readily.

Bertucci: Exactly!

Hameline: It's terrible. One of the things we've done to try to manage that is, we have a pretty quick release so that you can remove the joystick and put it in your carry-on luggage. Is there is chance that the arm rest will get ripped? Yes, there is. Will you get some scratches and dents? There's a chance. But the thing that will let you drive when you get to Disney World or wherever you're going, that piece will be all good and ready to go because you've removed it and you've taken that risk away, which is huge. Huge.

Bertucci: Huge! That's the part that would get damaged. And the airlines definitely don't make any effort to give you any money back.

Miller: I want to jump back. You had said the FDA approved it as a seat in a vehicle. Like, I could take out the back passenger seat and make space for the iBOT?

Yeigh: Yes.

Hameline: It's called occupied transport. That means that the wheelchair can be transported with a person sitting in it. It has to go through many levels of crash testing to be approved to be utilized in that fashion. Unless something says that it is approved for occupied transport, the intent is that the device can be transported but nobody's allowed to sit in it while it's in a moving vehicle.

Miller: Are any of iBOT users children or teenagers?

Yeigh: We have a couple of young kids, 14 or 15, two with cerebral palsy. We have a nine-year-old coming in

for a demo next week. I don't know if he'll be too young, we'll see.

Our labeling basically says that if your doctor is prescribing it for you and you're under the age of 18, that's fine, we can totally give you a device. But we need that prescription to work with a prescription medical device. Currently we don't recommend to younger than 14, young adult age.

Hameline: And they need to be at least 50 pounds. We say 50 pounds because that's what the device has been tested to, and the seating components that we use, I think the narrowest width right now is 15 inches. Again, that's why we're not into pediatrics, but we're using young people, for sure.

Miller: I know we're getting near our time to close, but what about training?

Hameline: Again, this is five devices in one. We're not just teaching a person how to use a regular wheelchair and just drive in and out of the bathroom. This is about, can you drive in and out of the bathroom, up to the sink, to the table, can you do balance mode and open a door and recognize what obstacle and slope is approved in balance mode? What about four-wheel mode? Let's teach you how to go over curbs. Let's teach you how to go through the sand, through the rocks. We do all of that type of training. And we also do stair training for one person, if they're able, by themselves, or we might train an assistant, a family member or a friend, to do that assisting if there's no handrail or if a person's not able to do it. It's a lot of training.

I think we are the only company, if I'm correct, that requires a driver's test at the end. There are two parts to that. There is a practical part that says, is the individual able to navigate obstacles? Are they able to manage slopes and select the right mode? Look at how they can use the device. And then there's a piece that's more oral questions. What would you do if you got stuck, if you lost power in such-and-such a situation? To make sure that a person is able to process and make good decisions around how to use the equipment and use it properly. When we have people come here for training, the entire

training takes about a day and a half, maybe a little bit more or less, depending on stairs. If someone wants to learn how to do stairs or if an assistant will be trained, it takes a little time to get a feel for that. Some people get it easily, and other people don't. We try to allow for enough time for that to happen.

Bertucci: Has everyone passed their driver's test?

Yeigh: Except for stair climbing, because it's such an advanced skill. We've had people who say they'll try it and they say, "This isn't for me. I don't need this." Or they might need an extra day of practice or some time with our clinicians before they get signed off. Stair climbing isn't for everyone.

Miller: And where is it manufactured?

Yeigh: Right here in Manchester, New Hampshire.

Hameline: We're pretty proud of that. Made in the USA.

I want to mention the Abilities Expos, we try to have some representation at expos so that people have the opportunity to do a demo and see it in person and get in it. It makes a difference to feel it. There is a facility out there called Casa Colina in Pomona, California. I've trained their staff there. We have a demo device in their hospital that they use for demo and evaluation purposes, and I do know that they're going to be present at the Abilities Expo out there.

We update our social media often, letting people know if we'll be in their area, and try to always tack on extra time to get an opportunity to get in and see the device. And clearly we need to try to get both of you in an iBOT to feel it. So keep an eye on our social media—we might be able to meet up sooner than you think.

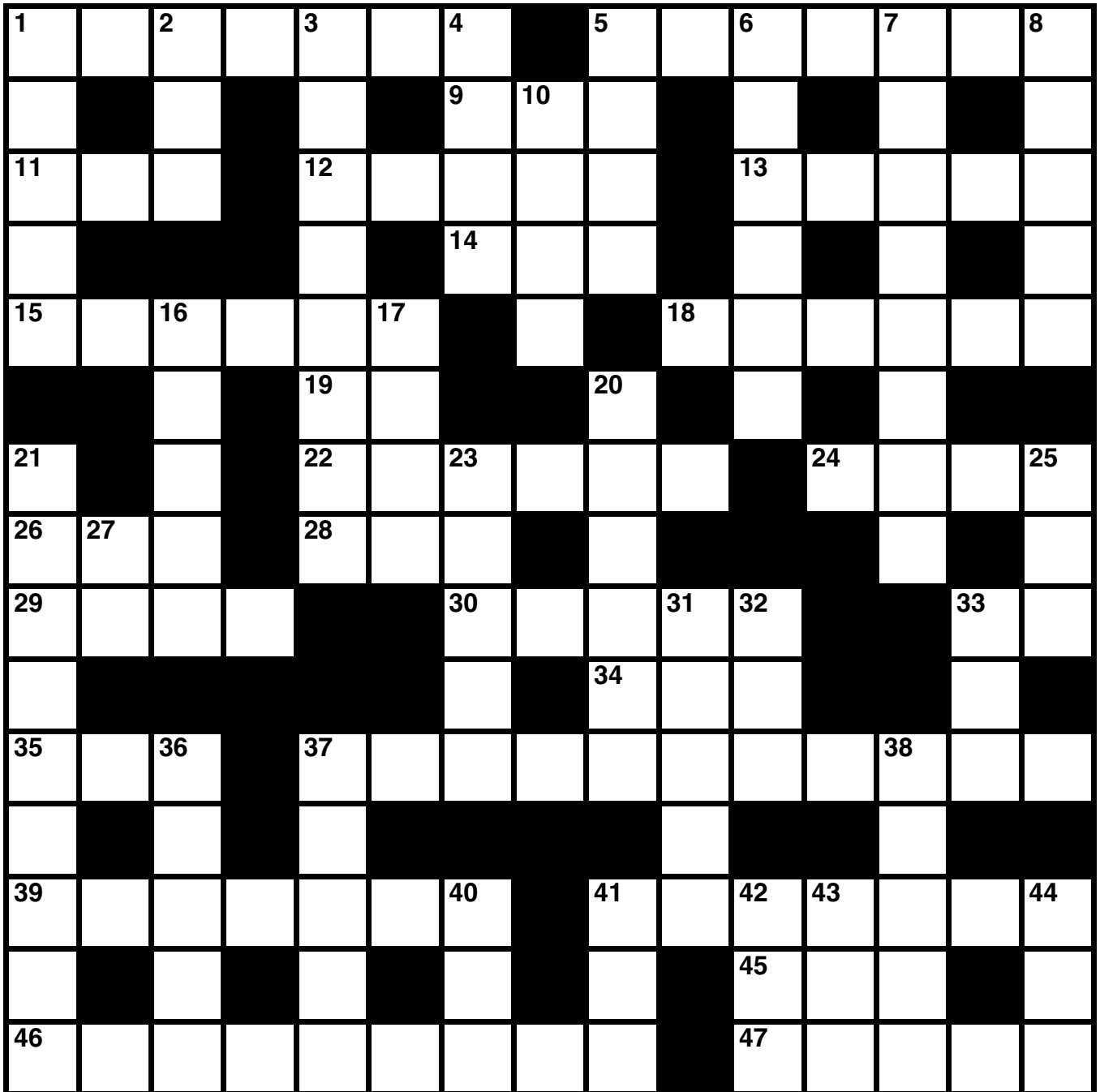
Denise Miller: Definitely put Sabrina in that iBOT!

Bertucci: Definitely! I can model for you! ■ **ABILITY**

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ACROSS

1. "Star Wars" actor who builds awareness of people with epilepsy and other disabilities in celebrity podcasts, Greg ____
5. Despite battling polio he honed his skills as a Chinese seal cutting expert, Wang ____
9. Home of the girl from Ipanema
11. First word of the lead actor in "Born on the 4th of July"
12. First deaf president of Gallaudet University, designed for people who are deaf or hard of hearing, __, __, Jordan
13. Main character in the children's book, "The Snowy Day"
14. Non-disclosure agreement, for short
15. 1950s classic film about a boy and a stray dog, "Old ____"
18. String instruments
19. William Penn's state, abbr.
22. "General Hospital" star wife founded a new jewelry line where all proceeds go to the Childhelp Foundation, John ____
24. "Almighty" one, in a 2007 film (actor first name)
26. Early afternoon
28. Longing
29. American Beauty flower
30. Terrific
33. Trucker's radio
34. Opposite of "post"
35. Cry at fireworks
37. Organization founded by Michele Erwin that advocates for wheelchair accessible air travel, 3 words
39. Blind lady who acted as a US cultural ambassador and also the Peace Corps, traveling the world, Elizabeth ____
41. Lady who runs Autism Connection of Pennsylvania offering art therapy, vocational training and education, Lu ____
45. Large coffee pot
46. Deaf woman from Bangladesh overcame challenges & helps other deaf people to live happier more fulfilling lives, 2 words
47. First name of the president who spent much of his life in a wheelchair

DOWN

1. Courageous
2. Old Testament book, abbr.
3. Condition where a person suffers from recurrent seizures
4. Smile
5. Discipline with stretching
6. Jacket closer
7. Founder of Women Enabled International to provide support and resources for women with disabilities, Stephanie ____
8. Guidance providers
10. Race car event, for short
16. "____ Worth Living" documentary history about the fight for disability rights
17. Evaluate
20. Publisher Pulitzer
21. Playful sea creatures
23. Financial backer
25. Catch
27. Evil doctor in a Bond film
31. Entertainment venue
32. Golfer's gadget
33. French wine term
36. Jeff Charlebois' specialty
37. Hawaiian welcome
38. Ben E. King classic, "____ By Me"
40. "Quiet!"
41. Cheerleading cry
42. Almond or cashew
43. Rap doctor
44. Produce an egg

answers on page 82

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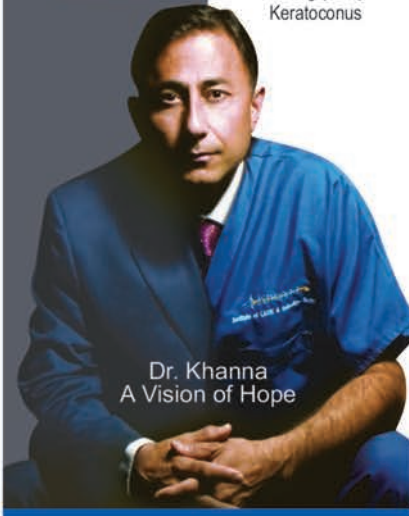
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