

CHRISTOPH GLÖTZNER LONG HAUL PAUL ASHLEY FIOLEK HUMOR — SQUEAKY WHEELS CROSSWORD EVENTS/CONF

ABILITY

ACCESS TRAX
A Path More Traveled

Keah Brown
#disabledandcute

The Journey is the Destination

DUSTBALL RALLY
a tribute to Dede Rogers

Accessible Airports
Hidden Disabilities

DURABLE ACCOMMODATIONS
by Diana Pastora Carson

Chandra Wilson

From *Grey's Anatomy* to
CVS's Mitochondrial Anatomy



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

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

ABILITY Magazine is published bimonthly

8941 Atlanta Ave. HB, CA 92646 (ISSN 1062-5321) All Rights Reserved

Send address changes to ABILITY Magazine, Attention: Subscriptions Manager
PO Box 10878, Costa Mesa, CA 92627; Chandra Wilson Issue Feb/Mar 2023

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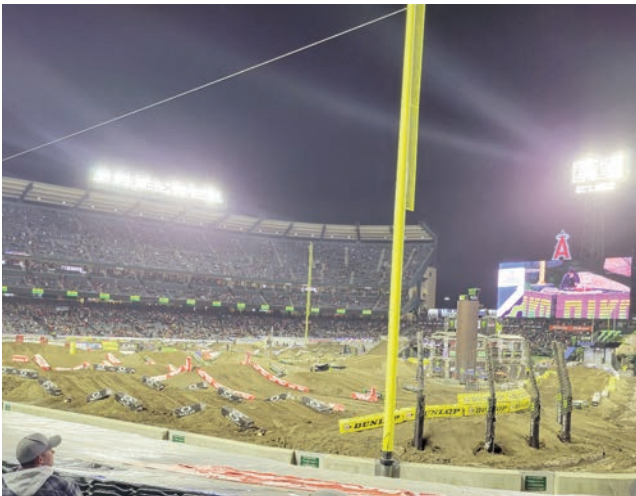
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Just got back from California, again! I had to go back and forth for both rounds of the SX races. It wasn't 2 trips I planned on making, but it was for an awesome reason! Yamaha asked me to be their brand ambassador which has been a dream of mine for some time now. I was so excited when they contacted me and asked me to come out and pick up a new YZ 125 and to watch the first SX race in Anaheim.



When I got my new bike we went up into the hills to ride it was so much fun we had a great time. We also got to hit Hanna sushi a couple of times, yum that is my favorite sushi restaurant! We went back for the second SX round in San Diego, because the Yamaha team asked me to be part of their presentation of their new bikes. The riders all met up at a K1 speed go kart track and I was introduced to all of the Monster Energy/Yamaha team. We all had such a blast racing go karts with everyone.

The drive out there and back met up with some problems 'haha', of course it was not smooth. When we started to head out we decided to stop in Vegas and ride out in the desert after that we would have a 5 hour drive to get to our AirBnB in San Diego. We had a great time riding and then loaded up everything. The drive was going well and then BAM everything stopped! A semi flipped over and was blocking both sides of the road. Ugh what was suppose to be 5 hours literally took 11!

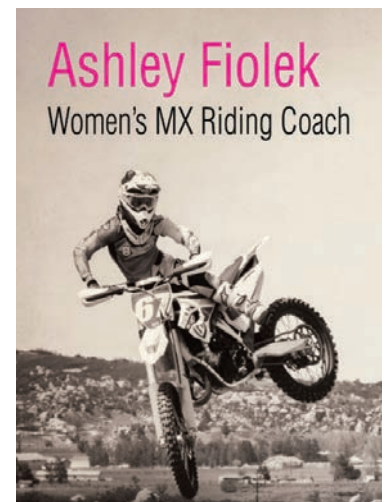
On the way back home we had to do the whole trip at once and of course there was a snow storm so a lot of

white knuckle driving. Oh well we still had a great time and the trip was definitely worth it.



We were going to ride at Fox Raceway with the Yamaha team, but times got messed up so we decide to drive up to Cahuilla Creek MX to ride some more on my new bike. I can't even explain how amazing it feels. It's so easy to control in the corners and the power is absolutely fast!

I haven't been to California for a couple of years now so it was nice to be able to get back and to ride on some familiar tracks. Hopefully, I will be back out there soon to ride some more and to watch some more incredible SuperCross races. ■ **ABILITY**



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The Future Isn't Curing Disability, the Future Is These Two Threatening Wheelchair Users We Found in a Weird Stock Photo

Genetic therapies and scientific studies have long been pointing toward a future where nobody is disabled, but a new stock photo indicates the future might be quite the opposite.

The picture shows two individuals who appear to be leading a strange cult of disabled supermodels. They are holding hands, but in a menacing way, not a cute way. Do they ever unlink those cold, oily palms? We don't know, but experts believe this gesture is a sign of solidarity, symbolizing a unification among disability communities in the future. Experts also note that the models' designer clothes and emotionless expressions are an indication of wealth and status.

You may think this is just a weird photo shoot that ended up on the internet, but it is clear that this photo

must be an artifact from the future. The most compelling evidence to support this idea is the fact that this disabled couple has clearly hired the lighting designer and camera crew from "Avatar." But under current societal conditions, a disabled couple most likely couldn't afford this, as it would force them to spend in excess of Medicaid's \$2000 asset limit.

While this snapshot gives a few insights into the future of disability, it has sparked more questions than answers. The photo might have you asking yourself, "Are those models actually disabled?" and "Would they be open to becoming a throuple?" We don't know, but we hope so! ■ **ABILITY**

by Steven Verdile





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DO TURKEYS FLY SOUTH FOR WINTER?

By the middle of January in New England, all the smart birds and retirees have migrated south, escaping the frozen world of winter.

As I typically spend the winter months riding to indoor motorcycle shows in places like Illinois, Wisconsin and Minneapolis, it has been nice not having to watch the weather channel for days on end looking for just the right time to leave, finding a path to circumvent the bad weather.

Cold doesn't bother me. I do have all the right gear for winter riding, heated jacket, pants, gloves and socks that get toasty as well as heated hand grips. I have ridden all day long, hundreds and hundreds of miles in temperatures way below freezing and survived to tell about it.

Snow, ice and freezing rain, are a different story. A motorcycle stays upright by balancing on two wheels; specifically the two center rubber strips of its tires. When the road gets slippery, it's pretty hard to keep the bike from sliding and well, losing control. Paying attention to changing temperatures as well as understanding the traction available are even more important in colder climates.

This year was going to be the first year I didn't have a snow storm story because between the middle of November and March, I only had one speaking engagement. It was just a three day trip, but it was going to add 2600 miles to my million mile goal of chasing the cure for MS. I was invited to speak at the 40th Winter Rally for a BMW Motorcycle Owners of America chapter. I thought *Winter Rally* was a funny thing to call it considering the campout was being held in the *Sunshine State*!

Florida, you know, where the beaches never close and the locals have never heard of The Burlington Coat Factory. Florida, where my greatly missed hummingbirds hang out with my snowbird elderly neighbors!

Those of us holding down the fort in New Hampshire had been having a mild winter, a few



cold mornings but warming up during the day. In fact, my lawn hasn't even frozen solid yet and any snow we did get turned to rain or melted in a day or so. My snow-blower was primed and ready, but by mid January, we hadn't had enough snow to use anything but a shovel.

A week before my ride south, the forecast showed my trip would be more of the same pattern, dry with temperatures starting in the low 30's for the first 600 miles of my ride. Perfect!

The day before leaving, it was a whole different story. It was in the teens, and with a few inches of snow expected. However, they said the temperatures would rise by 30 degrees overnight and the snow would turn to rain by the time I had to leave, around 4:00am. I don't know if you have ever watched 4 or 5 inches of snow accumulate on the road as you were packing saddlebags of a motorcycle for a 1300 mile ride 12 hours later, but trusting a weather forecast that seemed unbelievable, was a bit unnerving! Had I left a day earlier, I would've hit cold and the heavy rain the entire ride south, so I reluctantly trusted the meteorologists.

4:00am came and as I opened the garage door, it appeared they were right! It was pouring rain, but the snow was gone and it was 51 degrees! I couldn't have left happier. The rain stopped after the first three hours, but it slowly got colder the further I rode south. I repeatedly double checked my GPS to make sure I was headed south. I spent the night in South Carolina and it wasn't any warmer the next day!

I arrived in Lake City Florida about noon and it was barely 45 degrees! 6 degrees colder than when I left home! I felt like I got screwed!

My presentation went well, there were about two hundred hearty campers in attendance and hot adult beverages were being served. They passed the hat afterwards and collected about \$1500 for MS Views and News, the charity I work with that helps provide educational programs for people living with Multiple Sclerosis.

Originally clear and dry, my wife sent a text that I might want to check the weather for my ride home. She was right. It was going to be cold all the way from Florida to New Hampshire, AND the North East was getting sleet



and snow with accumulation after midnight. If I split the ride into two days, I would be stuck somewhere in Pennsylvania with a chance that I could not get home until the roads were cleaned up, possibly two more days before getting back home. I didn't have the time or want the added expense of extra hotel nights and food for this trip, and I had promised my dog I would be home after two sleeps!

I hung out some great folks, packed up my bike and finally got to sleep about midnight. Trying not to rouse or defrost the other campers, I snuck out of Florida at 4:00am when it was dark and... 24°F! I even put on my heated socks! I rode nonstop straight up the East Coast, through Jacksonville, Savanna, Raleigh, Richmond, D.C., Baltimore, Philadelphia, Newark and New York City without a single traffic issue. It even got above freezing for a few hours! I made it to Hartford Connecticut before the premature wet snow started and the last 150 miles home were interesting. I was getting tired, but because I know my bike's capabilities and my own, I decided to race the winter weather to make it home.

I made great time despite the wet, cold and snow. I was home by 10:00pm, riding 1260 miles in just 18 hours! As I pulled into my driveway, I glanced at my thermometer. It was a seasonal 31 degrees;

SEVEN DEGREES WARMER THAN WHEN I LEFT FLORIDA! ■ ABILITY

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ACCESS TRAX



There have been countless products created for accessibility, but few of them have the potential to affect society on such a profound level as Access Trax. That's because it's far more than just the only foldable, lightweight, durable pathway designed to increase wheelchair access over uneven terrain. And more than an awesome, environmentally friendly invention made of recyclable HDPE. In addition to bridging the gap between land and sea, it is also a perfect example of how one person can impact the lives of so many others. As a performer with a disability who's career started with a Christopher Reeve acting scholarship, I know what it's like to benefit from another person's passion. So I was excited when Ability Magazine give me the recent opportunity to interview Access Trax co-creator, Kelly Twitchel and learn more about her passion. Please join us as she shares the journey that led her to developing Access Trax and the path that lies ahead.

Toby Forrest: I first wanted you to know I've tried it before. It's very cool.

Kelly Twichel: Great. Where did you try it?

Toby: Surfing. I think they had it at one of the events for Life Rolls On.

Kelly: Nice.

Toby: Let's find out where it all started, the seed for the idea. What's your background? Where are you from? How did you enter to the world of disability, first and foremost?

Kelly: Sure. I'm based in San Diego, born and raised here. I really never left, even for school. I got my undergrad degree in biology here at San Diego State University. It was—there are two ways I describe my journey in the beginning. The typical way I describe it is when I go to grad school for occupational therapy, it started as a school project. But sometimes I add in that in everybody's journey in their life, there's always some sort of event that happens, whether it's in an instant or over a period of time, that shapes who they are and who they will become. For me, that particular event was when I was 12 years old. My mom suffered a massive stroke.

Toby: Wow!

Kelly: Yeah. It was two weeks before I started high school, and I woke up to paramedics coming up the stairs in my home. I ran down the hallway into her bedroom and she was on the bathroom floor and she couldn't move and she couldn't talk. I cradled her head in my lap and I was stroking her hair, and I said, "It's going to be OK," knowing that I had no idea if it was going to be OK or not. But you have to be that rock for another person you care about in that crazy moment.

Toby: Right. You switch roles.

Kelly: Oh, totally. Honestly, from the time I was 12 years old to—unfortunately, my mom isn't with us any longer. She passed away at the end of 2020. But I felt like I was the adult in the family since I was 12 years old. There are a lot of factors with that. I had to grow up in an instant. I had a lot of responsibility. How that event shaped me as a person is that I became more aware of what it's like to be in a family with somebody with a disability. Before that, I really didn't know. I didn't have that much exposure to it except for maybe my grandparents. But when you are in the same household, that's where it really starts to drive your thinking and your motivations for, "What can I do to make life more fun, more inclusive for this person I care about?" That's where my journey started into becoming who I am and caring about making the world more accessible and inclusive for people with disabilities.

Toby: So caring for your mom or having to start to, that was the catalyst for your empathy for this community?

Kelly: Yes.

Toby: And how did this idea come about of Access Trax, creating an ability for people who are limited to experience something that is otherwise unattainable or inaccessible?

Kelly: That journey started when I was in grad school for occupational therapy. Because of my experience with my mom I knew I wanted to be in healthcare, and I picked occupational therapy because I could be way more hands-on in part of a person's healthcare journey from whether they had an injury or an illness or they just were trying to learn a new skill. There are so many ways we can help. In grad school for occupational therapy, I was in school from 2015 to 2017, and during a specific class called Assistive Technologies, that was in 2016, the school project was to create something to help people with disabilities be more independent at some sort of task. It was very broad. My professor, Dr. Mo, Dr. Marie Johnson, challenged anybody in the class, "Can any one of your groups try to tackle the problem of helping adaptive surfers cross the sand at the beach in their wheelchair?"

Toby: That was so specific.

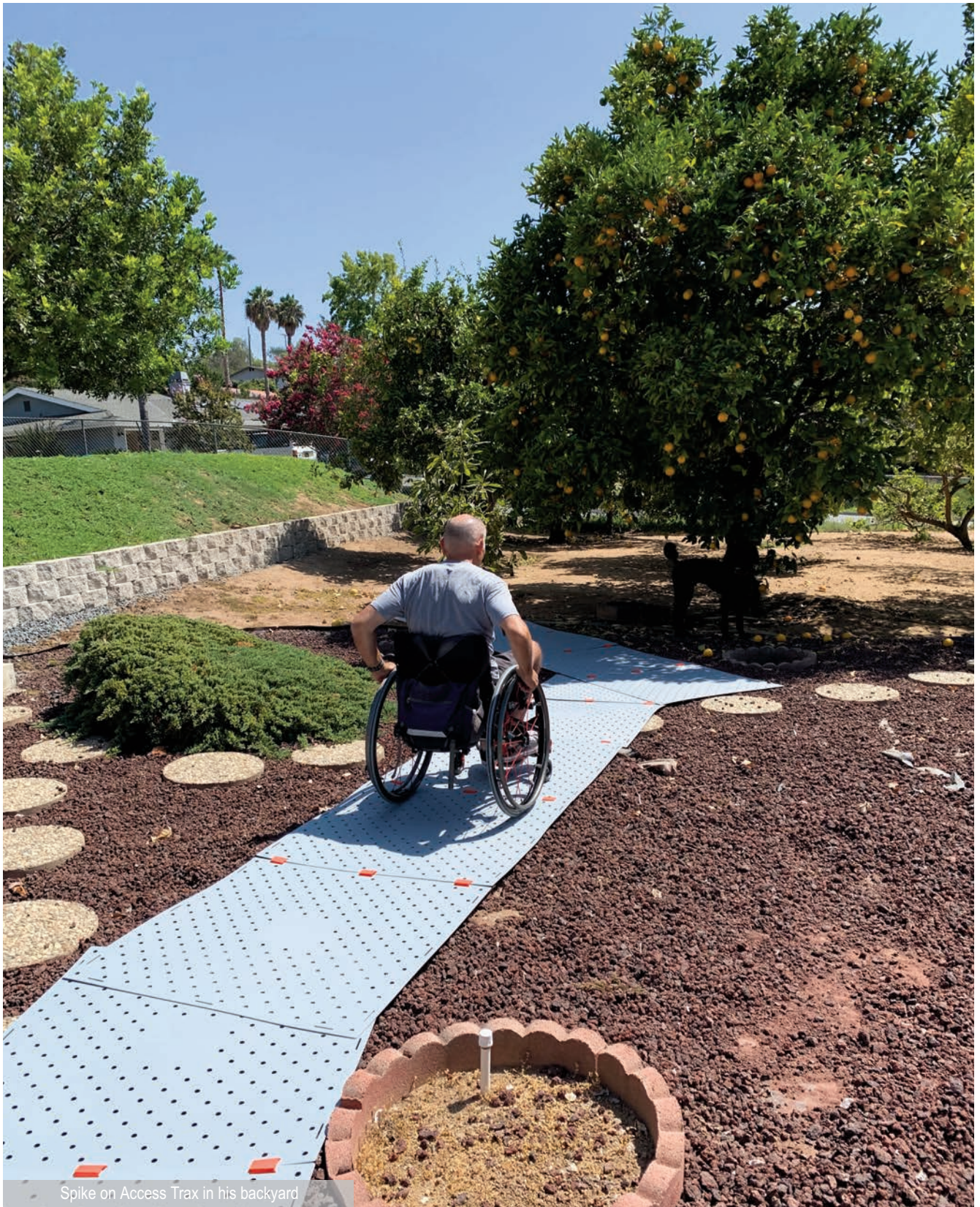
Kelly: She was a surfer. Contrary to popular belief or assumption, I am not a surfer yet (laughs). I always say "yet."

Toby: But you have the California look.

Kelly: (laughs) I mean, growing up here and starting a company that was inspired by adaptive surfers, you would think that. So my professor was a surfer, and she said, "I really would love for any of the groups to try this." So my classmate and I who were partners said, "Absolutely, we'll try it." We wanted to create something that wasn't just a wheelchair modification to help cross the sand, because if you create just a wheelchair modification, you're only helping one individual at a time. And everybody has different types of chairs, different customizations. I didn't think we could mess with that aspect of it. We wanted to have more of a universal design aspect, where if it's a portable access mat, it can help more than just one person at a time when you lay it down. You can see in the current design that people even benefit from walking on it, or parents with baby strollers pushing their children, or people have heavy equipment.

Toby: How many people hate hot sand, right?

Kelly: (laughs) Yeah. Or just getting sand in their shoes and socks. It's so funny. So my classmate and I said, "Hey, we'll try to tackle this on this school project." At that point, I had no idea I would turn it into a business. That wasn't our thinking, it was, "This is a really cool problem." We were so into trying to solve that problem,



Spike on Access Trax in his backyard

just being creative. We went to Home Depot three or more times in one day testing out what materials we could put together to provide enough traction so that the tires on their existing mobility devices, like wheelchairs, could be able to traverse the sand. We ended up zip-tying aluminum rain gutter covers in a track forma-

tion along a roll of plastic chicken mesh. So it's like chicken wire, but it's plastic, and it rolls up. We zip-tied these aluminum rain gutter covers, which are six inches wide and three feet long, in the pattern of where it would provide traction for the two main tires of a wheelchair as well as the smaller caster wheels.

Of course, we took it to the beach and made sure that we could put a wheelchair on it and that the dimensions were right. But the real magic happened when we got to volunteer at a surfing competition in Ocean Beach that happened to have five adaptive surfers that day. We had two about 10-foot sections of that matting, and we leap-frogged down the sand, so we had two individuals who pushed themselves independently in their chair as we laid down the mat. It was that moment when we heard from those folks and we saw the looks on their faces and heard what they said about it, that it doesn't matter what the product looks like, it doesn't matter that we threw it together with zip-ties. What mattered was how it made them feel. It empowered these individuals, who are grown adults participating in a competitive sort to get on the beach without being carried like a child, without dragging their bodies across the sand, which one surfer said that this was the first time in 10 years he had been on the beach in his own wheelchair.

The alternative was, one, they don't go, two, they have to use sub-par methods that don't provide dignity or independence, and we figured out—and I can't believe that something like this doesn't already exist that's this portable and lightweight and modular. We had to turn this into a business. There was no question about it.

Toby: (laughs) That's great!

Kelly: (laughs) Yeah! We wanted to help not only adaptive surfers but anybody with a mobility to be able to access outdoor terrain like sand at the beach or grass or gravel or snow, access the outdoors so that there weren't as many barriers in life. Because I understand that there are already way too many barriers to daily life for people with disabilities. If I can be part of a solution to make life more enjoyable and easier, that was really important for me.

Toby: It seems like a product that you started with such great intention has probably even more aspects and applications than you initially even imagined. When I saw this, I was like, "Oh, it's perfect for a wedding on the beach. Now you've got access for any event that could happen." I always think bringing stuff out to the beach is the impossible part. For me, being in a wheelchair, I've always just been lifted or I've jumped on someone's back and they've carried my chair out, and then you're just stuck in the one spot. But this is creating a literal environment that's accessible for all kinds of people. What are some of the other applications that you've found yourself dipping into or thinking about?

Kelly: You mentioned a good one, weddings and events. A couple of years ago I did my first beach wedding rental in Pacific Beach near where I live. It was so cool. I brought my camera and I got permission and I could hang back from the ceremony and take some

photos. It was so special to see the family members, maybe their grandparents or cousin or brother or sister, maybe the bride or groom, anybody can have a disability across their life span. It doesn't matter. To see that everybody's loved ones could come to their wedding, their special day, was really cool. Every year we get tons of rentals, and we ship the products across the country, like all the way to the Carolinas, Florida, for example, for those dream beach weddings that people have, and they happen to find us.

Other industries that have been super-interesting to me that I never would have thought is the film industry. You'll understand this better than most. When you're filming, it's never just always in a studio. You have locations. There's a lot of outdoor locations. And not only just using the Access Trax access mats to provide an access route for actors and crew members, but the film industry was super-interested in the ability for it to help them move their cameras and equipment.

Toby: I always say when they worry about accessibility, "The cameras are on wheels. All the equipment's on wheels," so honestly, they're pretty accessible places, when you think about it. But being in remote locations, where you need to build a fast, portable system of getting from one place to another, this seems perfect.

Kelly: Yeah. It's been super-fun. I don't get to be on set hardly ever, it's the equipment. I deliver it, they set it up and do their thing, and then I pick it up when they're all done. But I did get to go on location for a Marvel movie.

Toby: Wow!

Kelly: Yeah! To deliver. And it's so funny, because they have, like, secret code names for their movies when you're going. It so fun to learn things about a new industry. And I've worked with Lucas Films, too, for Star Wars.

Toby: Wow! It's amazing that that path, literally, you get to use "path" as your metaphor for life and for this business and how it leads you into so many different places. Like you maybe wouldn't have seen yourself stepping onto a film set, although you look like you fit in just great.

Kelly: (laughs)

Toby: Before you know it, you'll be in a Marvel movie.

Kelly: (laughs)

Toby: But your application, how did it start from the chicken wire and rain gutters and evolve into what is a—I don't know, a large Lego system at this point?

Kelly: (laughs) That's a great question! When it was



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the handmade prototype, that was when Eric and I, co-founders, were students still in OT school. We still had almost a full year left before we graduated. So we needed of course to get through school and field work and stuff. So I asked my school, “Do you have any grant funding or scholarships?” Because of course as a student you really don’t have a lot of free money lying around. I had to figure out how to pay for the prototyping and manufacturing of this so that we didn’t have to make any out of zip ties and plastic mesh.

My school happened to find out that the company that owned them at the time had a global business plan competition. We were very lucky, right place, right time, for a lot of things. This was one of them. It was the first time anybody from any of our University of Saint Augustine for Health Sciences school had ever competed in this competition. So we applied. We were the only finalists for the U.S. I want to say there were six finalists from around the world. We presented via Zoom back before Zoom got even more popular. (laughs) As we all know. It was so cool. They ended up not being able to decide a ground prize winner, so they split the winnings between the six different groups. So we got a little bit of money for the prototyping.

Toby: Oh, interesting!

Kelly: Yeah. And then the school’s board of directors

that summer invited us to present in Saint Augustine, Florida, at their main original campus. I had never been before, so of course I’ll travel and do this cool experience. They ended up surprising us with a matching check from that other grant.

Toby: Look at you!

Kelly: I cried. I was like, “This is so cool!” Because when you create something or feel like you’re on the cusp of something, it’s very daunting to know that the odds are stacked against you financially, resource-wise, time-wise. But to have another organization or person believe in you and to help you on your journey, that was really special. So that’s how we paid for the initial prototyping to get to our next-gen product, which we—it was a manufactured plastic product that isn’t the one we currently use today, but it was like an h-shape, and because it was an h-shape when we tested it out, we quickly realized that it wasn’t universal design, because it was very difficult for a person to walk on it, because it was a little bit wider of a stance than a normal gait pattern, and then it didn’t allow a person in their wheelchair to do a full 360-degree turn on any mat, because there were holes in it, and it would fall in the sand.

So very quickly I redesigned the whole thing myself. The product’s manufacturer we were working with at the time didn’t agree with any of my changes, thought I



Access Trax Makayla camping

was going backwards with it.

Toby: Wow! Although it's your thing? They wanted to come in make design choices based on their expertise?

Kelly: Yeah. Basically, what I think happened is, they found a previous patent that wasn't currently being used and they copied that design, which was the h-shape. They were supposed to be helping us with the design in general. They came up with this h-shape. It turns out, it looked exactly like something that was already previously patented, but again, it wasn't a product being manufactured at all. It's basically called "prior art" in the patent world. And when I changed everything, they didn't like that. So we had to cut ties with them and do our own thing. You learn through the process of starting a business and of course working with a product. You go through so many iterations. It

all comes down to, what does the customer need and what does the customer want? It doesn't matter what your manufacturer wants, and sadly, it doesn't matter what you want, really. Of course, it's all about designing for the people you're designing it for. And getting their feedback, getting their input constantly.

Toby: How did you do that? Did you have a little core group where you were like, "OK, I'm going to keep testing it with these people"? Or did you have a friend or someone who was in the community?

Kelly: We did a lot of volunteerism. We brought our mats, whatever prototype we had at the time, we would take it to an event where we knew there would be adaptive athletes at. In 2016, when we started this, again, as a school project, the adaptive surfing world and adaptive surfing movement had just started to take hold and

gain traction. Because 2015 was the first ever world adaptive surfing championship. In San Diego. I mean, how lucky, again, right people, right time?

Toby: Right attitude!

Kelly: Yeah! So we volunteered at all those events. And I still remain very supportive of the adaptive or para-surfing movement and community and sponsor a lot of events and provide the access. So that was huge for me, being face-to-face with actual users to see, “Does this work for you? What do you recommend? Do you like this? Would you buy it?” Really getting their feedback and seeing it first-hand.

Toby: Your intention was to be an OT and maybe affect a few people’s lives, or at least an individual, on a daily basis, but then you had to shift and go, “Now I’m a business owner/designer/marketer,” and you had to put the OT stuff on the shelf, I’m assuming, and focus on this?

Kelly: Yes, great assumption. Basically, when I graduated in 2017, I was working full-time as a clinician, because I had very expensive student loans to pay back, and every other moment I wasn’t working, I was trying to get this business started. At the time, in 2018, in February, I had been graduated for less than six months, my classmate and I officially started the business. And within four months, unfortunately my co-founder decided to take a step back because he was starting a family and he needed to keep his full-time day job with benefits. Which, I totally understand. That then put all of the weight on my shoulders, because if I didn’t carry this thing on, then who would?

Toby: Did you have a moment where you were like, “Oh, gosh, I’m putting a lot at risk here”? You were giving up that solid OT job. But you risked it.

Kelly: Yeah. I think there was no doubt in my mind that I had to keep this going. The sacrifice didn’t really hit me until a couple of years later. “Oh, my gosh, I am turning 32 years old this year. I don’t have my own car. I don’t have my own house. I really have sacrificed a lot over the years as far as salary and stability and things like that.” But back then, when I started this, there was no—I didn’t have time—I didn’t give myself time to think about the consequences and the risks, because the impact that I could have felt was too important, to help people. And you started to mention this. As an occupational therapist, as a clinician, I can help maybe 10 clients a day. But as a entrepreneur in assistive tech, I can help millions of people across the country that I may never get to travel to personally. That was very exciting to me, knowing that I could make an impact way larger than what I potentially could have as a clinician.

I’m not saying being a clinician isn’t amazing and isn’t

very impactful. It is absolutely, and just being in health-care in general. However, because I was starting this path, I felt that I couldn’t stop the momentum.

Toby: I know the same path in the sense of entertainment. I did my master’s in psychology.

Kelly: Oh, wow!

Toby: And felt I could affect a person or a roomful of people with psychology. But with entertainment, you can affect a world of people. But I find this amazing, because I’ve lived in Florida, I grew up in Hawaii.

Kelly: Really!

Toby: Yeah. Surfing was my first sport. I’ve done adaptive surfing. I’ve spent half my life in a wheelchair, half without. The beach was a place that I loved and is now a place that is frustrating because you go and you only can go as far as the parking lot will allow you, or the bike path. But this was always an issue where I thought, “How come they don’t have something?” And you obviously came in and solved the big question mark. The other question mark is, it seems like a lot of material is required in order to make an inaccessible space accessible. You’ve got to bring in pallettes of materials? How does that work? Do you have to haul that all in by yourself? Do you need a team?

Kelly: (laughs) Good questions! There are a couple of ways to do it. If it’s a family or a nonprofit that’s putting on a short-term event, maybe for a couple of hours, the mats themselves, each smallest unit is a 3-foot by 3-foot square that’s only an eighth of an inch thick. They only weigh 5.2 pounds each. When you’re doing, let’s say it’s a family, you don’t have to buy as many mats as the actual distance you’re going to go. Most families get between five and 10 of our mats. We do have a shoulder carrying strap that you can hook the mats to because they accordion-fold and stack into a single pile. So if you’re carrying five mats, it’s about 25 or 26 pounds. You can check that as luggage on an airplane, so when you’re traveling you can take it with you. So families have specifically purchased my product when they’re going to Hawaii. It’s pretty cool.

Toby: All you really need is two, right? One to be on, and another to move, and if you really needed to travel and you were going to go to the beach and want to be able to go anywhere, just have two of them and you’re able to access wherever you need to be.

Kelly: Yeah, you don’t need a whole lot. The reason I say five is because when you have fewer than that, the person who is moving the mats have to do a little bit more moving. So if you have more mats and you leave them connected in two batches or two sets, they can drag those in front and it’s a little bit less work in the long run. And the other thing is, let’s say you’re leap-



Kelly Twichel unfolding Access Trax on the beach

frogging the mats down to whatever area on the beach where you're going to hang out, typically you want to create a platform out of those mats so you can turn around and adjust yourself. Let's say the sun moved 30 degrees, you want to turn because you're hanging out, lying out in the sun. That way you can have a little bit more movement freedom when you get to your destination. But yeah, the concept is there. You only need a

bare minimum of two mats if you have a small standard manual chair, for sure.

Toby: Some of the questions that would maybe come up for a user would be, how close can I get to the water with the mat? Does it float?

Kelly: Yes, it does. Because plastic is less dense than

water, it does tend to float a little bit when the waves come up. We don't recommend leaving the mats untended at the shoreline when the tides come up. (laughs)

Toby: Or they float away.

Kelly: But in general, let's say it's an event that will be happening all day or all week long, you can leave the mats out, especially when there's, say, 50 mats connected together in a straight line and you have a platform. Because they get connected, it's a lot of weights. The waves won't pull the mats apart and break them away unless they're super-strong. And you can stake the mats down for long-term use. There are poles in all four corners, let's say it's the National Park Service and they want to have these down for the whole season, they can do that.

Toby: And the interlocking system to connect the mats, is that something that is difficult to do?

Kelly: No.

Toby: Does it become stronger or looser over time, anything like that?

Kelly: The method of connecting the mats was definitely a head-scratcher when we started this project. We wanted it to be a system that was very easy to use and modular and still lightweight. When the mats are laid out and folded back up, we wanted them to accordion-fold so you didn't have to disconnect every single square every time. It kind of limited our ability to design something without an engineering brain. What's lightweight? What's inexpensive? What's flexible? What's resistance to the elements like rain and sand and salt? What is readily available?

We ended up consulting, again, adaptive surfers. "Hey, what do you think about this?" I remember Bruno telling us one day, "Go to a marine shop and just look around on what materials they have there, and you might get an idea?" And then he goes, "Wait a moment, a surfer leash. A surf leash is Velcro, so you know it's resistant to the elements, it's lightweight. And it's already something people understand how to use." So we started using industrial-grade Velcro.

Toby: To keep the mats interlocked?

Kelly: Yes. They're reusable. You can quickly un-connect and rearrange the mats and connect them back together using the same hinges. They last a long time, surprisingly. But they're also very easy to replace if for some reason they fail. It was an all-around really sturdy option. And although it's not the most beautiful-looking item, that didn't matter in the minds of our customers as much as cost and functionality.

Toby: You can chrome it out if you really need to.

Kelly: Yeah.

Toby: You've gotten to this stage. Are there plans for the evolution? Are you up at night, at 4 in the morning, like, "Oh, my God, I've got a new idea!"

Kelly: (laughs) Just to give some background, ever since I started the company, my North Star goal is to partner with the Paralympics in 2028, because it will be in Los Angeles. Once again, being at the right place at the right time. That gives me time to form those partnerships with organizations that help host the event. We've already started that. We serve the USA triathlon national championships, which happen in Long Beach every year in July. They're the ones who will be hosting the triathlon and para-triathlon at the Olympics. So we're starting to form those partnerships already.

Toby: The Special Olympics? Is that an option?

Kelly: I have reached out to a couple different folks in that arena. It's interesting. There has been a nonprofit that worked with a smaller regional Special Olympics event, and they've used the mats. There's differently value there. But I think more folks will use it and benefit from it at the actual Paralympics versus Special Olympics. Special Olympics is a lot more of the intellectual disabilities.

Toby: And it's also a little bit more contained in the sense of environment.

Kelly: Yeah. There's always—honestly, you could argue that almost every situation could benefit from having Access Trax.

Toby: Absolutely!

Kelly: (laughs) But when I'm thinking about really big, pie-in-the-sky long-term goals, it's the Paralympics that's the premier thing, for sure.

Toby: I was going to ask if that was a pinnacle for you.

Kelly: Yeah.

Toby: I do a bit of consulting and things like that, so when I do come across something, I will absolutely keep this in mind.

Kelly: Oh, thank you!

Toby: For events and things like that, where it is just not accessible, how can we make it accessible? And what's next for you, aside from the goal for the Olympics? Where do you take Access Trax? Is it Shark Tank?

Kelly: That's funny! I have wanted to be on that show. I definitely have a lot of people telling me to try out. But I think at this stage in my business, as big as I make myself seem on the Internet as a company, it's very humble.

Toby: It's you!

Kelly: It's me, and my husband works part-time helping me as well. I feel like Shark Tank would want to take too much of my company right now. I have a very much hard line that I need to have the majority ownership, so obviously at least 51%. And I feel like they would want to take 60% or 70% right now. So I'm waiting. We'll see. I think as far as the next step, this year specifically I'm really focused on doing product improvement in the design as well as lowering the cost it takes to manufacture this in general. We currently manufacture in San Diego and it's pretty expensive. I want to make it to where I can scale up on this without losing the vision for how to grow the business and introduce more products if need be and expand what I can do. So this year I'm focused on making the product's surface texture more non-slip, more texturized. I've received consulting that we made need to change the way we manufacture it. I'm looking to get either through just cash from business operations or a business loan or a grant to help fund creating the next prototype and then being able to launch that. That's what I'm focused on this year.

Toby: And I would assume another way people might be able to help support you, aside from using the product, renting or purchasing it, is by putting you in contact with things that will help reach out to as many people as possible that this product will affect, because then it will speak for itself. Like you said, you'll think of a thousand different applications for it. It seems like one of those universal products that starts out specifically for one group, like a lot of things for disability do. I know elevators were originally for other things but the reason they're everywhere is for people with disabilities. But the majority of people benefit them from.

Kelly: Yes. Exactly.

Toby: I loved when you said that the personal effect is what drives you more than anything, the fact that you see families being able to come together in a place where they couldn't otherwise.

Kelly: Totally.

Toby: Did your mom get to experience it or see some of your drive and success? She must have been proud of that.

Kelly: My parents, when I was in grad school, they moved to the Palm Springs area, California. I was still in San Diego. They didn't get to come to a lot of my

events. I begged them to come to one of my events. I was volunteering at I believe it was a Life Rolls On event one year. Or it could have been—no, it was the US Open Adaptive Surfing championships or the World Adaptive Surfing championships. I finally got my parents to come. Now, my mom had a stroke in 2005, and she didn't go to the beach again, and I didn't think about this, truly didn't think about this, but she hadn't been on the sand again until that event, where she walked on my Trax. She was walking with a cane, usually, very short distances, otherwise she was using a motorized scooter. So she said, "Yeah, I haven't been on the beach in many, many years, and I was thinking about it." That would have been 2017, 2018, I think. So from 2005 to 2018 she hadn't been at the beach and she was able to come on the beach because of my product.

Toby: And the inspiration was her, essentially, that was the seed for what you've now created that has affected so many people's lives.

Kelly: Yeah.

Toby: That's a great accomplishment.

Kelly: I feel like she's still watching over me and proud of me, because there will be the most random things that will happen and there's no way, the serendipity of it. And I always think, "Thanks, Mom!"

Toby: Right, take it!

Kelly: Yeah. It's so strange. I never really made that explicit connection until after she had passed. "Whoa, this whole thing is also because of her, me becoming a therapist is because of her and my parents believing in me." My dad, as much as they were very cautious, like, oh, my gosh, they were more aware of the risk in what I was doing than I was. "Oh, you're giving up a full-time job with benefits to do this?" But they still believed in me and supported my decision. My dad loaned me money when I first started the business, and I still have the piece of paper on my fridge right now that he wrapped the check in, the envelope, and it says, "Go, Baby, go! Love, Dad."

Toby: Wow, that's great.

Kelly: It's nice to know that especially if a close family member or family members support you, to know that people like that really made an impact in your life and influenced your journey and your success.

Toby: And now you're getting to pay it forward.

Kelly: Yeah, absolutely. ■ ABILITY

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The Journey is the Destination

DUSTBALL RALLY

a tribute to Dede Rogers



A bountiful soul, this article is in memoriam of Dede Rogers, the backbone of Dustball Rally. Her charity endeavors, including the El Paso Humane Society, El Pasoans Fighting Hunger Food Bank, Ronald McDonald House El Paso, Polo Real, and Child Crisis Center El Paso, speak to her altruistic nature and selfless spirit.

Throughout my life, Dede never failed to inspire me. Beyond her philanthropic pursuits, her zest for life enlivened those around her, every presence graced by her radiance. Even enduring her battle with Diabetes, having been diagnosed at age 17, under no circumstance did she allow her condition to overrule her life, "Nowadays there are camps and programs to help you learn how to give yourself injections and make good nutrition choices. Dede was given a pamphlet on diabetes, taught how to give an injection using an orange, and sent out the door to college. It was a sink or swim situation and she chose to swim. She never let it hold her back. If you asked her about diabetes, she was happy to talk about it, but she





Sunbowl Thanksgiving Parade 2008_ Leandra, Caitlin & Amaris Medley

never sought attention about it.” Isha Rogers Santa-maria, Dede’s sister, said.

Her cherishment of Dustball and its values fascinated me as I longingly anticipated my first Rally.

Because of my parent’s involvement with the Porsche Club, and the beginnings of Dustball Rally in 2005, naturally, I was exposed to their world. I grew up around cars and car people, every car show and meeting being hosted in El Paso, my hometown, I was there. In fact, the blaring motor on my dad’s old 911, Tabitha, used to put me to sleep in the backseat. I have vague memories of early Dustball meetings in El Paso, especially ones that Dede would go to. I was maybe 6 or 7 when I sat in her Porsche for the Thanksgiving Parade that Dustball was in, and with the top down, she let me sit atop the backseat. She used to take pictures (flash, in particular) of my brother and I at Porsche Club and Dustball meetings, and as we got older, she accumulated our growth and lives in her camera roll, up until last summer. Even though I was never around Dede as much as I had liked to be, it didn’t take much for me to know that she would always be someone I aspired to.

As I got older, Dustball grew as well. Events increased from 1 per year to 3, and sometimes 4. When I was around 13-14, I started to resent Dustball for being what would take my parents away from home throughout the year, even more so because I didn’t understand why, and I couldn’t go with them, either. Throughout high school is when it started to get explained to me Dustball’s basic concept and its depths: why my parents had to scout roads

before they took a number of cars on them, why they were taking notes at certain stops and directions, why they avoided highways, all of it. My parents began to share anecdotes, take my brother and I on scout trips, and even showed me videos from past events. Eventually, my angered confusion shifted to intrigue and excitement as my dad would talk about taking me on my first rally once I was old enough. I began to see Dustball for what it really is, a family, one I would soon be a part of. It wasn’t until my first event that I realized why my parents were so passionate about this organization, because I had a taste of it myself. Above all, it was made clear to me what Dustball means to people, cohesive with the standard of values by which my parents hold their work to. Immutable values that, over the course of 17 years, has bound a tight-knit community, tracing back to Dustball’s noble beginnings.

A completely modified maroon 1984 911 Carrera, roll bars, supertrapp exhaust, spent most of its time on track days with the Porsche Club in the early 2000’s. Auto-crossing, for Andrew Medley, was just another pique-of-interest activity that fed into his thirst for motor-sports. It wasn’t until Willy Williams, Force Recon Marine, needed a co-driver for his time-speed-distance rally on behalf of the Porsche Club in 2004 that early influences of Dustball were inspired.

“He starts telling me about his sports car rallying days... everything from off-road dirt rallies to the Cannonball Run and Alcan 5000,” Medley said., He recalls Willy’s “rally computer” and traditionally written instructions for directions: “the verbiage, everything was very specific... it’s almost like a code, you have to



PCA meeting 2012 (bottom right) Medley family & Dede

understand what you're reading to know which way you're going."

Coming from the racetrack to this concept served as the pivotal moment, enlightenment, that set the foundation for what Dustball Rally has become today. From the very first event, co-organizers Andrew and Leandra Medley, which ran through the Black Range District in New Mexico, their dedication and commitment to Dustball prevail. A witness to the demanding labor, time consumption and attention to detail myself, my inquiries fixated on, why? What makes an open-road, cross-country rally worth your best efforts, your livelihood?

"The people," Leandra Medley said, "seeing what it means to them, how it takes them away from work, you know, their daily lives. How it pulls them away from everything, but it also brings them together. Wholesome people. It's a different type of person who does Dustball Rally." Justifying that it isn't just about the cars, but the driver's experience, which is the key aspect in what makes a Dustballer a Dustballer. As Andy Medley notes, "It has to be understood that the journey is the destination." Interstatephobia, or the fear of boring roads, is merely a third of the trickled factors that embody the mental, emotional, and even spiritual effects of Dustball Rally.

On an event, you're essentially mentally detached from your actual life, leading to new perspectives, relationships, and the opportunity for travel. The mental preparation aspect of Dustball is essential in embracing the experience, for the open road and –most importantly–

the disconnect from reality for great periods of time. With no cell phone service and little to no connection to the outside world, combined with the task of figuring out how to get to the day's location to avoid being lost, the revitalization aspect of Dustball is achieved.

"Dustball has given me an outlet with like-minded people that provides me the ability to put aside the stresses and challenges of everyday life, not only during an event, but also in day-to-day life. If I'm not at a DB event, I'm thinking and looking forward to the next one, which is very positive for my psyche," said Dustballer Nabil EIDib.

Speaking to mental preparedness and the flow of disconnect, "When we all gather in the morning to get our driver's packets. That is when I go from reality to get ready for another fun and amazing adventure. Considering a long-distance road trip I had to prepare for many miles of driving," William Marquardt, Dustballer and car enthusiast, said.

Dustballer's are encouraged to 'Find Your Road', the coined phrase that is the broader seek that leads to higher purpose on a rally, comprehensive of all physical, social, emotional, and psychological experiences individual to every Dustballer on an event; therefore, cultivating the ultimate -unconventional-getaway. "Well, it's truly a vacation...when you're in a car for eight-to-ten hours a day and you're driving, that's all you're doing. That, in itself, is a vacation from your normal days... you really do have to concentrate," David Hartcorn, Dustballer, said.



This style of road rally finds that people who would have no other reason than Dustball to be on these roads and in these places discover not only combined undeniable elements of family and genuine camaraderie, but a distinct adrenaline for more. “DBR has had a positive impact on my mental well-being first and foremost because of the presence of positive emotions and moods at DBR is contagious and prevails long after an event is over. This heightened sense of being promotes living life to its fullest every day of the year. There is no room for sniveling!” Eldib said.

Camaraderie, being essential in Dustball, is a key principle that adds profound value to the experience. On collective commitment in enjoying the journey together, “The interaction with and social networking of Dustball family members is incredible, making an emotional connection with all these other wonderful people. That is one of the strongest things that has brought the family of Dustball together...it is what drives me to return time and time again...the love for enjoying the most beautiful scenic roads. Driving masterfully engineered vehicles. All at the same time enjoying it with like-minded

and inspirational people,” Marquardt said.

On the 2017 main event, from New York to Los Angeles, as a result of catastrophic engine failure in secluded southern Iowa, several Dustballers contributed to purchasing a 1992 Buick Roadmaster for Marquardt. One of many testaments to the genuine affinity and benevolence, Will was then able to cross the finish line in Los Angeles, the longest event in Dustball history.

Gimmicking, a long-standing tradition, allows teams to fully immerse themselves in the event. Though predominately optional, those who gimmick reap the benefits of a unique, challenging component that makes calculating your next location twofold mentally engaging.

Each element that makeup Dustball completes each other, forging unparalleled adventure. Medley says, “It starts as a hobby, but it becomes a meaning to life.” ■ **ABILITY**

by Amaris Medley

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Airports Embracing Hidden Disabilities

On the Spectrum. Once those three little words label a child, youth or adult, a new journey begins. A voyage, steps into the unknown world of a vast horizon. Those who guide these unique individuals always face one certain element: problems. We do know with the wonderful progress in today's world though, problems are overcome too and progress is made. Just like similarities exist in behavior or traits for those that have disabilities, solutions exist too in terms of inclusion, exposure and motivational reinforcements.

In terms of exposure, we all deserve to see more, travel and learn. The pandemic taught us that being motionless within your vicinity on a mirror's edge does not instill any improvement. We should never allow a mind or soul to deplete itself of the joys of traveling, learning and growing.

A mother traveling recently to London was pleasantly surprised when she discovered a pamphlet pertaining to "Assistance and Accessibility for Passengers with Disabilities". The transparent layer of anxiety of possible hassles and hurdles was immediately peeled away as Heathrow Airport offered an abundance of information on the topic.

More importantly, in conjunction with Heathrow's charity partners, a series of guides showing you what to expect at all of the different stages of the journey have been established. They include quiet areas to relax, as well as where you can find help in the airport if you require assistance on the day of travel. These simple guides are available not only online but also at each terminal for both arrivals and departures.



What is the Hidden Disabilities Sunflower? Heathrow



Here are some of the key examples that aid and align for an easy travel experience:

You have the option of informing your airline, tour operator or travel agent of your particular need at the time of booking, or at least 48 hours before your travel. Arrangements can be made easily, especially with as much notice given as possible.

Your particular needs are not restricted either while alerting the airport. They can range from an assistant dog to your own mobility equipment.

More importantly, in conjunction with Heathrow's charity partners, we have produced a series of guides showing you what to expect at all of the different stages of the journey. They include quiet areas to relax, as well as where you can find help in the airport if you require assistance on the day.

There are assistance help points for all those traveling with a disability or mobility difficulties. They are placed in various locations all throughout the airport, centered in plain sight of the travelers. The passenger can also find a map of these on the website which we will insert here as well, so the reader has a clear view of how visually effective these can be when carried along.

As stated online, at Heathrow they understand all passengers are unique and they do offer different levels of support tailored to those passengers' needs. For a hidden disability such as autism, dementia or anxiety, help is always at hand at the airport. Heathrow has specially-trained staff that will take care of such a person responsibly.

For example, anyone with autism or dementia can let the airport know to take special care of them by wearing a sunflower lanyard. Such lanyards are available upon request and at the airport terminals themselves. Wearing such a sunflower lanyard at Heathrow enables staff and employees to recognise a passenger with a hidden disability without needing to declare it. This allows for easier travel independently through the airport whilst knowing that if you need any additional support during your journey, there is an alertness amongst members. The lanyard is free and can be reused as well for future travels.

Hence Heathrow is standing out as an airport that operates an Assistance Service in every terminal to help people with not one but a range of disabilities and health conditions (both visible and non-visible). The common assumption exists that at an airport, there are staff that only assist with mobility issues, as the visual emphasis is on the wheelchairs and buggies. To know that the



Lanyard wearer at Heathrow Airport

scope is beyond it assures safety and security to all passengers with any disabilities.

Upon further research you will find that other airports, even though unfortunately not as yet all, but definitely more and more are introducing such measures for people with disability. The Changi airport at Singapore is one of them, and it doesn't just start and end with assistance for persons with reduced disability. That general norm of course is still existent, with staff and wheelchairs being there for you from requesting mobility equipment, getting to and from the airport as well as immigration and security screening.

But in addition, Changi airport also offers assistance now to people with invisible disabilities. Here are a few examples of these means and they can also be found on their informative website.

Traveling and navigating through an airport or any unfamiliar environment for that matter can be quite challenging for the neurodiverse. What helps in these situations is to be prepared and theoretically familiarize yourself with the journey beforehand. The upcoming circumstances are what might not be known but Changi airport has partnered with Rainbow Centre to develop the Changi Airport Social Story. This tool is similar to a slideshow that demonstrates each stage of the journey in

comprehensive pictures and words. As mentioned above, it is available online via their website and it outlines both the departure and arrival processes.

Changi Airport, just like Heathrow, also offers the usage of the sunflower lanyard for those traveling with an invisible disability such as anxiety, autism, dementia, etc. Additionally, they also have a Land Transport Authority's "May I Have a Seat Please" lanyard. This can be viewed as a subtle or an indiscreet way to indicate, especially to the airport staff, that you may need a little more help or time when going through the airport processes. You may collect a lanyard from any of the Passenger Service Centers/Offices at MRT stations, bus interchanges and TransitLink Ticket Offices. Links for them are also provided on their website.

Last, but not the least, staff popularly labeled as Staff Ambassadors can always be approached for assistance at Changi airport in Singapore. They are selected meticulously and have been trained by Rainbow Center to assist with those that travel with hidden disabilities. They are easily recognized and identified through the badges they wear.

Nowadays neurodiverse assistance is not a luxury, but a necessity that needs to be addressed with the same support, care and concern as medical assistance. It is vital



Supporting persons with invisible disabilities at Changi Airport

Behind the Scenes of Changi Airport

Supporting persons with invisible Disabilities at Changi Airport

that we all be aware of this fact so that we can chip in as well whenever needed. This is particularly essential at busy places such as an airport, where crowds, lights, noises and other elements can be very overwhelming.

“Making the Skies Friendlier for Everyone” is a motto for The Arc’s Wings for Autism®/Wings for All (Wings). This is a program that provides families and aviation professionals training that includes “rehearsals” as well as presentations on aircraft features and various protocols to successfully prepare them for the journey ahead. It was created by Charles River Center, an affiliated chapter of The Arc, in collaboration with the Massachusetts Port Authority. The beauty of this program lies in the fact that it is for both the aviation professional as well as individuals and their families. Various events are held for preparation and teaching methodologies.

What exactly is this airline autism program and why does it matter? How can you help? All these aspects are answered beautifully on their website www.thearc.org

Basically in a gist, the program helps alleviate some of the stress that people with autism or other invisible disabilities face when traveling by air. This is done by providing the opportunity to experience and learn how such individuals will react, cope and deal with different stimuli in the airport. A fulfilled life for anyone on the spectrum includes being in the community and therefore being able to travel to faraway locations for both work and pleasure. People with intellectual and developmen-

tal disabilities deserve it so much and they should be able to navigate air transit comfortably. There should not be any barriers that lead to hesitation or fear.

Non-visible disabilities need to be addressed as well, especially in today’s world where the awareness has increased and as well as the disability impacts. Anyone is entitled to help while traveling, whether it is a person with equipment or with dementia.

It always starts with the parent, the guardian or the traveler himself. Never be afraid to ask! Security and body scanners can cause reactions and anxiety. Research participants have done their job in making sure that the right people are there to help. It is a huge inclusive support to know that a place as an airport is there for passengers with disabilities beyond what was the norm before. Stress free travel can be achieved for anyone. A fixation on the simplicity of the passengers’ needs is important in public places. Though every individual may be different and have various abilities, and disabilities, the requirements to them can blend cohesively into simple provisions of assistance and help.

We do hope that over time, more such circular awareness causes customers with disabilities to attain help in the right way at common yet unpredicted places and times. ■ ABILITY

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DURABLE ACCOMMODATIONS

A Story of Accessibility, Struggles & Love

This article is about Joaquin Carson, a 53-year-old autistic man, and his family, and a life-challenging access need. I am his sister, writing with his permission to share this story.

11 years ago, our family won a 3-year court battle and was able to bring my brother home from 15 years of institutionalization. Joaquin continues to heal from the physical and emotional wounds inflicted on him during his many years of segregation and dehumanization.

Our family and team have worked hard to make his community living a great success. And the first thing we had to do was create an environment that would ensure such success. So my husband and I bought a home in Jamul, a rural area on the outskirts of San Diego County. The home is on 8 acres, and has a barn. My parents dipped into their retirement savings and converted the barn into an apartment for Joaquin. But it wasn't just any apartment.



Durable Living Room

Because Joaquin has complex behavior support needs, his home needs to be durable. So his custom-home and its contents are indestructible and easily sanitizable.

This means that there are no pictures hanging from the walls. There are murals painted on the walls instead. Appliances and cabinets are bolted down securely. Furnishings are durable and easily cleanable. Windows are shatterproof. His shower is designed without doors or curtains, but a half-wall instead. His bed is bolted to the floor and he has a wall cushion for a headboard to protect his head if he bangs it, which he does when he isn't feeling well. We thought about Joaquin's specific needs and designed his home to meet them. We describe his home as "Joaquinified." But really, the bulk of the design revolves around durability.

This durable environment has worked out well for Joaquin. During our 3-year court battle, we were told that my brother could not be included in the community because he was a "danger to himself and others." But we knew that if we provided access to the right environments and the right supports, he could be safe and successful in the community, and have a much better life quality.

Eleven years later, we've proven that to be true.

But we've been lucky. Had we not had the financial resources, education, connections, energy, and tenacity, we could not possibly have pulled it off. Our success is a culmination of privileges that we know many others do not have, which led to a life for Joaquin and our family that many families cannot even imagine. And yet, having Joaquin as my next door neighbor, with 24-hour direct support staff, in a community where he is loved and appreciated, has been not only life-altering, but I believe, also life-saving.

However, during the wildfires of 2020, his security and life quality, and his life, were challenged in a big way. We had to evacuate, not once, but twice. And then again, we evacuated once in 2021. During the evacuations, we realized that we had nowhere safe to go.

It's bad enough to have a natural disaster and to have to flee to safety. But when you realize that there is no safe place to go, it takes the terrifying experience to a whole other level.

We had no safe place to go. For us, "safe" meant "durable." We wanted to go to a hotel for privacy, so Joaquin could at least use the bathroom, which, with gut issues and behavioral complexities, can be a difficult process for him, sometimes lasting hours and

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Durable Bedroom

resulting in the need for repeated showers and cleanup.

But there was no hotel that was durable, hence “safe,” and easily sanitizable. If my brother were to be having a day of intense body dysregulation, even with maximum sedation available to him, hotel lamps and toilet tank lids would most likely be thrown. The shower curtain would be torn down. Unsecured furnishings would be damaged. Hotel carpeting could quickly become soiled with feces. We discovered that this perfect environment we had created for Joaquin at home was not accessible to him anywhere else outside of an institution.

Although friends reached out to make sure we were ok, and generously offered to let us stay at their homes, we knew that doing so would be unsafe as well. Other friends were making calls to hotels and agencies to try and find a safe place for us, to no avail. Even a local agency that serves adults with developmental disabilities, and that has durable environments (and happened to be shut down during the Covid pandemic while still getting paid by the government to serve our community) told us that we could not take refuge in their empty facility. That was a huge blow. We felt very alone, abandoned, and disregarded by society as a whole.

Fortunately for us, two out of the three times we evacuated, we were able to return home the same day. And the one time when we couldn’t return home, Joaquin was having a miraculously mellow day. He and two of his staff were able to spend the night in a local group home that happened to be vacant at the time. However, the home was not durable. The windows were glass, there were delicate furnishings, glass shelving, and wall-to-wall carpeting. On a bad day for Joaquin, the arrangement would have been a disaster of its own making. I could not sleep that night, worried about him and his staff; worried about the potential damages to the home; worried that law enforcement would be called, rendering him another statistic of a disabled person hurt or killed at the hands of those employed to protect and serve; and worried about what we would do the next night if he couldn’t return to his own home. To my great relief, firefighters were able to save our valley, and we returned to Joaquin’s safe, durable environment the next evening. Given that this 6-foot tall, 180-pound man’s body dysregulation can be extreme, we dodged a bullet.

Although Joaquin’s safety, and the safety of all people, is central to this article, the story would not be complete without acknowledging that lack of safe and durable environments in our community is a result of

ableism. And as all “isms” affect people’s lives, ableism is no exception. Obviously, first and foremost, it affects my brother’s life. And as his sibling and closest life-long relationship, it affects me.

Ever since these traumatic evacuation experiences, my own health has been affected due to the added stress of keeping Joaquin safe. Shortly after the first evacuation, I was diagnosed with vestibular migraines, resulting in episodes of vertigo, and I retired due to disability after 25 years as a classroom teacher. Aside from my health, travel to visit my sister and in-laws on the east coast, and my extended family in Spain, as well as any travel for pleasure has come to a halt. I am not comfortable traveling for any extended period of time, and especially during fire season. The fear of being gone during a time when Joaquin and his direct support staff would most need me to advocate on his behalf has taken over my life. While I’m getting mental health support, working on self-care, meditation, and stress management, the reality is that I still feel trapped. If I pursue family weddings, holiday gatherings, vacations, and even work travel to supplement my income, I do so at the risk of not being here for Joaquin and his dedicated staff should he need to suddenly evacuate. And for obvious reasons, although I would love to take him along with me, it is not possible. Again, we’d have no durable place to stay.

To some, this may seem like unnecessary self-torture, co-dependence, and wasted energy. Perhaps. But those reading this who have loved-ones who depend on them for safety and care, and who are 100% committed to their safety and care, are more likely to understand.

So being the neurotic sister that I am, I’m not just sitting around waiting in fear for the next incendiary event. I am using my energy to educate, to network, and to find solutions.

So far, in the solutions category, I’ve got the following possibilities:

1. Pray for Rain (in Southern California)
2. Buy an RV (an expensive experiment)
3. Collaborate with local, state, and federal agencies (in progress, fingers crossed)
4. Create possibilities with the hotel industry (let’s talk!)
5. Expand our interpretation of the ADA

So let’s take a closer look at the options.

Pray for Rain—Rain in Southern California in the middle of summer...you do the math.

Buy an RV—As our family evacuated, our dear friends jumped into action, creating a GoFundMe page that raised \$5,000. It was the kindest, most heart-warming gesture of support. Furthering the action so that we’d be “prepared” for the next fire, our father bought a

\$13,000 trailer with the idea that we could tow it away and have a private space for Joaquin to evacuate to. I traded in my paid-off Rav4 for a truck (still not paid off) so I could tow the trailer in the event of an emergency evacuation with nowhere to go. But for the next year, I was stressed about not actually knowing how to tow a trailer and hook it up to water and electricity. So my father sold the trailer and upgraded to a used RV that ended up costing \$22,000 and is sitting in my father’s driveway, just in case we need to evacuate again.

So you might be thinking, “Great. Problem solved,” right? But upon further consideration, is an RV really a solution?

The reality is that the RV is an expensive experiment. So even for just one day, it’s a stretch to call an RV a “solution.” Although it’s the most concrete possibility we have for now, it has many notable downsides when it comes to keeping Joaquin and his team members safe:

- Not durable nor easily sanitizable: We anticipate that it would need extensive repairs and replacements during and after Joaquin’s stay in it. And we are concerned about the possibility of him injuring himself and/or others in the confined space due to lack of durable features.
- No place to take it: Even with an RV, we don’t have an assured place to go that would be safe for Joaquin. An RV park would likely be too crowded, and not likely to tolerate loud, sometimes aggressive, sometimes destructive, (and sometimes naked) behavioral episodes should they arise.
- Lack of appropriate community connections: We do not have any connections to campsites or know of any private spaces that would ensure Joaquin’s dignity in the event of a behavioral outburst in a new environment. He would not do well in a crowded campsite. So we’d have to hope that a private citizen would open up their land to us, and we’d have to drive to someone’s private property, which depending on location, could be restrictive in terms of staff being able to drive there as well, due to distance and transportation.
- Water access: Joaquin takes multiple showers per day due to bowel issues and routines that involve his hands and body not being in full control. Unless we are hooked up to a water source, we will run out of water quickly, leaving him and his staff in unsanitary conditions.
- Operator ignorance: We are not campers. We don’t know the first thing about how to hook up an RV and clean out the sewage, etc. (apparently, there’s a lot to learn!)
- Short-term possibility: Joaquin’s behavioral dysregulation cycles depend on his health. So although he may have a few mellow days, if he were evacuated for an extended period of time, an RV certainly would not provide long-term safety or a sense of security.



Durable Bathroom

So, although I am relieved to have an RV as a “backup plan,” we’ve learned with Joaquin that the “best laid plans of mice and men often go awry.” His big, strong, dysregulated body often changes our plans.

Aside from the cost of an RV, and limitations related to

Joaquin and his support team’s needs, having an RV be the solution for us is also problematic in that it is not a reasonable solution for others. There are many individuals, families, group homes, and supported living agencies out there that cannot afford to buy a used RV in the case of an emergency, or like us, know that an RV

would not actually meet their access needs. So what is their back up plan?

While other families around the country are able to stay in disaster relief shelters, or book hotel rooms, and people like Joaquin and our family have no place to go for safety, it painfully feels like discrimination. I do understand that this discrimination is based in ignorance and is unintentional. However, it is still discrimination: unfair, unsafe, unchecked, and unresolved.

For us, an RV as a backup plan feels like trying to plug a leak in a row boat with your thumb. First of all, water still seeps in. And your thumb gets tired and sore and can't last for very long. Eventually, you just sink anyway while others whiz by in their fancy motorboats.

I have no intention of sinking. Collaborate with Local, State, and Federal Agencies In the hopes of not only staying afloat, but helping others do the same, I've been reaching out to heads of agencies and departments, spreading the word about the need for "durable accommodations." I have bent the ear of many federal and state agencies including the US Administration for Community Living; US Department of Health and Human Services Administration on Disabilities; US Access Board; California Governor's Office of Emergency Services; California Commission on Disability Access; California Department of Developmental Services; the State Council on Developmental Disabilities; and Disability Rights California.

While all of these agencies continue to be interested in and supportive of my endeavors and some have partnered with me in seeking real solutions, the initial feedback I received from a few individuals was, "I've never heard the term 'durable accommodations.' What is that exactly?" Had it not been for Joaquin, the concept would be completely foreign to me as well. So I say, "Welcome to our world." My parents perfected the art of durable accommodations. I inherited their inclusive and life-saving wisdom, and aim to share it with the world.

I don't fault anyone for not knowing that durable accommodations are an actual access need. Historically, people in need of durable environments have been, like Joaquin was for 15 years, institutionalized. So there was no need for durable environments in public spaces. However, now that our focus is home and community-based settings instead of institutions, we must acknowledge durable accommodations as an access need. And once acknowledged, we must take action.

Action is the only way to demonstrate that we actually care. Yes, individuals, families, nonprofit organizations, must broadcast this need. Speak this truth to the powers that be. And yes, social services agencies and organizations must collaborate, without delay, to come up with federal, state, and local plans for housing people with

complex behavior support needs during emergency evacuations. But dare I propose a more confronting, yet more inclusive, and less discriminatory idea for action? Create Possibilities with the Hotel Industry.

What if the hotel industry, or even one chain of hotels or motels, seriously took on hospitality as an "access for all" issue, and made a decision to have at least one room at each of their establishments be durable? It could still be comfortable. It could still be designed with beauty and brand in mind. It could still be used by all guests. But most importantly, it would be accessible to individuals with complex behavior support needs. In the event of an emergency, it would be a safe place to go.

I fantasize that with leadership from within the hotel industry, in this era of diversity, equity, and inclusion, the implementation of durable accommodations will spread organically (like wildfire), because it is the right thing to do.

Who will light this fire? Who will do the right thing? Where are the caring corporate leaders and business owners willing to champion widespread inclusive solutions? Let's not ignore this injustice. Let's not wait for governmental intervention.

Expand our interpretation of the ADA Title III of the Americans with Disabilities Act addresses access to places of public accommodation and services: Public accommodations must comply with basic nondiscrimination requirements that prohibit exclusion, segregation, and unequal treatment of people with disabilities. They also must comply with accessibility requirements for new and altered buildings and remove barriers in existing buildings, where it is easy to do so without much difficulty or expense. - Pacer.org

The intent of the Americans with Disabilities Act is to ensure access for all people. Many of us think of the ADA solely in terms of wheelchair access. Yet even with our current interpretation of Title III of the ADA, and implementation of accessibility standards, many wheelchair users still experience challenges finding accessible hotel rooms. Given these challenges, some might assert that we can't even ensure wheelchair accessible accommodations, so we should first work on fixing that problem. I say that both scenarios, one in which a person with a mobility disability cannot access a hotel room, and the scenario in which an autistic person cannot access a hotel room, are examples of "exclusion, segregation, and unequal treatment of people with disabilities." Both are injustices. We must be a united front to ensure that everyone's needs are considered and everyone has access to safe, accessible accommodations. ■ ABILITY

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Chandra Wilson

From *Grey's Anatomy* to CVS's *Mitochondrial Anatomy*

Dear theater, *Grey's Anatomy*, and everything Emmy nominated Chandra Wilson fans! *ABILITY* is thrilled to share our interview with Wilson. Born and raised in Houston, Texas, she is an upbeat, positive, light of a human. Drawn to the stage from a very early age, seems like theater was her first love and something she found joy in. Since her daughter's diagnosis, she has taken on the role of caregiver becoming quite familiar with Cyclical Vomiting Syndrome (CVS) and its mitochondrial associations. They've had a long journey of symptoms and multiple binders full of information, results, and a cocktail of treatments. *ABILITY*'s Lia Martirosyan had the pleasure of speaking with Wilson amidst her not uncommonly busy schedule of advocacy, acting, directing and much more.

Lia Martirosyan: Is that Christmas behind you?

Chandra Wilson: Oh, yes. We have to get Christmas started nice and early. November 1st the town goes up.

Martirosyan: There's lots of movement.

Wilson: Yes, yeah. There are fancy Disney trees, got to have that, Disney princesses. Mickey's on the sleigh at the top.

(laughter)

There's a snowman over there.

Martirosyan: Santa Claus flying around.



People Magazine Chandra Wilson and daughter Sarina McFarlane — 3-29-2017, photo by Chloe Aftel

Wilson: Mickey Santa.

Martirosyan: It looks like it's actually floating around.

Wilson: Just flying, right? Yeah, yeah! (laughs)

Martirosyan: Could also be the drugs.

Wilson: Well, there's that.

(laughter)

Martirosyan: Have you gotten around to reading "Grey's Anatomy"?

Wilson: I have a big gigantic copy of it that I got in season one, and I can admit to having flipped through all the pages (laughs) and looked at all of the artwork, the graphics. The reading of it, not so much.

Martirosyan: I wanted to bring that up, because I think most people don't know —

Wilson: —that there is a "Grey's Anatomy." Yes, I have the hardback binder edition, that looks real nice on the bookshelf.

Martirosyan: Quite a large book. I read that, Dr. Grey,

became the standard for illustrations of anatomy. However, in the show Grey's Anatomy my mom and my favorite character is Chandra.

Wilson: Aw, look at that!

(laughter)

Look at where we're starting, good, good!

Martirosyan: You're amazing on-screen. We love it.

Wilson: Aw, thank you very much. I'm crazy about her. I love her. (laughs)

Martirosyan: If you don't mind, I'm curious about the connection between the cyclical vomiting and mitochondria.

Wilson: Sure, yeah. My daughter is diagnosed classic cyclic vomiting syndrome. The contributing factor with her is mitochondrial disease, to the extent that because mitochondrial disease has to do with a disorder in the mitochondria, where at the cellular level, her motor is operating not at 100%. Her median would be, like, 65%, 75%. So if at the cellular level she's not getting the energy that she needs in order for cells to do what they need to do, then in cyclic vomiting, the sympathetic



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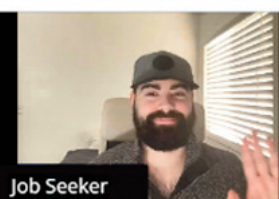
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Chandra Wilson and Dr. Richard Boles a press for Rock & Roll Marathon benefitting Cure Mito 2011

system shuts down, there's no energy supply there in order to do what needs to be done as far as the gut is concerned and any neurological connection that needs to send that brain signal to the gut to say, "Stop doing what you're doing." Her energy is already depleted at the cellular level, and this is a level that she doesn't even feel, because her normal may only be at 70%, so she wouldn't even feel that she was deficient. That contributes to the tendency to kick off into a cyclic vomiting episode. So making that discovery says that, "OK, so then you have to fortify that mitochondria with co-enzyme Q10 or L-carnitine, B2, those things, because her L-carnitine just runs through her body. We were able to find that out through testing.

It's really important to fortify those things, so that when that brain-gut connection doesn't want to speak the way it needs to speak, she at least is fortified with the energy to be able to bypass that signal.

Martirosyan: Did you discover this through genetic testing?

Wilson: Through genetic testing, that was making that mitochondrial connection. And also the fact that once she did receive a definite CVS diagnosis and she was initially placed on amitriptyline. The mitochondrial

cocktail was brought in right away, the L-carnitine, the CO-Q, the B2, and those things contributed to keeping her out of an episode. So if the cocktail was working, that was another signal that this was probably what we were dealing with. You could also see the energy depletion. Sometimes it would come before an episode, but certainly during an episode, in a way that she wouldn't necessarily notice that it was happening, because that was her baseline, where someone else would look at her and say, "She seems a little under on the energy."

Martirosyan: Is there a known trigger?

Wilson: In all these years we haven't been able to figure out a definitive trigger. When she started, she was 16, and it seemed like any time she would go into an episode, especially one that led to hospitalization, within a couple of days of being in the hospital, her menstrual cycle would drop. We made the connection that going into that premenstrual time is an energy depleter, of course. That may have been when her sympathetic system started to shut down. And when we introduced things like Depo-Provera to take away the menstrual cycle so that the signal wasn't ticking out, that was a time when she went two years without a cyclic vomiting episode. Even though she was still getting her menses, that signal wasn't there.

Wilson: But age, maturity, life circumstance change, all those things would come in, and that's not necessarily the signal any more. We haven't been able to pinpoint—we can't say, "We're going on this trip, you're going to have an episode." Or "The holidays are coming, you're going to have an episode." We haven't been able to make that distinction since she's been an adult.

Martirosyan: When there is an episode, are you now able to stop or prevent it from getting worse?

Wilson: Yeah. We have a good abortive protocol now, especially now that she's an adult, and because we are 13 years into her having CVS cycles, so there's a trust between her doctors and her and me to be able to use the medications that we need at home in order to abort episodes or at the very least, stop her from having to constantly go into the ER. As an adolescent or young adult, that trust wasn't there, so we always just had to go straight to the ER, which would usually end up in a hospital stay of five to seven days. That was happening month after month. It was debilitating to quality of life. She was a college student during that time, so since 2019 we've been on the abortive protocol that we're on now, so that we can hit an episode the minute (snaps fingers) she can feel that something is going off, as opposed to having to go to the emergency room, wait three hours, go through triage, get assigned a room, wait for the doctor to come in, hours and hours go by at that point before she would even get hydrated or get the first line of medication.

Martirosyan: I'm glad you figured all that out.

Wilson: And the good and the bad of it is, so you figure all of that out for abortive, for help to curb symptoms, but we still haven't gotten to the trigger yet, to how about let's not have these at all? That's what we're still working on. That's why I'm excited about the book that's coming out, "Cyclic Vomiting Syndrome and Cannabinoid Hyperemesis." It isn't necessarily to make the correlation between cannabinoid use and CVS, but showing the similarities between the type of nausea and vomiting that occurs with CVS that sometimes gets mistaken as cannabinoid use, especially with adults going into hospital situations, as something else to make medical professionals turn away and say, "That's just marijuana," or whatever. To be able to make those distinctions and teach medical professionals what those distinctions are and thereby be able to come up with effective forms of treatment.

Martirosyan: Is the disease considered rare?

Wilson: Not any more. I think we just went past the rare phase of it. I think the only reason that it had the rare title to begin with was because of doctors not exactly knowing how to report it and less rare in pediatrics, because at least you are compelled with your pediatrician, and the pediatrician is trying to work with the family. Whereas

adults, most of that care is coming from the emergency room, with your primary care physician not quite knowing what to do. So there were fewer titles associated with adult care versus pediatric care. Now all of that's changed, even in the last 13 years since my daughter was first diagnosed. It's global, not here in the U.S. Fortunately, there CVS associations internationally, in Canada, Europe, Germany, I believe, all talking with each other to say, "Wow, OK, I didn't think there was any place else that this was happening." All of the episodes for the most part, regardless of what people's triggers are, the presentation is so similar, the language is similar, the behavior is similar. And people are using words that they don't even realize they're using, like "conscious coma" and "level of lethargy" and "overwhelming, all-encompassing amounts of nausea." Everyone's using the same language, without realizing they're talking about the same thing.

Martirosyan: Incredible. Any stats on gender or race?

Wilson: What I know off the top of my head, though, is—you know what? I don't want to say it wrong. It's in the book "Cyclic Vomiting Syndrome and Cannabinoid Hyperemesis."

Martirosyan: What I was thinking about was, is there a trend that appeared with what's been reported to date?

Wilson: Between the genders?

Martirosyan: Gender and race.

Wilson: I know it was in the chart. This looks like a college textbook the way I've highlighted the whole thing. "That's an important point! And that's an important point!" (laughs) I'm trying to distinguish between all of my highlights. But the bottom line is that it ended up that it really didn't matter, because it's all coming out even in the wash and there's no—in younger patients, pre-adolescent, it was more boys than girls, but adolescent it ends up being more girls than boys because of the introduction of the menstrual cycle. And then as adults, I think it was more [men] than [women] again, but men, it's adult-onset cyclic vomiting, whereas [women] may have had cyclic vomiting as adolescents. Those are kind of recurrent cases.

But then, CVS also transitions to where as an adolescent, you may be experiencing the vomiting but then as an adult it transitions to migraines. So there's also a whole section in here about that correlation. It's basically the same kind of signal but the manifestation is different.

Martirosyan: Can we talk about what that cocktail is?

Wilson: Sure. In the mitochondrial community, the well-known "mito cocktail," they call it, is L-carnitine, co-enzyme Q10, and B2 or riboflavin. Those things



Daughter Sarina McFarlane on "The-Doctors" TV Show 2011

specifically have to do with energy at the cellular level. It's kind of like—the way my mitochondrial specialist explained to us early on it, you've got to keep the train chuggin' down the track and fuel it as it's goin' down the track, otherwise it stalls on you. It's keeping the fuel at the cellular level so that the cells can keep doing what they're doing. A lot of that doesn't translate to energy that an individual can feel. We don't know if our cells are depleted of energy, we only know that we feel tired. Mitochondrial depletion doesn't necessarily feel like tired. It's just that your body at the cellular level isn't functioning at its full capacity. That affects muscle, organs. Organs aren't doing what they need to do at 100%. The biggest organs that we have are the brain and the gut. Those are the things that need all of that energy at the cellular level so that they can function at their highest capacity. That's what the cocktail is supposed to do, in order to pump those things into the cellular level so that cells can do what they need to do. Make sense?

Martirosyan: Yeah, I love that explanation. Do you have to be over 21 for the cocktail?

Wilson: No. Hahaha! (laughs)

Martirosyan: Is it all in pill form?

Wilson: Pill form—well, no, there are liquid forms of L-carnitine. CoQ 10, I've seen liquid versions of that, too. But it all comes down to the level that you need. Every individual is different. One person may need a certain amount of milligrams, another person might need another. It also comes down to—because my daughter as an adolescent, I could give her the liquid version, which was great, because I could get more bang for the buck. But she just hated the taste of it and would rather take pills, and if you do that, it's more pills, and a big, big horse pill. That's the trade-off. Do you want to take big gigantic horse pills or take the liquid? The L-carnitine forms now come in flavors, like lemon, cherry, something like that. It's all about what you can handle and what your taste is. But for most kids in particular, because that's as far as I've gotten with my knowledge, the kid level as opposed to the adult level, it takes high levels of L-carnitine in order to make up for it. And your CoQ, one physician explained it to me this way: "If you take CoQ 10 and you feel a burst of energy, then that means you needed the CoQ 10. If you don't, you're cool, maybe you don't need that much." That's been very true in my daughter's case."

Martirosyan: Have you tried it and gotten a burst of energy?

Wilson: I have, because just in order to keep heart health good, we have heart disease in my family, I don't know that I necessarily feel a burst of energy, but I also know that I don't have the deficiency. If you have the deficiency, then you definitely benefit from higher doses of L-carnitine and CoQ.

Martirosyan: I guess this is anecdotal, but any problems with insurance picking up the cost?

Wilson: On the Cyclic Vomiting Association website, there are certain pharmacies around the country that treat it as a prescription. Otherwise, it's over the counter. Because we have an insurance code now, and that's something that's come about in the last five or six years, for cyclic vomiting syndrome, you basically have to check with your insurance company and see if you're able to use the cyclic vomiting syndrome code and thereby have your L-carnitine and CoQ prescribed. But you can get them over the counter, and most people prefer health food store versions as opposed to your regular drugstore version, in order to make sure that you're getting the most potent—is that a good word?—version of L-carnitine and CoQ.

Martirosyan: So everything that you've been told by

your physicians is over the counter, you don't need a prescription?

Wilson: For the mitochondrial deficiency, yes. Or at least in my daughter's case there is no pharmaceutical that she's been asked to use on the mitochondrial end.

Martirosyan: I'm just getting to know a bit more about the mitochondria, how it operates and is passed down from—

Wilson: There is a maternal link, yes.

Martirosyan: Is there a genetic mutation as well, now that you know what gene it is?

Wilson: Right. My daughter and I both went through genetic testing together. She has two gene mutations that her mito specialist has pointed to and said that those are the two that are giving her the problem. I have the exact same gene mutations but am without incident, it's a strong word, (laughs) but it's not affecting my body the way it's affecting my daughter's. One of the things that we discussed is how we have so many genes, and many of them sit dormant, many of them are sister genes to something else that's functioning and the whole purpose is when something that's functioning that's going bad, there's a sister that could potentially come in and pick up the slack. It's about being able to wake up the sister and say, "Hey, come on over here and start working!" (laughs) I know that's what a lot of the research is about right now, trying to tap into those sisters to get them to come over.

Martirosyan: Mitochondria is so fascinating.

Wilson: It's incredibly fascinating.

Martirosyan: There's so much to it. What you learn doesn't seem enough.

Wilson: (laughs) And then the learning of it and then turning that into something practical. Something that's actually helpful. It's like, "OK, we got it. Now let's make these connections and let's figure it out."

Martirosyan: Are there any conferences or events? Since it's more well-known now, is it being pushed out?

Wilson: We just had a conference sponsored by the Cyclic Vomiting Syndrome Association. I spoke for the opening of it, but it was basically the breakdown of everything that's in this book. It went through what CVS is in particular, how it presents itself, who's affected by it, what triggers are, that's where the mitochondrial component came in. That was the first half of the first day, and then it got spread out into sections talking about neurological connections, about that lovely brain-gut connection, about pharmaceuticals and food and all of the other environmental things that could come in

that may or may not have some kind of effect. It was incredibly thorough for the specific purpose of alerting healthcare professionals, especially emergency room workers, nursing staff, as well as family members to be able to get information out to physicians to say, "Hey, take a look over here. This sounds like my kid, my husband." For all the caregivers out there. It was incredibly informative. I think that we have put excerpts online.

Martirosyan: You say "we," is that the doctors that you're associated with?

Wilson: Cyclic Vomiting Syndrome Association, CVSAonline.org. It would show up here so people would be able to have it as a resource.

Martirosyan: Is there a specific doctor you think is the most knowledgeable in mitochondrial research?

Wilson: It seems like people are really working in tandem with one another right now in being able to share information. Dr. Richard Boles here in California basically spends all of his time breaking down genetic work and finding those connections and trying to be very specific with each patient to say, "OK, there's a deficiency here, let's work on that one." That's been the cornerstone of his research for at least the past 20 years.

Martirosyan: Fantastic. Is there a decision about the direction of "Grey's"?

Wilson: Wow! It's hard to say that our show reinvents itself, because we just kind of go with the wave all the time! (laughs) The best way to put it is, we never lose what our show has always been about. It takes place in that hospital, no matter what name it is that we call the hospital in a given season. And it's about being a surgeon and going through that residency and having goals, personal goals and seeing if you can achieve those goals and watching life come in and make a mess of all of those plans. That never changes. Whether you're dealing with folks who have been on the show all 19 seasons or people who just got here five minutes ago, everyone's goal is the same, even though the execution of it is individualized. That's what keeps our show familiar and exciting. That's what we're going through right now.

Martirosyan: Every episode has you thinking, "Oh, now what's going to happen? How is this going to work?"

Wilson: "Where is that going?" Just the fact that you ask that question, that means, "OK, so they'll be back next time."

Martirosyan: The people are hooked! What happens when you go into a hospital? Do staff and doctors immediately recognize you and get a kick out of it?

Wilson: Not immediately that I can see, although it may



Finish Line with daughter Sarina and Joylin 2012

be a different story. Any time I go it, it's as my daughter's mom. I used to just carry the big binder with me with all of her information, (laughs) and I was the one who asked the questions, I'd look it up and show you that this is what so-and-so said. Later on, once we've gotten past crisis, we can talk about recognition. I'm always an advocate first when I step into that role.

Martirosyan: The handy binder!

Wilson: There's that similar language. You wouldn't think you had that in common, and then you find out that no, everybody's got a binder!

(laughter)

Martirosyan: Absolutely.

Wilson: I hear it when I talk to parents, mostly. The kids, they don't have it, but all of the advocates do, the long line of advocates that we speak to. Or if you go on the message boards just to hear other people's stories, that's when you'll hear from the advocates, "I have all

the records from this test and I can tell you when this happened." You've got to keep it. That's the only way that you can walk in and be of assistance with carrying the information. The medical professionals will look at your charts, but they won't necessarily have all the back story. That's the importance of the advocate with any sufferer, somebody to walk around with the back story. Because when you're in crisis, the hardest thing for you to do is to be able to communicate effectively. And without that person standing next to you, it's impossible to be able to have that effective communication with physicians.

Martirosyan: Many people don't understand that, especially if you're by yourself, if you don't have an advocate with you, a friend, a parent, a loved one.

Wilson: And when you're in crisis, you'll present a whole lot different than you would in a regular day. My daughter has gone back to emergency rooms when she wasn't in crisis, maybe she left something in the lost and found or something, and they don't even recognize her. (laughs) She's a completely different creature when not in crisis.

Martirosyan: You're right. That's a good point. Are you close to UCLA? Where do you typically go?

Wilson: We went to our local hospital initially. It was Provident St. Joseph in Burbank, and we were referred to Children's Hospital LA when she was 16. We were able to keep that relationship and get a medical team together there and she was able to go there until she was 22. And then they said, "OK, you have to make that dreaded transition into adult care." It was definitely a dreaded transition, no matter how much you prepared for it. I had already spoken to doctors, all the records were passed over, you had an ER relationship—it doesn't matter. It was still kind of like starting over from scratch. We realized that when she would go to the hospital, the hospital was just treating her symptoms and nobody started to research again. After realizing that, after quite a few visits, we decided to go back to the drawing board and went into the UCLA Health system and said, "Let's just start this thing all over. Act like you don't know anything. Act like I don't have a binder. Let's just start over."

As a result of doing that, they basically co-signed on everything that she had going on as an adolescent, "Yup, this is what it is. This must be it." And as an adult, we were able to try a couple of other different anti-nausea meds and things we weren't able to use as an adolescent. But it was mostly about that abortive care so that she wouldn't have to continually get to the emergency room. If we could abort at home, if we had the right medication at home, without being a doctor or even a nurse, just whatever that right combination was going to

be for her body in order to cut off that signal that would send her into an episode, that would at least help that part.

Like I say, it's been 13 years. At some point we're going to lose some doctors, they'll switch hospitals, retire, whatever, I'll have to start with somebody else, and that person may be like, "Nah." We realize that we will continually have to start over as necessary and respect that that's what the process is, as opposed to walking in mad that we're having to do it. (laughs)

Martirosyan: What does your daughter do now?

Wilson: She wants to be a writer. She graduated from Cal State Northridge with her screenwriting degree. It took her a little longer to get through college than she would have liked, only because she sometimes would get to the end of semesters, go into some cycles, miss finals, miss turning in some things and have to take those classes over again. As a result of doing that, it got stressed out, but there's her degree right there on the wall. (laughs) She has her bachelor of arts, which is amazing, because sometimes you start to think you'll not achieve certain things. It's very important to me to always show her her achievements anyway. "This is what you did anyway." I don't know if it means as much to her as it does to me, (laughs) but it means a lot to me. I say, "Look, even with all of this, look at what you did!" And one day she'll be able to appreciate that.

Martirosyan: Does she know anybody in the industry, maybe an actor on a long-running show who could try to—

(laughter)

Wilson: Listen to you! She's a novelist. That's the journey that she's taking right now. That's the kind of writing that she enjoys. It's about taking that leap when you're trying to get your first book published and deciding that, "This is the one that's ready. I'll take the leap with that one."

Martirosyan: And then try screenwriting after she gets something published?

Wilson: Maybe, she'll see. You don't have to decide everything any more, apparently. (laughs) You can just figure it out on the way!

Martirosyan: How did you know you wanted to get into acting?

Wilson: My mom started me in dance class and acting classes when I was four years old. I did my first play, a musical, "The King and I," when I was five. And the thing that I really enjoyed about doing that play is, I was playing the youngest of the king's kids, if you know the musical, and at one point all the kids come out in order

to be introduced, and I was the littlest one to come out at the very, very end. I came out to bow to the king, and I bowed the wrong way, and he had to come over, and they had rigged a little loop on the back of my pants so he could reach his finger into my little loop, twirl me around, and put me down the right away. The audience just busted out laughing every time. I was like, "Hmm, this is cute!" (laughs) "I can make people laugh! It's entertaining!"

So I always looked at plays as a place where audiences could come and sit down and be invited into this world for two hour or so, and you're not thinking about your bills or the drive home or how your day went, you're just immersed in this world. There was something about that that I really liked. I just felt like I was taking people away from their stuff. I still feel like that to this day, even, with "Grey's," because people say, "When 'Gray's' is on, don't talk to me, don't call. Leave me alone. I'm watching my show." It's very similar to me as audience response from the first play I did at five. (laughs) That's my full circle moment of being an actor.

Martirosyan: How many times do you say goodbye to people by turning away and bowing?

Wilson: That's very, very funny. I kept that part of the circle away. (laughs) But doing something different, yeah, I'm still there. Going against the grain, yeah, that's still me.

Martirosyan: Did you go to college?

Wilson: Yes, I did. In Houston I graduated from the High School for the Performing and Visual Arts, and I went to NYU, the Tisch School of the Arts. I trained at the Lee Strasberg Theater Institute. I was there for four years. And then when I graduated I was doing a play off-Broadway that I started my senior year, otherwise I would have probably wanted to go to grad school just so I didn't have to start paying back my student loans, but I was in a play. (laughs) I did that instead, and six months later my student loan bill came and I couldn't understand. I said I hadn't called them and told them I had a job and it was time for me to start paying that loan back, and they started telling me something about some things I signed. And I was like, "Really? Really?" (laughs)

So there I started my 11-year journey of paying my \$197.94 a month, and in 2003 I officially owned my bachelor of fine arts. (laughs)

Martirosyan: Such a weird system we've created!

Wilson: Yes, indeed!

Martirosyan: Congratulations on that!

Wilson: Thank you! (laughs)



Martirosyan: You came out from New York to California?

Wilson: Yeah. I was in New York the whole time, and when I came out to do the pilot for the entitled Shonda Rhimes project, a play on Broadway called “Caroline, or Change,” we were moving from the public theater to Broadway, so we took off two months to make that move, in that time I did the untitled Shonda Rhimes project. And then our Broadway run ended at the beginning of September, and we found out that—I don’t think it was called “Grey’s Anatomy” yet, but it was going to get picked up as a midseason show that October, so I needed to go to LA in October. And then “Caroline, or Change” closed in September and moved to the Ahmanson Theater in LA in October! So I was going to say, “Oh, great, so I can keep doing my show and then do whatever this untitled Shonda Rhimes project thing is.” But the schedule didn’t work. (laughs) I had to let go of the show, but I still would go backstage a couple of times a week and sit with my peeps while I was filming the show. Once we got picked up for a second season, that’s when I came out full time.

Martirosyan: Nice! You got a career!

Wilson: Yeah! (laughs)

Martirosyan: That’s a beautiful set of events.

Wilson: An interesting set of events. I had a mentor very early on back when I was doing my first play off-Broadway who talked to me about what a career as an actor was. She told me, “You’re doing this play off-Broadway

now, and at some point you’ll do a play on Broadway, and then you’ll do some staged readings and then you’ll book a national commercial, and that’s good residuals. And then you’ll do a pilot but it won’t get picked up for a TV show, and then you’ll do some regional theater. And then you’ll do a pilot that does get picked up and it’ll run for a little bit and then you’ll come back and do Broadway and then you’ll do a voiceover, and you’ll keep doing all of these things in this circle. And in that circle is where the career is.” And what she taught me was that you’re never really trying to get to a thing. “I’m just trying to get this movie.” It’s all in a circle. It all goes into your insurance eligibility. (laughs) It gives you your union card.

It set me up to never covet anything that anybody else had, because there was room for everybody. Work was work. Doing a voiceover is no different than doing a film. It’s about keeping your instrument ready, this thing that we have, so that you can fall into whatever the medium is that you end up getting into because of your auditions. Because of that, people will say, “Wow, you made it, you made it!” Because of “Grey’s Anatomy,” and in my brain, the fact that I was doing my first off-Broadway play in my senior year in college and I had my union card and medical insurance, that was it for me. (laughs) Everything else after that was icing on the cake. That was it back then, in 1991.

Martirosyan: Did she also mention in that circle the other thing that’s occurring is your life?

Wilson: That’s the career circle. And life is all the stuff that’s outside of it, right? So let the circle do whatever

it's going to do inside, but then still live your life surrounding it. Because that's the thing that will support the circle. And as long as that circle is spinning around, it doesn't matter what you're doing in life, meaning that the eight years I spent working in the document processing department at Deutsche Bank, I was still an actor. But I was able to pay my rent on time without having to call home and ask my mom to help. I worked my graveyard shifts and during the day I'd do my auditions or I would do shows during the day and the curtain would come down at 10:30 and I'd head down to Wall Street to work my 11-7 shift. That's kind of what you do.

And all that's happening at the same time —

Martirosyan: How did you get a job at Deutsche Bank in some form of data entry or accounting? How did that happen?

Wilson: Temping is what you do as an actor in the '90s. I don't know if that's the case now. (laughs) But then, coming out of college in '91, my last semester, I had to take this class called Computers. I had to learn this Windows software, this Word, this Xcel, this PowerPoint, whatever. So I came out of college with this title called an Operator, which meant that I could do more than data entry, I could create things. So as an operator, I was able to get the highest-paying of the temp jobs, and if I worked the overnight shift, that was the highest-paying of those. (laughs) So I worked overnight in document processing as an Operator. Back then, that was \$27 an hour. I'm like, "What?" (laughs) "What?" Now babies know how to do what I did then. But back then, you were an Operator. So that was important to have just to be able to be independent while I was pursuing the things that I was. It never stopped me from being an actor. Everybody in there was some form of an artist. (laughs) But we weren't starving artists.

Martirosyan: All that energy!

Wilson: My mutations had not flared. (laughs) Yes, indeed! My daughter she doesn't even notice if she's under, and I'll say, "OK, you seem a little under today." "No." Not aware at all, because that's not where it's happening. I think I first noticed when she was in seventh grade and she was playing soccer. All the kids were running down the field and she would walk. And I would say, "Why aren't you running after the ball?" She was like, "I am!" (laughs) OK, OK.

I've worked with the Mito Action Committee for a lot of years as well, because cyclic vomiting for my daughter was in the lead. I guess it depends on who you talk to what came first, right? I kept relationships with both communities. I know sometimes, I've got all that information in my head and in my binders, and sometimes my daughter is just tired of all of this and just wants to say, "You be the keeper of that. I'm just trying to do today." I completely understand that.

Martirosyan: I was about 10 when we started seeing doctors. My parents were definitely my advocates. And then there comes a point in your age where you start taking over. It's difficult. I took a couple of years off every so often. It takes a toll on you. You want to do exactly what you mentioned your daughter said, "Just forget it, I want to live today and see what happens."

Wilson: Yes. And there's only so much on the advocate end that you can push. You're looking at it from the outside in. And you say, "How about we try—?" And my daughter's like, "No, let's just keep everything right here where it is." Like, "I'm fine today, and today is good enough." As an advocate you have to learn how to say, "I understand that, got it." And that's the human part of the journey.

Martirosyan: As an advocate and a parent, you have to disconnect the emotional aspect of it, too. That can completely take over. I've seen it in my parents plenty of times.

Wilson: It's easy to say, "What do you think you would do? If it was me, I would do this. But it's not my issue, so I don't know that." Just like somebody else can look at me and say, "If I was me, I wouldn't be doing—" You don't know that until you're in the person's shoes. All I can do is give the information, and if it comes to a point where she say, "You know what? I'm kind of tired of all this. Is there something we can try?" "Oh, yes!" (laughs) "Let's try some things!" You learn to wait.

Martirosyan: Your highlights in your text!

Wilson: "Yes, I've got many highlights! It's all here! Let's go here!" (laughs)

Martirosyan: You may not be aware of how important your support is. Even when she wants to take it easy, it's not possible without you.

Wilson: Yeah. And being able to have conversations. I just had two conversations in the last two weeks with two new moms I met who were kind of at the start of their journey. You don't want to look too far in the future and say, "OK, this is what your kid's going to go through." (laughs) But you can at least validate where they are right now. I remember what that felt like when I first heard people repeating things that I had—or being able to finish my sentences. I'm like, "Oh, my God, you know what I'm talking about?" It was so—the relief and not feeling like you're the eight-headed object in the room, that was so important in the journey. I try to provide that wherever possible just to let people know, "No, you're not crazy. This is happening. There are names, there are labels. You're not by yourself. And even though your journey will be different from the next person's, the similarities there, it all can get housed under the same umbrella." That's helpful.



Chandra and Sarina

Martirosyan: Your daughter's doing well?

Wilson: Actually, she's been going through a cycle this week. It started on Tuesday, and we thought it was over on Wednesday, and then it kicked back up on Wednesday, so she's resting through this morning. It's been since the summer, since maybe August, and again, it was just out of the blue this Tuesday morning that she woke up and she was like, "Something's wrong, I'm coming over." And then we go into abort mode.

Martirosyan: And she takes notes of the day before, of anything that might have been that trigger?

Wilson: Yeah, because that's always the conversation. "Was there anything?" "No, there wasn't." She just immediately felt like something was off and she was starting to salivate and not knowing why. She said, "Let me just come over and let's get it early." And usually that's good enough. We can get it early, cut off the trigger and she can rest and get through the day. But it

didn't want to calm down this time. This was an aggressive one. And there's no rhyme or reason that we know of yet between when it's something that gets cut off right away or sometimes we can cut something off right away and then it'll show back up maybe three or four days later. It wants to go all the way. It wants to do it. It gets really upset (laughs) when we don't just let it go! To where she's vomiting for a day and a half. It knows how to get there and it gets mad at us when we stop it.

Martirosyan: What can you do to be really aggressive in attacking the trigger?

Wilson: Like if she was in the ER, they would immediately start her with doses of Benadryl, sometimes they would use an opioid like morphine if they would have to. If I can get an anti-nausea like Zofran in early enough or before vomiting. I have to hear what her symptoms are at that moment and that'll let me know what the things are that I can load in order to get it to rest.

Martirosyan: When she starts vomiting, she can't do anything orally at that point, right?

Wilson: Exactly. So we have intra muscular (IM) remedies. We have a Benadryl ketorolac IM that we're able to do. And then if there's a lot of writhing, a lot of behavior, we have to add Ativan. There's a sublingual version that we're able to use. The sublinguals are pretty good, too. She doesn't have to swallow. We can do it like that.

Martirosyan: You definitely have gathered interesting medical experience.

Wilson: Very true. It's all about, you watch, you note, clock the time, load, watch, clock the time so I can report all of that back to her physician and he can take a look and say, "OK, got it, got it, got it, got it, got it."

Martirosyan: Have you done anything on the show with CVS?

Wilson: I directed an episode in season 9 where we introduced a character with cyclic vomiting syndrome. He was known as a Santa, a drunk Santa, because he usually had some alcohol with him. It turns out that he'd been a cyclic vomiting sufferer since his early '20s and didn't know that that was it was. His life had been so debilitated by these episodes of nausea and vomiting that he wasn't able to work and his family didn't understand. He ended up being out on the street dealing, and he would drink in order to see if that could calm down the symptoms. And then he'd end up going to the hospital and he'd throw up there and they would accuse them of being a drunk.

Finally one of our physicians looked at it and was like, "Wait a minute. He's presenting like some of my kids in pediatrics. I think he might have cyclic vomiting." He started to do the research, he talked about his life, and we gave him that diagnosis, and it was about the light-bulb going off, like, "You mean that actually something's been wrong all this time? How much that could have affected my life early on if I had known that something was wrong and that something wasn't just wrong with me." And that was—we wanted to be able to say cyclic vomiting syndrome out loud in prime time and give validity to patients out there who had never heard it before or family members who had been trying to tell their family what their kid was going through and the family was like, "No, they're just trying to get attention," whatever it took to be able to say, "No, this is actually a thing."

It was really important for the community. I was so honored that the one pitch of a story line that I've ever made in all these 19 seasons of an episode, that they took the pitch and gave me the honor of directing it.

Martirosyan: Thank you for that, is there a beautiful

note you'd like to end on?

Wilson: Oh, my!

(laughter)

One thing to note is, and this is kind of like a general life lesson, is regardless of who you're looking at or who you think they are or what they're known for, you just never know when somebody's journey is. And every single body has some kind of journey going on that not everybody would know about. It goes to the level of compassion that we have for each other as human beings, the fact that we may make mistakes, we may get something wrong, may not do something the way that you may do it, but everybody is on their own journey. People will look at me and say, "I don't know how you do all that," and my answer to that is, "You wear the shoes that you have. You play the cards you're dealt." You don't know what you're capable of until the thing is put in your hands, and then you have to rise to that occasion to say, "OK, so now what do we do?" Because in the end, it's all about trying to have the best quality of life that you can and being grateful and thankful for every single day that you get to have people in your life and get to do the things that you think you want to do in this life, just staying open.

As an advocate, my role has been to stay open, to hear, to implement, and to report in good faith so that those relationships can be built on trust and ultimately be able to give the best care and the best resulted care to my daughter that we all could do. It's a collection, a collective. It requires a great deal of patience. (laughs) You bring your patience cap and your gratitude cap with you and—if you know that that's what your life is about, then don't assume that the person that you're walking next to on the sidewalk or you see on the subway or who cuts your car off by accident or whatever while you're driving isn't in that same situation. We all have to give each other a break in this life so that we can get through it with as much success as possible.

Martirosyan: Certainly a lovely message. Give yourself and others a break!

Wilson: Yeah, exactly!

Martirosyan: Your daughter is fortunate to have you.

Wilson: Oh, my!

Martirosyan: Indeed.

Wilson: It's definitely a journey, a big journey. ■ **ABILITY**

mitoaction.org
cvsaonline.org
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keah BROWN

The Power of Delusion or Determination

Keah Brown loves cheesecake and Paramore and Usher and Demi Lovato. “These are things that matter to me just as much as conversations around disability and cerebral palsy,” mentions the journalist, writer and creator of the viral hashtag #disabledandcute. She has released two books, “The Pretty One” in 2019 and “Sam’s Super Seats” in 2022. Her new young adult novel “The Secret Summer Promise” in 2023. *ABILITY Magazine*’s George Kaplan spoke to Brown about her work and her life.

George Kaplan: You’ve been very candid in your writing and talks about growing with a disability, especially in contrast to your twin, who does not. Can you talk about that experience?

Keah Brown: When we were in high school and even when I went away to college, I was just hyper-focused on this idea that my sister was the more idolized version of me, that she had everything that she could ever want and that her life was perfect. That impacted our relationship, because instead of getting to know her, I thought “I don’t need to know her, she’s my enemy. She’s number one on my bad list.”



Durable Living Room

It wasn't until I went away to college, and I was meeting all these wonderful women who made me laugh and they were funny and loyal and kind that I realized that all these things that I love about them, my sister has. All of our lives, I spent comparing myself to her and being like, I have to tear her down in some way so that I can feel better. I think it's so funny now, because as an adult I realized that it didn't make me feel better. It just made me feel terrible, because I knew the way that I was treating her, the things that I was saying in the heat of arguments or just to myself was really just hurting and hurting her. As an adult, I'm 31 years old, I now know that there's room for both of us. Having somebody love you deeply despite the fact that you don't yet know how to love yourself is wild. I'm grateful for where we are now, because where we were growing up, I made a competition out of everything.

Kaplan: I think so many disabled people can relate to that feeling of having a sibling who's not disabled and taking it out on their sibling and themselves. You said your family never let you feel different. How important was that upbringing to you?

Brown: Oh, my gosh! Most important! Of course, you never realize it at the time, but after learning about other disabled people who had guardians and family

members and parents who sheltered them, to have the opposite has been—it's gotten me to where I am today. Inherently, my mom always believed that no matter what it was, I could do it. If my older brother got skates or my sister got skates or a scooter or whatever, my mom was like, "We'll figure it out. We'll get you that. You'll figure out how to do it. I'm not going to let you use disability as a crutch."

That determination carried over to me and allowed me to be where I am today. I feel like I can do anything. I was talking to my friend Laura earlier, telling her, "People always ask me, 'How do you do all the things you do? How do you write the books? How do you cope with all the ideas?'" And I said part of it is delusion, like I'm delusional.

Kaplan: (laughs)

Brown: I think if I work very hard for something and I want it bad enough, it's going to happen, no matter what it is. I don't want to spend my life being a person who's like, "I wish I had tried this or done that, wrote the thing, said the thing, tried this thing." I want to make sure that I did it, and even if it doesn't work out, at least I can say that I tried.

One of the biggest things, and I don't think I've ever told this story before, is that I was desperate to ride horses. I was like a horse girl through and through. It was me and the Saddle Club. I don't know if you remember that, I might be aging myself. My mom found a place where I could ride horses. I never stuck with it, but I remember being like, "I really want to ride a horse." And her being like, "OK, we'll figure it out." That belief that she had in me absolutely translated, even when I didn't think so myself, to me being able to do all the things that I'm doing today.

Kaplan: That's great! And I love what you said about delusion! I feel like delusion is such a powerful tool! (laughs)

Brown: Yeah! It is! Listen, I tell people all the time, delusion is changing my life. To me, it's like that and letting the universe know what you want. I firmly believe in speaking things into existence. I'll be the first one to say, "I want to meet this person. I want to do this thing." And when they happen, people ask, "How did you—?" And I say, "I just willed it into existence and worked for it." Between delusion and thinking things into existence, it's gotten me to where I am. That and hard work, but you know what I mean.

Kaplan: Of course. You've got to back it up with hard work.

Brown: Yes.

Kaplan: What was the genesis of your viral hashtag #disabledandcute?

Brown: I wanted to celebrate feeling good about myself. I started thinking of four things that I like about myself every single day. By the time I got to February of that year, I was like, "I'm going to celebrate! This is the longest it's ever stuck!" I don't have any "you're being ridiculous, you're not pretty, or this or that." I didn't have any of that. I wanted to make sure that I was celebrating the small moments, because any ounce of joy that I can squeeze out of something, I will. To make the hashtag was me being like, I'm disabled and cute. There's no either/or situation. I had hoped so deeply that other disabled people would use it, and I'm so glad that they have. I wanted to celebrate us.

I wanted initially to celebrate myself and to finally be like, "It's happening, guys!" My sister was like, "All this time we waited for you to see what we see. Now you do!" I think the hashtag was me being openly excited about the fact that I had begun the journey of loving myself, that I had done the work to make sure that I was celebrating the moment. I was like, "OK, Keah, you're cute! It's good! Have that. Live in it for a second."

Kaplan: I love that. I feel like we're so keen to tear our-

selves down just because of the messages we receive from the world, we internalize that and we become our worst enemy.

Brown: Absolutely! When you don't see yourself represented properly or with nuance, does this mean my stories don't matter, that I don't matter, that I hold no value? Why am I not getting the opportunity to tell my story? Why do people think that disability is just sad people all the time who end up dying before the movie or TV show is over? I think that we as disabled people often have to do the work of being like, "This is not how disability is." I think it's getting a little bit better now, but we have so few ounces of representation that I think we end up getting the short end of the stick.

Kaplan: In 2019 you released your first book, "The Pretty One." What inspired you to be a writer and to tell your story?

Brown: I've been telling stories all my life. The very first thing I ever did, I was eight and I used to write songs and I was convinced that I would be like Taylor Swift. I used to write poems about boys who didn't like me back. To me, writing has always been the way I express myself. I wanted to be a journalist. I got a degree in journalism and nobody would hire me. They didn't want me. As soon as I disclosed that I was disabled, all communication/offers were off the table.

I was like, what am I going to do? I'll have to write online. I'll just have to figure it out. For me, wanting to become a writer was at first about wanting to talk to people and figure out who they are and why they are. I thought journalism would be the best way. I'm a naturally nosy person, and I was like, I can talk to people for a living and write about it. It'll be great. I realized post-college and when I was writing these articles and talking to celebrities and all these people I love, that I can write and tell my own story. It was a combination of telling the stories of other people, it's fun, it's amazing, but also people seem to be interested in how I live my life, how I navigate the world. I took "The Pretty One" as an opportunity to talk about the things I never get to talk about when I write articles for other people. I talk about love, hardship, pain, grief, the ways people show up for you, my love for music. I would put every topic I could think of at the time in an essay to put together in "The Pretty One." I wanted to be able to talk about the things that people often don't allow disabled writers to talk about.

Sometimes if it's not about disability, they're not interested. I wanted to show that I was a fully realized human who had conversations about disability and wanted to talk about it, but also had other things that she wanted to explore. "The Pretty One" was me saying, "Here's who I am so far. Here are the things that matter to me. And yes, disability is a part of it, but it is not the sum of all of it. It's just a way I see the world,



Keah and sister Leah

and here are these other things about me.”

Kaplan: You also entered the children’s book space last year with “Sam’s Super Seats.” I love the message about how important rest is. I feel like as young disabled people, we’re always trying to catch up with everyone else, and we end up putting ourselves through so much harm.

Brown: Yes, we do! “Sam’s Super Seats” is so special to me because Sam is a kid I wish I had known when I was that age. She’s precocious, she’s sure of herself. She feels fine asking for help. I was never that kid. I wanted to keep up with everybody else, keep moving, never wanted to admit when I was in pain or when I was hurting because of disability. Sam was the wish fulfillment in some ways, the girl I wish I had known and I wish I had been friends with. She’s very assertive. She knows when she needs to stop. She has an idea of herself, she’s sure of who she is. She has a really great community. She has best friends. Her parents love her. She’s excited about school.

People always ask me, “What part of you is in the book?” It’s the excitement about school. I loved school. I loved going back-to-school shopping. I loved buying clothes and books and all the supplies. It was my

favorite thing. Sam is only possible because the editor I worked with, Sidney Monday, on “Sam’s Super Seats,” read “The Pretty One.” In the book there’s an essay about chairs. I talk about the ways in which I give my chairs personalities and thoughts and ideas and names. She said, “I want you to be able to talk to children about the need for rest.” That’s how “Sam’s Super Seats” was born, because I wanted to talk to kids and let them know that rest is also an adventure. You don’t have to push your body past its limits to be seen as worthy or a functional member of society. It’s OK to take a moment, take a breath and sit with the people who care about you and let them take care of you.

To me, Sam is a dream come true in that even I take from the characters I create. It’s the idea of interdependence, letting people care for you, letting people care about you, telling people what you need. I loved creating that book, thinking I need to be eager and excited to tell people what I need instead of looking at it like, “I don’t want to burden you with my problems.”

Kaplan: It’s so cool that it’s teaching kids how to advocate for themselves because especially if they’re going through medical stuff, being treated by doctors, they might be experiencing pain and going through certain things, and having the language for that, learning to

advocate for yourself is so important early on.

Brown: Yeah, I think so, too. I always tell parents of disabled kids, when they ask, that you need to make sure that you're not just speaking over your child but you're asking them for what they need. When they get older, you won't be in the room, and they should be able to speak for themselves in whatever way that is, not just verbally, but whatever way they can speak for themselves, you should teach them that at an early age. Doctors and the like will try to steamroll you if you don't. I wanted Sam to be a sort of guiding light in that way, whether you're disabled or not, but specifically if you're disabled, to ask for what you need. To me, Sam is a really good example of the ways in which we should teach children how to care for themselves, how to trust their instincts, and how to speak up for things they need.

Kaplan: You've gone viral, you've written books, profiled people like Brie Larson. When you look back on the career you've built for yourself, what are you most proud of?

Brown: Ooooh! I think I'm most proud of the ways in which I've been able to connect with people. As a person who loves to tell stories, I'm a storyteller in any way possible, I'm most proud of the fact that I've been able to connect with people, people like Brie, or I did the Town & Country cover with Selma Blair or any other profile I've done, any person I admired that I now speak to or am friendly with. I'm very proud of my ability to connect with people, whether they're disabled or not. I always tell—poor Mandy. For many years Mandy Moore has been one of my favorite people. I used to always want to be friends with her so bad. She's brilliant, funny, smart, so cool. She is all of those things. And when we became friends, it was because a bunch of people reached out to her saying, "Hey, there's this girl named Keah. We can vouch for her. She's a normal person. She's not weird. You should be following her." So she did. I remember the first three weeks of us being mutuals, she was so kind and so funny and so sweet, and I was so nervous. I was like, "I can't say the wrong thing."

Once we had a conversation when we did an Instagram Live for "Sam's Super Seats," and she said, "You never have to worry about being annoying to me." And she said all these kind things. It's really nice to have people who care about you share with you the things that they care about and why they care about you. Out of all my career things, personal and professional, I'm really proud of the way that I can communicate and the way that I allow myself to be myself. That seems to be good for people, to be the thing that people want to be my friend because of, my natural excitement, my eagerness, the way I smile all the town. I have been able to tell stories about real or imagined people and have still been able to communicate the importance of being just



Young cheerleader Keah Brown

who you are.

Kaplan: You have a new book being released later this year, "The Secret Summer Promise," a young adult novel. Can you give us any kind of tease about it?

Brown: Oh, yeah! I am a fan of the romcom. I love a romantic comedy. One of my favorite tropes in the world is friends to lovers. People are always like, "Oh, my God, friends to lovers, it's so tired!" No, it's not. It's wonderful.

The book is about a girl named Andrea who has spent all of her last summer in bed after a surgery. She wants to make sure that this summer she has the best summer ever. So, she and her best friend Hailey make a list. It's called "The Best Summer Ever List." They do things like go to a thrift shop pop-up, a Lizzo concert, the amusement park. They go skinny dipping at one of their friends' lake houses. They're creating this list. And Andrea realizes that she's falling in love with Hailey, her best friend. She's so eager to have the best summer ever and to keep it a secret. So, she meets a boy named George, and there's this whole thing. It's very cute. I'm so proud of it. It's all the things that I've always wanted a novel to be. It's got the friends to lovers trope. I'm queer, so it's got this LGBTQ representation that I personally have longed to write, but now that I'm out, I can actually write it. It's a story about our connection to people and the ways in which we love ourselves and love each other and the ways in which life can happen in just one summer.

It's all of the things I tend to talk about in my real life, but in a way where you meet these characters you fall in love with. Drew Barrymore is my favorite person in



the whole wide world. Do I know her? Not yet. It will happen. Again, delusion. We'll meet. We'll be friends. She's going to love me.

Kaplan: (laughs)

Brown: It's an homage to her in so many ways, in the ways she has created characters that you instantly fall in love with, you root for, you care about. It's a sort of homage to romance and my desire to see as many romantic people, romantic characters who are disabled, get their happy ending, and also just tell a story about friends who are figuring it out along the way. The ways I love to tell stories is happily ever after. We don't know what will happen with Andrea and Hailey, but we know that Andrea will survive until the end of the book, that she'll thrive, that she'll figure it out. That's very important to me. I'm so proud of this book. I'm proud of my other two books, obviously, but there's something special to me as a romcom love and a YA lover to be able to tell the story and hope that people like it. I think they will. I might be biased. I'm very biased. But I think that they will! (laughs)

Kaplan: (laughs) I think will, too, and I might be biased because you have a George in there.

Brown: You're like, "Yes! A George!" (laughs)

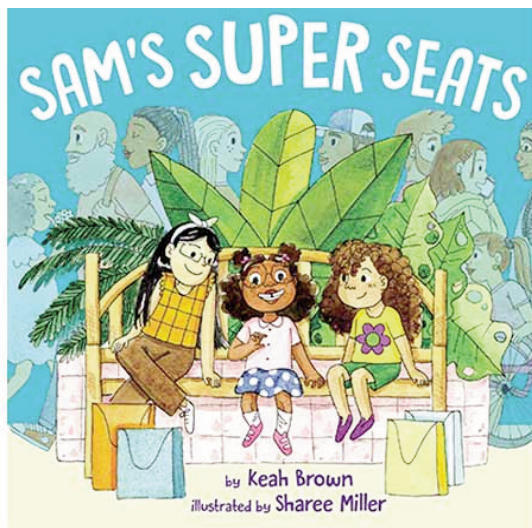
Kaplan: (laughs) That sounds exciting. And I agree with you about Drew Barrymore. One time I saw her in person and I just stared at her for five minutes because

I was so nervous and I did not know what to do, and then she walked away.

Brown: And you were like, "OK, cool!" I would do the same thing. It's so funny. I try really hard to manifest things. I don't know when it's going to happen, I hope this year, but I'm convinced myself that I'll meet her and maybe go on her show and we would be friends. But I would do the exact same thing. I would be like, (whispers) "God, it's Drew Barrymore, it's Drew Barrymore!" I was on the "Today" show after "The Pretty One" came out, and I saw Venus Williams walk through the dressing room. My mouth was completely wide open, I was like, "Oh, my God, it's Venus Williams!" It was me and my literary agent being like, (whispers) "Oh, my God, did you just see her?" (laughs)

Kaplan: (laughs) You've accomplished so much already. What do you have next on your docket? What's on your bucket list?

Brown: Ooooh! I've been taking acting classes since the start of the pandemic. I desperately want to act. I want to be in a movie or a TV show. I want to sell a movie or a TV show. A lot of what I want to do professionally is in the film and TV space. I want to write more books, obviously, but I really want to give myself the opportunity to try. That's next on my docket. I want to write another book. I want to travel to London and Paris and Rome and Spain. I want to be able to look at my life and think the sky's the limit. That's next on my



docket, to do it all.

And at some point, I don't know when, but maybe before my 50th birthday, I'm going to sky dive.

Kaplan: Oh, man! (laughs) That is one of my biggest fears!

Brown: (laughs) I want to do it so bad, and I'm not even good with heights, but I want to do it.

Kaplan: That's great. It would be wrong of me not to plug this, but we do have a site called abilityE that connects casting with disabled performers. If you are curious about that, feel free to hit me up. We have that. And we are expanding to jobs behind the camera as well. That's something that we've been working on.

Brown: That's so cool! My film and TV manager, shout-out to Rachel, she's had to handle me being like, "It's going to happen, it's going to happen, right" every five seconds. And she's like, "Yeah, it's going to happen. Just keep working at it." I will definitely check it out. Any and every opportunity I'm looking for. I think it's another way to tell stories. I love it so much. Every time I talk to one of my friends who get to do it for real, even though you're really doing it when you're in class, but to do it for real, they're like, "I love how much you love it." I don't think I'll ever stop. Again, it's the Drew Barrymore fan in me, to be able to create characters who you instantly fall in love with and let that be across genres, whether it's in a book or a screenplay, or I'm saying somebody else's words. Any way I can do that is a dream come through. I hope to break into film and TV and have a show or a film catapult me to a place where I'm doing it for real.

Kaplan: I see that for you. I think you're one of those people who can do it all.

Brown: Oh, thank you! I hope so! The more people can see people like me and like yourself doing the things

that they want to do and trying, it makes it easier to say that we might not have the representation we need yet, but we can be our own representation. For me, often-times I am my own representation. We've got Jillian Mercado on "The New L Word," and we've got Lauren Spencer on "The Sex Life of College Girls," but it's interesting for me because I desperately want to see somebody like me on TV or on film, people who don't use mobility aids but are still disabled, invisible disabilities as well. It's never to take away from those people doing the work right now, but it's the idea that we have to treat disability less like a monolith and more like an opportunity to tell stories.

Kaplan: In "The Pretty One", you said you grew up hating mirrors. What do you see in them now?

Brown: Oh, goodness! Do we have enough time? I see a woman trying her best. I see a woman who is excited and eager. My friends can all vouch for this, I'm the kind of person who if I'm excited about something, I'm texting you in all caps. I'm using exclamation points. The person I see now is a person who is trying her best, who looks great in a red lip, most of the time, and a person who just wants to be in the world and is excited about life for the first time. Before I hated mirrors so much because they reminded me of all of the flaws I knew I had, all of the things I thought were "wrong" with me. Now I see somebody who is a fully realized human being who wants to live her life and make herself proud and make the people who love her proud and who is a person whom, thankfully, people like to be around. Before, I never thought that. All I saw was things I thought were wrong, that I needed to fix.

Now when I look at myself, I see a person who is just a person. Sometimes I have good days, sometimes I have bad days. Having both, either/or, is a part of who I am. I look at myself and I'm like, "Yeah, girl, you're doing your best. I'm proud of you." ■ **ABILITY**

keahbrown.com



Christoph Glötzner

Young Paralympian Racing Towards Gold!

60, 59, 58 — Christoph Glötzner can see the countdown ticking down on the large black clock right in front of him. 57, 56, 55. He's wearing a yellow and black suit and holds ski poles in each hand with mini skis attached at their ends. The athlete in front of him had just started his run. Glötzner is next. But his ski is still missing. Shortly before the race, his mechanics noticed a technical problem with the ski. They quickly removed it from Glötzner's foot and took it apart right in front of his eyes. 4, 3, 2 - Last minute, the ski is attached back to Glötzner's leg; he hops down the ramp and starts the race. He is not showing any nerves, though.

It's warm and sunny on this day in Beijing, where the 2022 winter Paralympics were hosted. Glötzner started for the German Para Ski alpin team. "I was one of the younger participants. In fact, I was the youngest in my starting class, which was really cool," Glötzner says and follows up by asking





Maike Hujara.

how his new beard suits. He has grown up quite a bit since our last interview in 2018; the teenager became a young adult (with a mustache). What hasn't changed, though, is how down to earth and humble he is, but also the determination and undeflectable focus with which he works relentlessly towards his two main goals: First, he wants to become a medical doctor, and secondly, he hopes to win a Paralympic medal.

Both of those goals are rooted in one tragic accident. It's June 13, 2007, a sunny summer day in a quiet little neighborhood in Bavaria. Three-year-old Glötzner plays on the lawn close to his house. The grass was almost as high as himself, and he was not supposed to be there. When he sees the colossal lawn mower, it's already too late. His right leg is caught up in the lawnmower and separated at the thigh. Minutes later, a helicopter circles

over the area, searching for a place to land. Crowds of neighbors are standing by in shock while young Glötzner is fighting for his life. He's transported to the next larger hospital 20 miles from his hometown. Not many are equipped to deal with children this young. "When can I finally get back home?" he says during a short conscious moment up in the air. Looking back to this day, Glötzner recalls only tiny pieces of what had happened. "I remember a few details from before the accident, but the moment I got under the lawnmower, I blacked out," Glötzner shares.

For two weeks, he is in and out of consciousness and endures 13 surgeries. Every day when his parents come to visit, yet another doctor tells them he is in the operation room. Nobody knew if he'll survive. Besides fixing the severe injuries, the surgeons also try to increase the



Glötzner at the Paralympic Winter Games 2022

length of his remaining portion of the thigh to create more space to properly fit prosthetic legs later in life, but Glötzner's body rejects the transplant, goes into sepsis, and the three-year-old almost dies again. Once he is out of acute danger, the open wound needs to be closed, but due to his age (and size), the only area on his body offering enough skin is his little head. Therefore, a large area of connective tissue is removed to cover the amputation area. In solidarity, Glötzner's older brother shaves his head as well.

After four weeks, the boy is transferred to a rehabilitation facility where he is taught how to walk with a prosthesis, but for Glötzner, of course, that wasn't enough. At the facility, he meets an expert doctor who has had one of his legs amputated after a traffic accident. He teaches Glötzner how to ski with one leg and, more importantly, becomes a role model to the boy. "Up till today, he is still a big inspiration of mine," Glötzner adds. So here he is, a three-year-old child who just had an amputation six months ago, racing down a mountain on one leg. Glötzner always felt at home in the mountains. Then, five years later, he gets recruited by the German Paralympic ski team. "During a family ski vacation in Austria, we were approached by the Austrian Para alpin ski team's trainer. He wasn't happy when he learned that we weren't from Austria but from Germany because he had hoped he could recruit me for the

Austrian team," Glötzner laughs. "He then gave us the contact information for the German Para Ski team, and one thing led to another. All of a sudden, I was part of the German youth team, took place in the first race, then later, in my first international race, and my path to competitive sports was set."

Today, Glötzner is 19 years old and lives in Innsbruck, Austria, because here, he can follow both his destinies: Becoming a doctor and a para ski pro! And he's on a clear trajectory to both. Currently, the young man studies pharmaceutical chemistry before moving on to medicine. When he is not at the university or studying for a test at home, he is training for another race on the weekend, or, in case it is summer, he can be found at the gym, preparing for the winter ski season. He never misses a training; he scores high on all his tests. "Right now, it's winter, so it's the racing season. This means we are either at training camps or participating in competitions. My day looks like this: I get up, warm up, eat breakfast, then more training or the actual race, then study in between in my apartment, then do some stretching before I go to bed." Glötzner doesn't have much leisure time. "I think you need to have big goals and dreams in order to be able to handle all this pressure. It's for sure tough some days, but I am enjoying the journey," Glötzner says. When asked what he prioritizes: school or sports, he takes a moment to think and then



Glötzner is biking for fun

states, "I really try to do both equally well because you can't really make a living off of para skiing, unfortunately. So for me, school was always as important, especially because I always wanted to become a doctor from an early age. However, skiing is my passion, and winning a medal at the Paralympics is my other big dream. So don't make me choose," he laughs.

Glötzner is a bright, polite, and a hundred percent determined young man who thrives with new challenges. His latest passion is long bike tours through the mountains. When he started to learn how to ride a bike after his amputation many years ago, he occasionally would lose his prosthetic limb along the way, which a child close by commented with: "Oh my, he lost his leg!" These days, his whole life is defined by sports. He goes paddle boarding and makes handstands on the wobbly board; he jumps through an obstacle course with one leg with hurdles as high as 51 inches above the ground; he swims

like a fish; he climbs and tries whatever activity poses an athletic challenge to him. "I would not say that I have a disability, but more that the amputation is a part of me, an experience that made me stronger," Glötzner states. However, being able to participate in all these different sports also means he needs many different prostheses because his everyday one for walking doesn't work for racing or swimming. Since Glötzner was very young when he lost his leg, he constantly outgrew his artificial limbs, making it difficult to accommodate his urge to move. In the beginning, the rehabilitation facility had to build him a leg prosthesis from an adult's arm prosthesis. Glötzner kept all his old prostheses in a box in his room, and each one of those is a little piece of art, showing pictures of spider man and others of Glötzner's heroes. Another piece has the quote "Veni, Vidi, Vici" printed across it - I came, I saw, I conquered. This a very fitting quote that couldn't describe Glötzner any better.



Three-year-old Glötzner with his one ski. Image by Walter Glötzner

Since he joined the German Paralympic team, he has won the "Deutschlandcup" in 2020, came in third place at the Europe Cup in Zagreb in 2020, and achieved second place at the German Championship in 2020 before winning the German Championship in 2022. However, he still had to win a World Championship or Paralympic medal. When he was nominated to start for the German Para Ski alpin team at the Beijing 2022 winter Paralympics, a dream came true for the young man. He traveled to Beijing the same year he finished high school and started to study. "I was really nervous because those were my first Paralympic Games, and I didn't know what to expect. But at the same time, I was looking forward to starting at the races and fulfilling this life-long dream," he says. "The attention and the media hype: I had never experienced anything like it. I'm grateful for all the impressions and can hardly describe how emotional the whole time was." He has trained for this day since he was four years old.

However, the Paralympics didn't go quite as planned. During the warm-up race, a practice race where all athletes can test out the course without pressure and without gates, Glötzner slips and crashes into the guard net that marks the border of the slopes. He tears a muscle on his upper arm and injures his leg badly; it is unclear whether he can start the actual race. Miraculously, he recovers fast enough. Then, last minute, a problem with his ski arises, which the mechanics fix only seconds before the gate opens, and it's Glötzner's turn. He jumps onto the slope and delivers a flawless run until he arrives at the last gate. Glötzner accidentally misses it and gets disqualified. "Something like this never happened to me in any race, but then, of course, it does at, you could say, the most important race of my life so far. Everything bad that could possibly happen happened right at this big event," he shares with a smile. He took the loss with humor. When he arrived back in Germany, his whole school was filled with fellow students waving national flags and cheering him on. They watched his race live at school in the middle of the night to show their support. So did the local volunteer firefighters, Glötzner's family, and his many social media followers. Nobody cared that he did not bring home a medal.

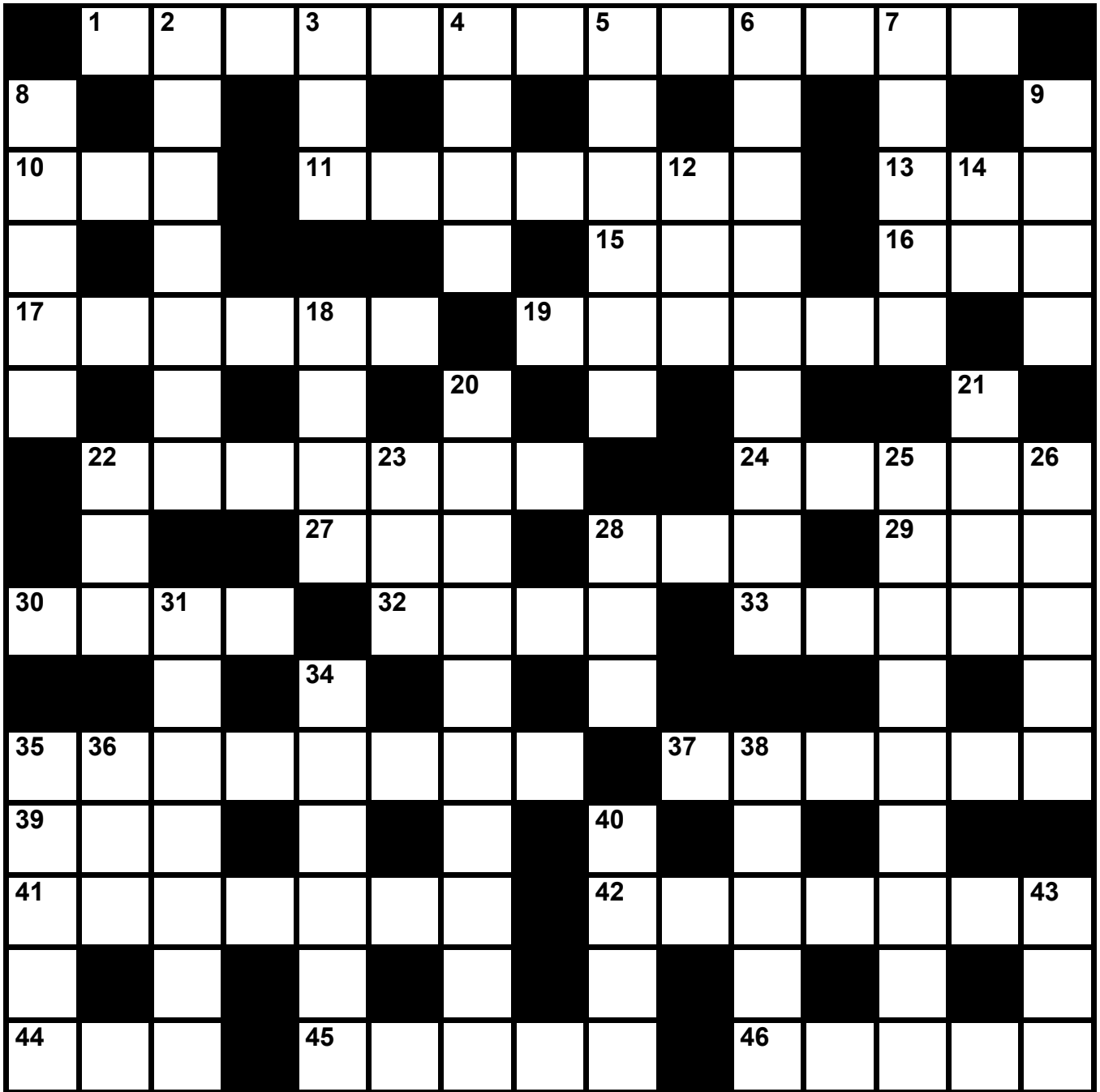
In January 2023, Glötzner started at the World Championship in Espo, Spain. His goal was to score in the top ten, and if he puts his mind towards something, he delivers. Glötzner finished in eighth place. "Sure, winning is important, but not as important as the progress you make. Seeing that I am getting better every day, every week, every month, and seeing my hard work reflected in the results of those races is just as important. But that doesn't mean I don't plan to win a Gold medal at the next Paralympics!" Glötzner ends. And knowing the young man, there is no doubt about it.

■ ABILITY

by Karina Ulrike Sturm

[instagram.com/grisugloetznr](https://www.instagram.com/grisugloetznr)

ABILITY'S



Crossword Puzzle



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A C R O S S

- Worldwide association of artists with disabilities founded by Leroy Moore, 3 words
- The Godfather's people
- Indie film maker known for "A Bold Choice" at the Focus on Ability Short Film Festival, Jessica _____
- Compass direction, abbr.
- Chesapeake _____
- Shy
- Heart in slang
- "The Girl with the Dragon Tattoo" computer whiz
- Deaf Access Services community manager. David _____
- Facebook approvals
- Compass point
- Term from tennis, golf or poker
- Get on in years
- Rainbow shapes
- Goes back, as a tide
- Mumbai instrument
- Comedian Maria Bamford's company that gives 11% to charity
- Frequent extra on "Law and Order"
- Time for celebration
- Squeaky Wheel editor-in-chief Steven _____
- Writes down in a diary, for example
- "The Billion Dollar Brain" novelist Deighton
- Gadget
- Rap feature

D O W N

- American disability rights activist who is the first US Disability Rights Program Officer for the Ford foundation, _____ Cokley
- Service dog, for example
- Burden of proof
- Quick-witted
- Blind and partially deaf, he travels the world independently- 2 words
- Shot glass capacity, roughly
- The eighth CEO of AmeriCorps and one of the people who launched the My Brother's Keeper initiative, Michael D. _____
- Lock openers
- Org. that can give you a tow, abbr.
- James Bond doctor
- Consumes
- Reward for winning coaches, 2 words
- Very large
- Large conflict
- Put into practice
- Celebrity singing at the True Colors Festivals- promoting diversity, 2 words
- Help others unselfishly
- Culturally deaf woman's motorcross star, _____ Fiolek (familiarily)
- Director of "Avatar: The Way of Water"
- Roman Polianskyi from Ukraine won the gold medal in this sport
- Angle
- It often crosses a street, abbr.
- Disabled actress Marlee Matlin won one
- Cookie
- "When will I _____ you again?" Three Degrees song

answers on page 76

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AUTHOR

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

VOTED BEST

- Newsweek Showcase Top Doctor
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- Olympic Athletes

FOR PATIENTS

18-45

- Thin Flap Lasik
- ICL

FOR PATIENTS

45-65

- Superlasik
- Pi in Eye

FOR PATIENTS

ABOVE 65

- Pi in Eye
- Laser Cataract Surgery

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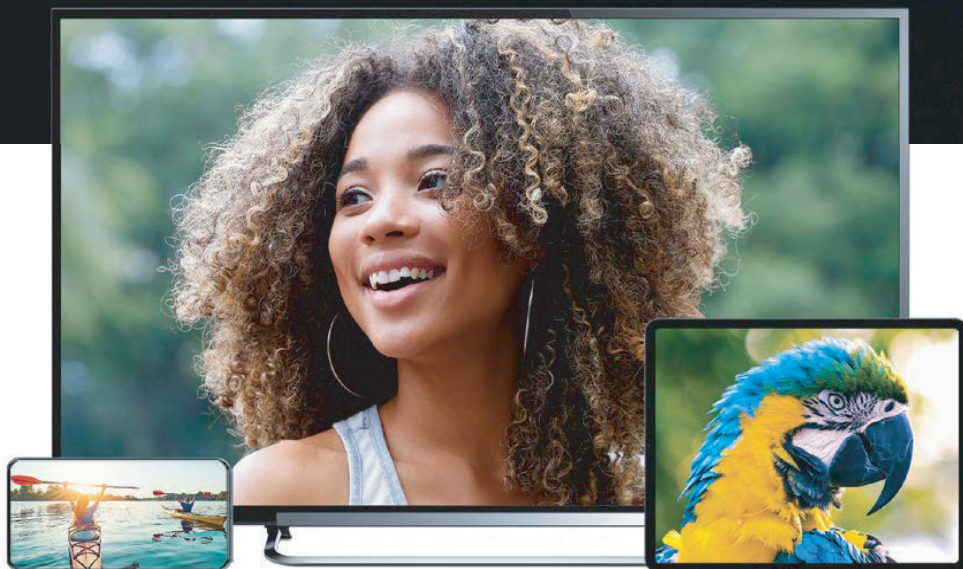
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- For the tenth consecutive year, readers of **CAREERS & the disABLED** magazine recognized Wells Fargo as one of 2021's Top 50 Employers of people with disabilities.
- **Equal Opportunity** magazine ranks Wells Fargo No. 15 on the 30th Annual Top 50 Employers 2021 list.

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