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My name is Michael Mahoney. When I was 22, I broke my neck in a diving accident. I didn't know how my medical bills would get paid, or if I would ever work again.

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#### COVER STORY TAKING ON THE UNFRIENDLY SKIES

In his 2017 story, KENNY SALVINI spoke with industry experts, policy advocates and fellow wheelchair users as he tried to make sense of the dismal situation facing air travelers with mobility disabilities. Six years later, he's back, and guess what? Things are still terrible — and maybe even worse. Salvini examines what went wrong and looks at behind-the-scenes work that offers glimpses of a more accessible future. We've also got great air travel tips for wheelchair users, as well as readers' flying nightmares and success stories.

#### 30

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### **BULLY PULPIT**

By Ian Ruder

#### THE BULLY PULPIT GETS BULLIED

I had planned the perfect Bully Pulpit for this issue.

A cross-country trip to attend a conference seemed like the ideal opportunity to write about my first flight in almost four years. Surely the hours I'd spent agonizing over how to handle my first trip with a colostomy and my first time traveling with my current power chair would translate to a thoughtful Bully Pulpit.

I'd packed my bags and started writing the column in my head. Then, with less than 12 hours until my 4 a.m. wake-up call, my body started writing its own story. Much to my chagrin, it focused on dysreflexia.

I've written here before about my battle with my bladder. To make a long story short: After 25 years with a suprapubic catheter, my bladder and I no longer see eye to eye and have been locked in a struggle for dominance for the past 18 months. Part of my excitement for the trip was thinking I had finally found a working solution that would allow the two of us, my bladder and me, to travel in harmony.

Five problem-free days leading up to the trip helped diminish my concerns about the tube causing an incident on the five-hour flight. Two bouts of dysreflexia in less than four hours brought it all back again. Most frustratingly, neither followed the pattern of the issues I had been struggling with.

In the comfort of my home, both flareups would be manageable — a catheter change and some time in bed were all my body usually needed — but on a plane? My attendant and I tried to wrap our heads around a possible solution, but not knowing the exact cause made an already-difficult problem seem impossible.

This was supposed to be my big return to flying! Column material aside, I'd built the trip up in my head as a needed reminder that air travel is doable and that after a few years of dealing with some tough medical issues I was back on the upswing.

Now I was just stressed about what to do next. In my mind, canceling at the last minute was akin to admitting that the upswing was a lie. At the same time, going forward with the trip was like going all-in on a weak hand.

Adding to the cocktail of stress and frustration was a sense of guilt. The event organizers had gone above and beyond to accommodate me. You can say that's what they should do, or have to do, and you'd be right. But there were a lot of speakers they could have invited who didn't come with all the added costs and hassle of traveling with an attendant. I wanted to validate their effort and show why the extra effort was worth it.

Physically and emotionally worn out, I eventually decided to cancel. I wish I could say it felt like the right decision, but at the time it felt like failure. When the dysreflexia passed, my body felt fine. Maybe if I just went ahead, everything would go smoothly and I'd come away with the confidence boost I'd been looking for. Doubt corrupted all my thoughts: Did I stress myself into dysreflexia? Had I been looking for an excuse? Was I afraid of flying again?

Later that night, a few hours before I would have been transferring into an aisle chair for the flight, the dysreflexia returned with a vengeance. As much as I hated writhing in bed in discomfort, it did make me feel better about my decision to cancel.

I've yet to pull any life-changing or revealing insights from the whole incident, aside from the fact that sometimes there simply aren't any appealing choices. Sometimes even the Bully Pulpit gets bullied.



### **BEHIND THE STORIES**

With Ian Ruder

In this issue's cover story, **Kenny Salvini** reexamines the state of accessible air travel. Don't miss the article for his findings, but rest assured, the airline industry would be hard-pressed to keep up with the rapid advance of his personal life in the six years since his last airline piece. He received an honorable mention award for excellence in reporting on disability from the Ruderman Family Foundation for his 2017 NM cover story, got married to an amazing woman, became a father, and continued to advocate for improved accessible air travel — all while growing the Here and Now Project, the SCI-focused nonprofit he start-



ed. "I guess it's just about doing life and embracing the path in front of you," says Salvini. "I'm in a very privileged position to get to live the life that I have and do meaningful work."



Alex Ghenis was the easy choice to profile fellow Cal-Berkeley grad Austin Whitney, a leader in music festival accessibility. It turned out the two had already crossed paths over a decade ago. Ghenis nailed the story, just like he did earlier this year when he profiled Wheel the World founder Alvaro Silberstein. When he's not writing about interesting wheelchair users, Ghenis works as the deputy director of Sustain Our Abilities, a nonprofit focused on health and climate justice for disabled people. "People with disabilities are arguably the hardest-hit group when it comes to climate change," he says. "Climate ad-

aptation and the transition to a green economy must address our needs and protect our rights. That way, our community can continue to grow and thrive."

**Doug Davis**'s angry airplane illustration from our December 2017 issue remains one of our most iconic covers, so of course we had to bring him back for the follow-up story. Not surprisingly, he hit it out of the park again. He's been doing that consistently for NEW MOBILITY since 1998, contributing more than a dozen covers and too many interior illustrations to count. Years of inking award-winning editorial cartoons have helped Davis hone the process. "It's fun," he says. "I get to get a little loose and try and figure out something that's funny but also make a point." Davis lives in Pasadena, California, with his wife and son. You can follow him and find more of his work at douginks.com.



Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org

United Spinal's Resource Center provides information on any aspect of living with SCI/D. Contact: 800/962-9629; unitedspinal.org/ask-us; 120-34 Queens Blvd, Suite 320, Kew Gardens, NY 11415.



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#### **FEATURED WEB PARTNER:**

Curb Free with Cory Lee is an awardwinning travel blog devoted to sharing the world from a wheelchair user's perspective. Featured in National Geographic and on the Travel Channel. Curbfreewithcorylee.com



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## SHARE

## "How did they even get on the table?"

#### When an Accessible Hotel 'Reservation' Doesn't Guarantee Anything

**Discrimination:** I've had this happen three times in the past six months with Marriott hotels. This is discrimination. It happened occasionally pre-COVID but seems more frequent now. My situation is that on both occasions they were able to at least find an accessible room on the property, but they were clearly rooms that were not intended to be used. They were in poor repair with toilets not working, blinds broken, towel racks off the wall. I would be interested in speaking to the author of the article and discussing organizing a class action suit. Not because I want money, but I want this discrimination to stop!

#### Kristi Saul

Newmobility.com

**Taking Action:** Thanks so much for writing this article! I pulled it up and quoted it to the hotel clerk tonight! I'll be filing a complaint with the DOJ! And entering my experience in your form! @the\_squeaky\_caster

Instagram

Marriott Makes the Cut: I'm sure this happens with other hotel chains as well, and maybe even more specifically with individual hotels. I typically stay with Marriott-affiliated hotels. I have had outstanding experiences, even when confronted with obstacles. I stayed at a Marriott-owned W Hotel in Atlanta while doing driver's training at Shepherd Center. When I got into my room, the bed was a platform bed. The front wheels of my lift would not go under the bed. They sent up a maintenance supervisor, who was very compassionate. Within an hour, he had gone to the local hardware store, purchased what he needed to raise the bed enough for my lift to work, and the issue was fixed. I had an amazing stay for the week. I've had other situations where the folding shower bench blocked me from using my personal shower chair. Again, maintenance comes up and either removes or modifies the shower bench. I suppose I've been very fortunate. I understand not everyone is.

**Benjamin Elstad** Newmobility.com

#### Marriott Misses the Mark, Again:

Marriott brands are THE worst when it comes to this. They don't block the rooms in the system. I've not had problems with Westins or Hiltons. But it's a big problem — sorry that you went through it!

**@debrajackson0419** Instagram

## Five Pro Tips for Flying with a Power Wheelchair

**Too Tall to Travel:** I'm 6'2" with an SCI, and I don't even fit on the damn airplane chair because my legs are too long. I still don't get why they can't have one seat at the front of the plane to roll right onto and then just lock the chair in place like they do on buses. Or have a removable chair to replace with a wheelchair. I quit traveling by plane.

#### Michael A.

Newmobility.com

#### Airline Seat Prototype Could Change Travel for Wheelchair Users

**Would Love to Fly with My Chair:** I hope we're able to see this happen in my husband's and my lifetime. His Per-



mobil chair is a beast. I just don't know how it would even maneuver on any airline. That's why we never fly with it. *TLC Newmobility.com* 

**Priorities:** That's great, but first they need accessible bathrooms. The cart before the horse.

**Joseph Koval** Newmobility.com

#### Wheelchair-Using Teachers Give the Next Generation a More Accurate View of Disability

**Real Impact:** Love this article! I am paraplegic and teach part-time. Yes, the interaction is huge with young people. I am never surprised with lack of access in a classroom — especially with the current classroom size. All-in-all, people that love to teach do it!

#### Shirley Johnson

Newmobility.com

**Teaching Benefits:** I taught history and language at a design school, and being a wheelchair user, I was able to make students more aware of the effect of language they used, as well as designs, especially architectural interiors (such as where to put a light switch).

#### Tim Vermande

Newmobility.com

#### **Doctors Still Have No Idea How to Treat People with Disabilities**

**Technique, Please:** How did they even get on the table?? When my paraplegic hubby goes to the doctor most don't have a table he can transfer to.

#### be.hapie

Instagram

**Clueless:** My experience with the medical profession over my 30-40 years is that they are all clueless! Now add almost deaf to the mobility issue ... I can't get them to even face me when they speak. As frustrating as it is, I've learned to not let their ignorance upset me. I have more important things to spend my energy on, so I can't let them sap my remaining abilities! I'm constantly amazed at how appreciative some people are — even the carry-out clerks at the grocery store! — to learn a trick to help folks like us. It helps to display the ability to laugh at things/situations, too.

Mary McHugh Facebook

гасероок

Education Key: I have been quadriplegic since 1972. I also worked as a health care clinician for over 26 years in Eugene, Oregon. I agree with the article's assessment regarding knowledge of physicians related to persons with disabilities. I've had to educate my PCP since we first began working together properly 25 years ago. My biggest concern now that I'm a senior is that when he retires, I will be in a more critical position, as I have several underlying conditions in addition to my quadriplegia.

Even though I have several of these conditions, I'm sure as I age there will be more. I do have knowledgeable specialists – fortunately in the town where I live – that provide excellent care and follow-through. Having said that, anytime I've been hospitalized, I make sure I have someone on my personal care team from home - i.e., my wife, kids, friends or caregiver - in my hospital room 24 hours a day/7 days a week to make sure there is follow-through with my protocol in the charts. It is unfortunate that many nurses and physicians in hospitals are clueless about spinal cord injury in topics like autonomic dysreflexia. I've also had to take precautions related to making

sure I have a hospital bed with a mattress that will help me prevent pressure ulcers while I'm a patient.

Education is always ongoing when it comes to healthcare as well as other aspects of my life related to my disability. ADA is an important tool, but very few of my personal physicians work in medical groups that have treatment rooms with beds that I can transfer onto, a scale to weigh me or diagnostic equipment (most recent eye doctor appointment) that I can access to get the full scope of the health of my eyes.

#### Tim Shearer

Eugene, Oregon

**Editor:** Read about a recent case where DOJ sued and settled with eyecare facilities in Arizona at justice.gov/crt/case/us-v-barnet-dulaney-perkins-eye-center-pc

Left Without Treatment: My husband was in the hospital for a pressure sore that needed dead tissue removed. Unfortunately, I tried fighting for a special bed and had limited success. They refused to understand. They also did not understand that he does not know when he is going to have a bowel movement, so I wanted them to do manual stimulation each day to ensure no problems. It never made it onto the chart, and even if it did, the nurses were not willing to do it since they were too busy or they didn't understand why it needed to be done. I came in after the surgery to find him lying in his stool, and the nurses said he didn't tell them. They said they would have put a bed pan under him. I told them that they couldn't do that. I ended up doing his bowels every evening after that. He also was not rolled, so that by the time they got him to a specialty hospital, he had four pressure sores rather than one. I could not be there all day. Treatment was horrible. Here we are seven months later at home - still working to get the wounds healed.

#### Amy Rupert

Newmobility.com

**III-Equipped:** It is horrendous that the hospitals and doctors' offices and imaging facilities do not have patient lifts and, if they do, do not know how to use them!

They sent a couple of staff members to transfer a 250-pound man into a power chair. What a liability waiting to happen!

On several occasions we have had to leave, against medical advice, because of ignorance on the part of the medical team. Dysreflexia, bowel program issues, lack of mattress support, all of the above. The VA has the best trained medical personnel and medical equipment accommodations that we have interacted with.

#### Ellen Esposito

Newmobility.com

#### We Must Compel Change: Out-

standing article. Michael Hickson's case is a tragedy. We spoke out against the egregious ableism that resulted in his demise, requesting the Department of Health and Human Services Office of Civil Rights to investigate the matter. As your article points out, physicians do not know their federal nondiscrimination mandates under the ADA, Section 504 or Section 1557 [of the Affordable Care Act]. In large part it's due to little or no coverage of those obligations in any of their medical training. But that's only the half of it. As a community, we have to look at ourselves while we try to assess the reason for not obtaining the care and treatment we need (as we do not advocate and enforce our rights). In my experience, unless healthcare providers are compelled to comply with those nondiscrimination mandates, they simply will not.

We have been waiting for the Department of Health and Human Services Office of Civil Rights and the Department of Justice to issue their notice of proposed rulemaking, which is forthcoming. Those regulations will be helpful in providing clear specificity on what healthcare providers must do by way of having accessible medical diagnostic equipment, which includes accessible exam tables and weight scales, among other things. Specific and robust regulations are meaningless, however, if we as a community do not become better patient advocates and enforce our rights.

#### Andrés J. Gallegos, Chairman, National Council on Disability Newmobility.com

### POSTS

#### A Wearable, Multipurpose Gripping Aid

Living with a limited grip presents a lot of challenges when trying to get through your day. Many adaptive products are designed to help with specific tasks, but it can be frustrating and expensive having different devices for different activities. Adaptive-aid company Hominid X has introduced a new product to address this problem: a single device to help



grasp most of the items you might need during the day.

Hominid X's Fiber wearable device is secured with two adjustable straps — one around the wrist and another around the fingertips. A cylinder on the watch-style wristband contains a spring-loaded cable to be drawn around an object and clipped to a hook at your fingertips. Once the cable is hooked, the spring retracts the cable and

creates a strong natural grip using your fingers. Fiber allows you to confidently grasp items as small as a pen or as large as a roll of paper towels.

You can purchase Fiber for \$99 at hominidx.com, which includes a 30-day return policy to see if it is right for you. Check newmobility.com for a review by our gadgets guy, Michael Franz, a C5-6 quad.



Ryan Kennealy's entry into our Al image contest didn't make the deadline, but we thought it was cool enough to share anyway. See the winning entries on page 28.



**ISTEN** 

IF YOU LIKE YOUR RAP WITH A GOOD DOSE OF DISABILITY PRIDE, LISTEN TO SHINING AND ROLLING FROM WHEELCHAIR-USING MC NAMEL "TAPWATERZ" NORRIS. THE CO-FOUNDER OF HIP-HOP GROUP 4 WHEEL CITY COLLABORATED ON THIS NEWLY RELEASED SINGLE WITH MULTI-PLATINUM PRODUCER HIT-BOY, WHO HAS WORKED WITH JAY-Z, BEYONCE AND EMINEM.



"I TURNED A BEAT INTO A SONG, A SONG INTO A MOVE-MENT, AND THEY STILL ACT LIKE I DON'T KNOW WHAT I'M DOING," NORRIS RAPS ON THE SONG, WHICH HE RELEASED DUR-ING DISABILITY PRIDE MONTH. HE HOPES HIS MUSIC CAN "HELP PEOPLE WITH DISABILITIES FEEL PROUD OF WHO THEY ARE." SHINING AND ROLLING IS AVAIL-ABLE ON MAJOR STREAMING PLATFORMS LIKE SPOTIFY AND APPLE MUSIC, AND YOU CAN WATCH THE MUSIC VIDEO AT YOUTU.BE/AR7SOB4DTUC. READ

OUR 2014 PROFILE OF 4 WHEEL CITY AT NEWMOBILITY. COM/4-WHEEL-CITY.



#### Youngest Ever To Win at Wimbledon

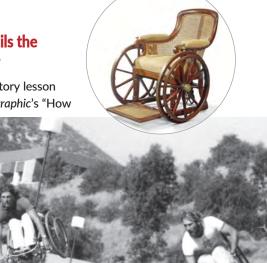
In July, Japanese teenager Tokito Oda became the youngest man to win a tennis singles title at Wimbledon. Oda was 17 years, 69 days old when he beat Alfie Hewitt in the men's wheelchair final, breaking the record held since 1985 by Boris Becker, one of the greatest nondisabled tennis players of all time.

"I'm still 17. So, I want to open a champagne, but I couldn't," Oda said to reporters following his victory. "So I have to drink sparkling water." Read more about Oda at paralympic.org/news/japan-s-oda-becomesyoungest-man-ever-win-wimbledon-title, and follow him on Instagram at @tokitooda.

## National Geographic Details the History of the Wheelchair

Anyone up for a fascinating history lesson should check out *National Geographic*'s "How

the Wheelchair Opened Up the World to Millions of People." Did you know that the world's first selfpropelled wheelchair operated more like a handcycle and was built in 1655 by a disabled clockmaker in Germany so he could get to church? If you did, bravo, and



Eric Walls, left, and Brad Parks side wheelie down a steep hill in the early days of the Quadra.

thanks for your work as a disability studies professor.

The rest of us can learn a ton from the article, including how wheelchairs were known as "Merlin chairs" for more than a century, and that the hotspot for rich disabled people back in the 1800s was the Roman baths in Bath, England. The big takeaway from hundreds of years of wheelchair development is that most of the innovations have come from wheelchair users themselves, looking to take more agency over their lives.

Read the full article at urlis.net/ mwn26q14 and check out NEW MOBILITY's history of the revolutionary Quadra wheelchair at newmobility.com/quadra-and-thelightweight-wheelchair-revolution.



#### A New Take on Disability Life Skills

There are countless "how-to" videos for wheelchair users on YouTube, but a functional mobility skills course from the nonprofit More Than Walking takes instruction to a new level. Each activity is broken into two videos — one of a wheelchair user demonstrating and explaining their process, and a second where a physical therapist breaks down the activity into separate steps and explains key muscles, precautions and progression strategies.

So far, they have a three-part "Getting Out of Bed" series for low-level quads, but the end goal is to build a step-by-step course of major dailyliving skills for every SCI injury level group. Go to morethanwalking.com/course to see the videos. The nonprofit also offers a wide variety of well-made skill-demonstration videos at morethanwalking.com/demonstrations.

## WATCH

QUINN BRETT WAS AN ACCOMPLISHED ROCK CLIMBER WHO SUSTAINED A T11 SCI IN 2017 WHILE SPEED-CLIMBING EL CAPITAN, THE WORLD-FAMOUS VERTICAL GRANITE FORMATION AT YOSEMITE NATIONAL PARK. THE DOCUMENTARY AN ACCIDENTAL LIFE FOLLOWS THE EARLY YEARS OF HER RECOVERY, WITH AN UNFLINCHING EYE. THE FILM IS AT TIMES JOYOUS AND OFTEN RAW AS BRETT CONFRONTS THE PHYSICAL AND EMOTIONAL STRUGGLES OF LEARNING TO RECLAIM SOME OF HER PREVIOUS PASSIONS WHILE ACCEPTING HER NEW REALITY. YOU CAN WATCH AN ACCIDENTAL LIFE ON BOTH APPLE TV+ AND AMAZON PRIME.



By Shannon Kelly

#### Nebraska Chapter Gets Rolling

Nebraska member Nancy Berg started an Instagram page in 2019 to share accessible and adaptive activities for wheelchair users in the Omaha area. "The account, @accessible402, connected me to people in the disability community. I helped start a women's SCI support group, and scheduled monthly meetups for those with spinal cord injuries," says Berg, who has an L3-4 SCI.

Through the account, she met a friend involved with the Iowa Chapter of United Spinal. From her, Berg saw the value of creating a chapter in her own state and got to work doing so. Her goals for the chapter included a peer-mentoring program, social events, and opportunities for disability-related businesses in Nebraska to network with the group.

"Sustaining a spinal cord injury is life-changing. When I was first injured, I didn't know anyone with an SCI and the first years of adjusting to my new life were difficult. I had so many questions and I would have loved to have a group that I could go to for support," she says. "By joining a United Spinal chapter, it gives those impacted by SCI/D the resources, support, assistance and the opportunity to get involved with people who are going through similar circumstances."

To get involved with the Nebraska chapter, email unitedspinalne@gmail.com. To learn more about United Spinal's Chapter Network, visit: unitedspinal.org/support/chapter-network.





#### Parents of Kids with SCI/D Unite

United Spinal's newest support group aims to be a virtual safe haven for parents and guardians who are caregivers of children, adolescents or young adults with spinal cord injuries or other mobility or developmental disorders. "Although parents of children with SCI/D have always been valued members of United Spinal, we recognized that there wasn't a set space for them to come together," says group facilitator and occupational therapy doctoral student, Elena Martino. "The group so far has included parents of children ranging from 7-30 years old, and has been a wonderful opportunity for parents from all around the country to share their experiences and provide advice on challenges."

Meetings consist of guided discussions on parent-chosen topics which include navigating through tough transitions, home exercise programs, skin integrity education, adaptive dressing, resources for adaptive recreation and assistive technology, and more. The cohort plans to meet online monthly. For more information, contact Lindsey Elliott at lelliott@unitedspinal.org.

#### **Meet New Member Ryan Price**

C7 Complete SCI, Age 46 from Fairfield, Connecticut Hobby: Live performances and exercising, including Zumba

#### Why did you join United Spinal?

I met [VP of Community Support] Matt Castelluccio at an adaptive sports expo at Burke Rehab; based on the many good things he said about United Spinal Association, I knew I just had to join.

#### What is the one product you couldn't live without?

I am very lucky to have a Chrysler Pacifica with BraunAbility Ramp conversion. My van provides me with a great sense of freedom and purpose: I can travel to adaptive sports events and take my children to various sports practices and commitments, or just simply go out for a drive.

#### If you could change one thing in the world to improve quality of life for wheelchair users, what would it be?

I would make airplane travel policies and procedures for wheelchair users much more standardized and accessible.

#### Find Us at the Abilities Expo

The popular Abilities Expo showcases innovative products, shares knowledge and fosters a sense of community among the disability community. It demonstrates cutting-edge assistive technologies, mobility devices, adaptive sports equipment and other products designed to enhance

NM Editor-in-Chief **Ian Ruder and Lindsey Elliott, Senior Director** of Community and Peer Support, staffed the United Spinal booth at the Los Angeles Abilities Expo in March.

MIMINI

MAR

Dallas: Dec. 1-3, 2023.

New York: May 3-5, 2024.

die

Los Angeles: March 15-17, 2024.

independence and improve quality of life. The Abilities Expo is also a platform for learning and growth: The event provides a diverse range of workshops and seminars, covering accessible housing, employment opportunities, adaptive sports, inclusive education and disability rights. Most importantly, it brings together individuals, families, caregivers, advocates and professionals, creating an environment where experiences can be shared, stories can be heard and connections can be made. Come visit United Spinal at upcoming expos to learn more about our programs and services! Phoenix: Sept. 8-10, 2023. Fort Lauderdale: Oct. 13-15, 2023.

#### **Roll on Capitol Hill Recap**

In June, United Spinal Association's 11th annual Roll on Capitol Hill brought more than 100 advocates from 35 states to Washington, D.C., meeting with more than 150 Congressional offices and advocating for policies that will help wheelchair users and people with mobility disabilities live their lives to the fullest. This year's policy and advocacy priorities were safer air travel, more accessible ground transportation and improved insurance coverage of wheelchairs.

"Sharing the perspectives of wheelchair users with policymakers is critical to ensure that the laws and regulations our government makes take our members' lived experiences into account," says Steve Lieberman, director of advocacy and policy.

This year's event was the largest ROCH to date, bringing together an eclectic mix of veteran advocates and first-timers. Many reflected on invaluable experiences they had on the Hill.

"I'm excited to have new members here to add different voices and experiences. When you add fresh new faces, that means greater voices and greater accomplishments in the work that we are trying to do," says Monica Wiley, a United Spinal board member representing Maryland.

The Roll on Capitol Hill brings together individuals, organizations and businesses committed to disability rights. United Spinal and its partners have formed a powerful coalition capable of driving significant advancements in disability policy and projecting a collective voice advocating for change.

"I always say that 'this isn't my thing.' I'm super uncomfortable when speaking about myself and expressing any needs I have. However, (ROCH) taught me just how important my voice can be. My voice matters. And when individual voices come together to express the same needs, the (sound) can be deafening, and that's when the change happens," says Meg Hammond, representing Ohio.

By amplifying voices and advocating for legislative change – on Capitol Hill and beyond – United Spinal continues to progress toward a more inclusive and accessible society. Learn more and get involved at unitedspinal.org/advocacy-program.

## HOW WE ROLL

#### editor, writer and comic book geek dad Aaron Broverman



Aaron Broverman, 37, has been writing How We Roll since 2019. For the final entry, he's pulling back the curtain on his 17 years as a journalist and his recent foray into fatherhood.

### The Man Behind How We Roll

I've been writing How We Roll for four years, and I've enjoyed every second of it, but as my life gets busier and busier juggling parenthood and being the Lead Editor at *Forbes Advisor Canada*, it's time to end this column and look back on how I got here.

When I graduated from Toronto Metropolitan University in 2007 with a bachelor's degree in journalism, I didn't get the big, flashy newspaper internships at the *Toronto Star* or *The Globe and Mail*, and no editors were waiting with an entertainment reporter job or taking my pitches about Canada's comic book community. Sure, I got to interview celebrities like Dog the Bounty Hunter, Criss Angel and Stan Lee every so often, but it wasn't enough to make a comfortable living.

So, I made a conscious decision to write what I knew and exploit my status as a guy with cerebral palsy by writing about disability. Even then, it still took bumping into the editor at a book fair before I was regularly featured in *Abilities Magazine*, Canada's only national lifestyle magazine for people with disabilities. But after a few years, I grew tired of its tendency to comfort the afflicted without afflicting the comfortable. In my university's journalism review, I wrote about the fact that Canada's disability



media had no teeth. In 2009, I started freelancing for NEW MOBILITY. I was excited to cover disability issues with a little more depth and without the inspiration porn.

Meanwhile, my handling editor on that disability media feature, Bruce Gillespie – remember the name – was also the editor of Bankrate Canada and invited me to contribute. At the time, I saw it as consistent freelance work until I could make those entertainment-reporter dreams work, but that one job led to more personal finance freelancing with AOL, Yahoo and creditcards. com, since the editors who syndicated my Bankrate articles on those websites took notice.

I still wasn't sure personal finance journalism should be my career until I sat down for coffee with my former teacher at TMU — the late, great Stephen Trumper — who had a huge influence on me as the only wheelchair-using teacher and journalism professor I ever had. He gave me some great advice:

"Everyone is going to always need personal finance help and investment advice. Entertainment lives and dies by its funding model, and [entertainment is] the first thing to go when budgets get slashed. Don't struggle along with that

**CAN'T LIVE WITHOUT:** Right now, my highly detailed and articulated collection of Hot Toys figures.



**GREATEST ACCOMPLISHMENT:** Making it through the fiery gauntlet of the Season 21 Hot Ones chicken wing challenge on Father's Day 2023.



boom-and-bust cycle - go where the money is."

So, even though I passed high school math with just over 50%, I leaned in. I got better the more I worked at it and realized personal finance journalism isn't just about the numbers, but also the human stories behind them. Eventually, I built up a freelance resume that featured almost every prominent personal finance outlet on the web, from NerdWallet to Money Under 30.

It was a great 15-year freelance career, but by 2021, with a 1-year-old in tow (see sidebar), I needed a steadier paycheck, and who should come back with a recommendation at just the right time but Bruce Gillespie, the man who gave me my first opportunity at Bankrate. Turns out, the chief copy editor from back when we worked there, Katie Doyle, was now the senior vice president of content at *Forbes Marketplace*, and after successfully launching *Forbes Advisor* in the U.S., she was looking for someone to lead an editorial team that would launch the same personal finance brand in Canada. Bruce recommended me.

Thankfully, she remembered me, and I haven't looked back since. I finally get to pass on my knowledge and experience, while getting the opportunity to build something significant from the ground up.

### **Parenting: A War of Attrition**

Broverman details his successes and struggles as a new father of a son with dwarfism, along with his hopes for the future.

Ouring World War I, the front shifted no more than 80 kilometers until 18 months before the war's end. That's what parenting can feel like a lot of the time to me. I'm killing myself every day only to see a little bit of progress. Not to mention, raising a 3-year-old in particular is like someone just threw a grenade into a

crowded room — you are just going about your day and then suddenly, chaos.

So why did I make this decision? Why did I go in with an inadequate support system, knowing that as a person with a disability, taking care of your own needs can already be taxing? Because the little



moments of success are worth it. When my son was first born, I wondered how this thing that sleeps, eats and needs to be carried everywhere would ever become a full-fledged human being. I can tell you that watching that evolution take place before your eyes is nothing short of magical.

Besides, even though I'm not the preferred parent now, and he doesn't listen to any instruction I give him, my day will come. After all, I'm the one with the comic book and action figure collection.





#### ONE THING PEOPLE WOULDN'T KNOW ABOUT

**YOU:** I am a purple belt in Brazilian jiujitsu.

#### WHY DID YOU JOIN UNITED SPINAL?

I didn't so much join as I was sucked in. It keeps my ear to the ground in the SCI community I cover.



## PRODUCTS

By Seth McBride

#### LIGNORIM WOODEN HANDRIMS ARE MORE THAN A NOVELTY

I first heard of Lignorim handrims from a NEW MOBILITY reader. When we published our Gear Guide detailing all the handrims available in the U.S., a helpful reader pointed out that we'd left out a new wooden handrim from Austria. I was intrigued — wood with its natural texture just feels nicer than metal or vinyl, plus it doesn't transfer temperature like metal does. How would the material do in hot or wet weather? Just as important, how would it hold up over time?

Fortunately, it wasn't long before I started learning answers to my myriad questions, because Vapor Wheels had just signed on as the U.S. distributor for Lignorim, and its sales rep offered to send a pair for an extended review. Here's what I found.

#### The Details

Lignorim are made of ash, a hardwood used in tool and shovel handles and in baseball bats because of its natural shock absorption and resistance to impacts. It is durable and resists cracking. That's nice to know when you drop your wheels when pulling them into your car, or when an airline employee starts throwing them around the baggage belt. To shape the wood into circular handrims, Lignorim uses a laminate process common in Europe for structural timber in houses, which the company says further increases durability and water resistance, while reducing possibility of splintering.

The wooden rims are available in four models: light, medium, big and prime. Light is a small-diameter round rim about the size of a typical metal handrim. Medium and big are both oval-shaped, which some find more comfortable to grip. Prime is the largest rim, with an ergonomically contoured gripping sur-



face. All rims are available in 24- and 25-inch sizes, and come with six-tab mounts drilled with three holes for narrow, medium and wide mounting. You can choose from a variety of colors, from natural — a light tan — to flashy, including bright blue, green, red, pink, jet black and more. I opted for the lightweight model in a natural color, as I wanted to be able to see how they wore and how dirty they got pushing everywhere from the farm to the city.

#### **Initial Thoughts**

The rims are beautiful. I can count on one thumb the number of times I've said that about a mobility product. The wooden texture adds a classy, natural touch to a type of product often defined by harsh functionality. To be fair, I have a thing for Scandinavian cabins, so anything with clean lines and light wood is likely to hit my aesthetic sweet spot. But I've also gotten more comments about the Lignorim than other piece of wheelchair equipment l've used. Other wheelchair users and even nondisabled strangers stop to ogle my rims and ask if they're really wood. "Yes, sir, I'm all natural."

The light model Lignorim isn't featherlight, but it's not heavy. It weighs about 10% more than a standard aluminum handrim, at about 0.9 pounds each versus 0.8 pounds for aluminum. I have run them on a pair of demo Vapor X carbon fiber wheels and on my everyday Spinergy LXLs, and didn't feel like the handrims were weighing down either pair like vinyl ones do.

Straight out of the box, the Lignorims felt tackier for pushing than metal handrims, and more slippery than fresh vinyl handrims or any other quadspecific offering. I have no grip strength, so I push and brake entirely by friction. Pushing inside or on flat, smooth surfaces was fine without gloves, but for any hills, rough terrain and/or distance, I used a trusty pair of rubber garden gloves for grip. Braking power was good enough that I didn't need gloves. Immediately I noticed braking was easier than with metal rims, and generated significantly less heat than vinyl or foam. I could stop myself on a hill without burning my hands or wrists. I don't have any way to quantify this, but they also just felt nicer on my hands than metal or vinyl.

#### The Long Haul

I've been using the Lignorims for over eight months now, starting in a hot autumn, through a snowy winter, a wet spring and now into a bone-dry summer. If anything, I like them better now than when I first put them on. They still look great and have proved way more durable than I would've guessed.

I've dropped them from my car, rimdown, on rough asphalt multiple times. I've scraped them against concrete curbs



and bumped them into metal poles. They have a few small scratches to show for it, but those mostly disappear into the wood grain. Importantly, they don't have any sharp burrs like metal rims produce and no jagged flaps like those that appear when you gouge vinyl rims. They are as smooth as the day I got them and have an even better hand-feel after months of use. There are no cracks, and I've had no splinters.

Where the wooden rims really excel

is in wet and cold weather. They don't transfer temperature, so they don't freeze your hands off in cold weather like metal handrims do. And when it's raining out they still give you braking power, a rare quality for any handrims.

#### **Final Verdict**

Lignorim is the nicest handrim I've ever pushed. It looks good and pushes better, and is more durable than anything else I've tried. Sure, as a quad with limited grip, it would be nice if they were tackier. But grip comes with drawbacks - typically heat while braking, and durability issues. For my uses, the trade-off is more than worth it. At \$479 a pair, they aren't cheap, but they are in line with other top-quality handrims like CarboLife's guad-specific offerings or Spinergy's titanium handrims. When buying mobility products, we often pay luxury prices for bargain-basement quality. Lignorim at least has something to show for its high price tag.



## R E T H I N K I N G

Hiking the accessible trail to take in the view from the top of Mogollon Rim is one of many highlights at Camp with a Ramp. BY CHERYL ANGELELLI





#### t's time to go home. You'll figure it out."

(()

That's what Joe Rohling heard when he was discharged from inpatient rehabilitation one month after a rare genetic disease caused his spinal cord injury. He left wanting more. "I felt they did a good job, but there were things I never really got to do ... there just wasn't enough time," he says. "You learn the basics and then you just have to move on."

Over the past 50 years, SCI rehab stays have drastically shortened to an average of 26 days, and to 13 days for a nontraumatic SCI — a far cry from the three- to six-month stays of earlier times. For a newly injured person, it is difficult to imagine and work toward a purposeful future given such a short window.

"With shorter stays we have patients leaving while they are still in a cervical collar," says Tina Fisk, a home and community occupational therapist, and co-founder and director of the nonprofit Camp With a Ramp. "At that point they aren't ready for real-world education and learning about activities."

As a physical therapist, Carrie Callahan grew tired of watching people get sent home simply because their insurance said it was time. "We are so focused on survival (at traditional rehabs) that we never quite get around to teaching someone how to get back to living," says Callahan, president and co-founder of the nonprofit Empower SCI.

To help address this and many other issues arising from shorter inpatient stays, Fisk, Callahan and others are building new experiences to teach and instill the skills and confidence needed to live life after SCI to the fullest. Combining physical activities, daily living skills, community building, peer mentoring and more, these new transitional rehab experiences are changing the face of SCI rehab. Here's a look at three of these transitional rehab providers and how they are filling the gap in the current "survival" rehabilitation model by thinking outside the box.

#### **EMPOWER SCI**

"I remember staring at a box of cereal on the fridge. I didn't know what a panic attack was until that moment," says Eli Ramos, 31, describing his anxiety when he was discharged home just eight weeks after sustaining a C6-7 SCI in 2012. Ramos was one of only two people on his rehab unit, and to commemorate the two-year anniversary of their injuries, the two friends decided to attend Empower SCI's twoweek boot camp at Stony Brook University, in Stony Brook, New York.

At the time he was a hotheaded 22-year-old with a lot of pent-up anger and trauma anxiety. "I almost left the first day, after a tense interaction with a staff member. Cooler heads prevailed and by the end of Day 2, I learned how to self-cath," says Ramos. "I realized how valuable an opportunity like this was, and I'd never forgive myself for leaving prematurely. By Day 3, I was fully entrenched in the Empower program and culture. Discomfort is vital for growth, so I got uncomfortable, but with a whole community rallying behind me."

Launched in 2012 by Callahan and two of her colleagues,

Empower SCI is a summer residential program for individuals at least one year post-SCI whose rehab benefits have been exhausted but who are ready to expand their knowledge and seek ways to live happier, more meaningful lives. A typical morning at Empower SCI consists of physical, occupational or massage therapy, yoga, rehab counseling, and educational sessions. Afternoons involve activities such as swimming, kayaking, cycling, surfing, rugby, painting and music classes.

The Empower SCI program is client-centered and intimate, with only 10-12 participants who choose two to three goals they want to accomplish during the program. Goal attainment is one way the program measures success. "We see a huge change from beginning to end because the program is designed to cater to whatever the person's goals are," says Callahan.

Participants come from across the U.S. This summer, Rohling, 68, will travel from his home in Weston, Wisconsin,

to attend Empower SCI's twoweek program, after participating in their one-week program last year. In the wake of his SCI three years ago, he had received almost 30 days of rehab at a local community hospital that covered basics but did not offer specialized SCI rehab.

Just getting to Empower SCI last year was his first accomplishment, because it was the first time he had flown since becoming a wheelchair user. In addition to enjoying all the adaptive sports offerings at Empower, Rohling got back into a pool again, and worked on wheelchair skills like curbhopping and how to transfer better. This year he wants to try kayaking.

#### **EMPOWER SCI DETAILS:**

**ACTIVITIES:** Adapted sports and recreation; peer mentoring; rehab counseling; physical, occupational and massage therapy.

**LOCATIONS:** Missoula, Montana, and Stony Brook University, Stony Brook, New York.

**PARTICIPANTS:** Adults with SCI, at least one year post-injury.

**DURATION:** One-week and two-week programs offered once a year in June and July.

**CAREGIVER SUPPORT:** Available on-site.

**cost:** \$2,000-\$4,000. Participants can apply for one of Empower SCI's scholarships to offset costs.

WEBSITE: empowersci.org

Peer-mentoring and knowledge-sharing are important aspects of the program. Mentors are matched with participants based on level of injury, hobbies and interests, among other factors.

"Meeting all the other SCI participants and hearing their experiences was really great," says Rohling. "I think at the end of the week, none of us really wanted to leave. Being away from home, away from your caregivers, the program really pushes you out of your comfort zone, but that's OK. If you fail at something, you have all these experts on hand to support you."

As for Ramos, he entered college as a full-time student shortly after his Empower SCI experience. "I remember telling myself, 'You can do this.' Empower SCI gave me more confidence: physically, emotionally and socially." Today he

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lives on his own, moonlights as a stand-up comedian and works full time as a business engagement associate in the New York City Mayor's Office for People With Disabilities. Even with his busy schedule, he finds time to volunteer as a peer mentor for Empower SCI.

"I owe a tremendous debt to this life-changing organization. I get to pay it forward and impart the wisdom and knowledge I acquired," he says. "I think that's the true testament to the success of the program: integrating into mainstream society and not becoming a professional patient."

#### SARGOOD ON COLLAROY

Forrest Campbell, 47, of Alberta, Canada, was looking for accessible accommodations to visit his in-laws in Australia on what was to be his first trip since becoming a quadriplegic in 2015. After what he described as a "lackluster" inpatient rehab stay, his wife and family worried they'd never be able to travel together. His mother-in-law suggested he look into Sargood on Collaroy.

Located on a spectacular headland at Collaroy Beach with breathtaking views of Sydney, Sargood on Collaroy is the first health-and-wellness resort built for people living with an SCI. Opened in 2017 and operated by Royal Rehab, a private Australian rehab provider, Sargood takes recovery beyond the clinical environment, tailors it to the individual, and integrates it with everyday life.

"When we arrived at Sargood, we were blown away by the accessibility," he says. The rooms were modern, comfortable and spacious, with automation of essential amenities: adjustableheight kitchen tops, adjustable beds for easy transfers, automated windows and blinds, and doors with easy-opening features.

Campbell was further blown away by the breadth of activities on offer. The recreational experiences at Sargood had a huge mental impact on him. "I was like, 'What do you mean, you can take me surfing?' The staff acted like everything was not a problem," he says. "I had just not run across anything like that in Canada."

Guests can choose from a variety of activities designed for people living with SCI, including surfing, golf, cooking classes, even whale watching. Sargood helps guests engage in new experiences and discover new skills. "(We are) not advertised as a rehab, but through recreation and other activities, you get the benefits of rehab, just delivered in a different way," says General Manager James Dakin.

Campbell's wife, Cassy, will never forget watching her husband surf. "Forrest went out on a jet-propelled board and caught his first wave. The look on his face was magical. I cried," she says. "We invested every emotional penny we had into recovery to get to this point. Now we were finally living again, not just recovering."

"Our concept was to provide this service where people aren't patients, they are guests," says Dakin. "It's a place people want to keep coming to." Instead of nurses doing rounds, Sargood's staff of care workers provide assistance to guests who need it. The \$22 million development features 17 accessible rooms, three designed for families.

Jodie Parker hadn't been away from home in nearly four years. "Before my accident I was naturally adventurous," she says. "I had ticked skydiving and snorkeling the Great Barrier Reef off my bucket list, and I was on my way to getting

my pilot's license." But after her SCI in 2011, she struggled with her physical limitations and rarely left home. All of that changed on her first of many visits to Sargood.

"The staff and adaptive technology there made a difference in my ability and desire to travel," she says. "Staying here has given me a better understanding of what equipment I need, and opened up a world of ideas on how to make my own home more accessible. I am now waiting on a quote to install doors at home that are just like the ones at Sargood."

Guests come from all over the world. "It creates a sense of community, where people can speak openly about their injuries," says Campbell,

#### SARGOOD ON COLLAROY DETAILS:

**ACTIVITIES:** Adapted sports and leisure, fitness, physical therapy, and educational courses.

**LOCATION:** New South Wales, Australia.

**PARTICIPANTS:** Adults and children with SCI.

**DURATION:** Single and multiple overnight stay packages available.

**CAREGIVER SUPPORT:** Available on-site.

**FAMILY FRIENDLY:** Couples and families are welcome.

**COST:** \$600–\$1,100 USD per night (can vary with international exchange rates). NEW MOBILITY readers can get a discount by entering promocode "New Mobility" in their booking form. That will allow you to book seven nights and only pay for five (valid for stays booked until Jan. 31, 2025).

**WEBSITE:** sargoodoncollaroy.com

whose family eventually moved to Australia. He has returned to Sargood many times and even uses its community



fitness center. "They are like family to me now," he says. According to surveys, 80% of Sargood's guests say they leave with some new skill or knowledge.

More than that, Parker says her time there grew her confidence and broadened her sense of what is possible. "I now have a new bucket list of things to see and try."

#### **CAMP WITH A RAMP**

The rising sun casts a warm glow across Arizona's Mogollon Rim as a group of manual and power wheelchair users ascend the trail. The sunrise hike at the Rim is just one of many "firsts" that wheelchair users get to experience at Camp With a Ramp. CWR co-founder and Director Tina Fisk says watching campers experience "firsts" is the best part of camp.

Since 2006, approximately 80 campers with SCI or neurological diseases, caregivers, family members and volunteers gather once a year for a three-day cabin camping experience at Whispering Hope Ranch in Payson, Arizona. Each camper gets to tailor their retreat experience to their own interests and abilities, choosing from horseback-riding, fishing, kayaking, archery, crafts, yoga, lacrosse and, new this year, pickleball. Evenings feature a campfire with s'mores, live music and dancing, and a casino night.

Jordan Scott, 21, felt like the only wheelchair user in her community of rural Ruston, Louisiana. At 12 years old, a blood clot in her spinal cord resulted in a C6 SCI. Six weeks later she was discharged home with nowhere to turn for peer support. But at Camp With a Ramp, it was a different story. "When I first got there, it was like, oh my gosh, other people in wheelchairs," she says. "It was so comforting."

As an outdoor enthusiast and bike rider prior to her injury, Scott was particularly excited to try adapted mountainbiking. "I hadn't had an experience like it since my SCI," she says. "I could easily go out in the woods. It was nice to have that adrenal rush again and realize I can still do these kinds of things, just differently. It was reassuring to get that feeling back."

Peer-mentoring, matched to campers, is also offered. Mentors lead educational courses such as intimacy after SCI, navigating Social Security benefits, and self-defense strategies.

Camp With a Ramp has given Brittany Johnson, 32, of Peoria, Arizona, a whole new outlook and group of friends. After her T1 SCI in 2010, she used to shelter herself and find excuses to not do something. "In the hospital," she says, "I was around all these people ... and all this support, and then you get out and it was a huge shock. Real life is so much harder."

She has been to Camp With a Ramp every year since 2021. "I thought it would be cool to be around people in wheelchairs like me, but it was more than that," she says. "It was being around people who experienced life like me ... and pain ... and kept going. Being able to talk about those struggles, it was just mind-blowing."

Her own list of post-SCI firsts at Camp With a Ramp is extensive: hiking, hand-cycling, bocce, horseback-riding, wheelchair basketball and kayaking are among the many. She remembers the first time she went kayaking at camp: 'They couldn't keep me out of the water. It didn't matter that I couldn't walk. I was out there on the water like everyone else and it just felt so good.

"Before camp I just wouldn't go anywhere," Johnson says. "At camp everything is so scheduled and jam-packed. I thought it was going to be horrible and my pain would be ridiculous, but I was having so much fun that I didn't even think about



it." She made a new group of friends that motivated her. "After camp, I started working out (and) got back into a pool for the first time in 10 years. I was into activities, even joined the boards of a couple nonprofits," she says. "I just started putting myself out there."

Wiping away tears, Johnson says, "I'm a full-time single mom, (and) everything I do is for my daughter. So being at Camp With a Ramp, away from her, and being able to do

#### CAMP WITH A RAMP DETAILS:

**ACTIVITIES:** Adapted sports and recreation, peer mentoring, and educational sessions.

**LOCATION:** Whispering Hope Ranch, Payson, Arizona.

**PARTICIPANTS:** Persons 18 and older with an SCI, or 13–17 with adult supervision.

**DURATION:** Three-day weekend held once a year in September.

**CAREGIVER SUPPORT:** On-site.

**FAMILY FRIENDLY:** Family and friends are welcome.

**COST:** \$200 per person, with scholarships available to offset costs.

**WEBSITE:** campwitharamp.com

something for myself ... it breathed life back into me. It felt like a major accomplishment.

"Since Camp With a Ramp, I've become a peer mentor with the Christopher and Dana Reeve Foundation, been active in my local disability community, and I'm even helping with Camp With a Ramp this year as an assistant director. Camp changed my life and mindset tremendously. It definitely gave me back that breath I lost a long time ago."



## EUSPhurh9hgy

MAKING THE BIGGEST MUSIC FESTIVALS IN THE U.S. MORE ACCESSIBLE

he two-weekend, six-day Coachella Valley Music and Arts Festival, in Indio, California, is one of the most famous and well-attended annual music events in the U.S. With over 100,000 attendees packed into a sprawling venue and 100-degree desert temperatures, it's also a potential nightmare for accessibility.

Austin Whitney, the festival's ADA compliance coordinator, is responsible for making certain that nightmare never materializes. As the president and founder of Ten Fifty Entertainment, the leading provider of accessibility and guest services for large events, Whitney works behind the scenes to ensure that other disabled people can enjoy whatever shows they choose to attend.



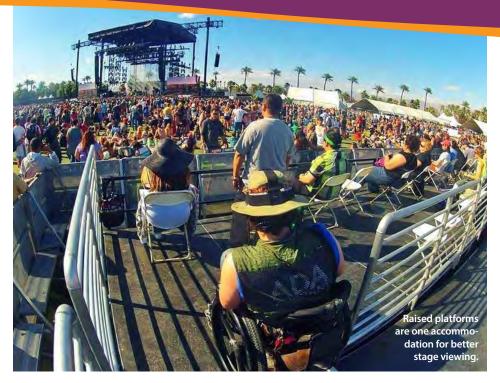




For Coachella, that means organizing a fleet of accessible golf carts for shuttling attendees; overseeing ADA viewing areas; coordinating accessibility service hubs around the venue; providing sign language, captioning and digital accessibility services; ensuring there are food options for people with allergies; and providing people who experience overstimulation a place to decompress. That's not to mention countless other smaller and more mundane responsibilities.

Providing an excellent accessible experience is personal for Whitney. He attended his first Coachella in 2008, only nine months after sustaining a T12-L1 injury in a car crash. Whitney was still getting used to life in a chair, with bouts of depression and doubts about what he could do, when a college friend invited him to go. He almost said no. "I imagined Woodstock," he says. "I imagined these huge crowds, and I'm like, 'I'm not gonna be able to see the main stage. I'm not going to be able to use the restroom. No, that's not for me.""

But with nothing to do during spring break, and feeling a need to lift his own



spirits, Whitney answered yes. He and his friend navigated the crowds and a good amount of inaccessibility — and had an absolute blast. He saw some of his favorite artists, made new friends, got energized by the crowds, and just felt free. "If I look back on that time," he says, "the first year after my car accident, that was kind of the breakthrough moment of that time period, where it's like, 'OK, things might go on. I might be able to be happy again."

#### AN EDUCATION IN DISABILITY

That positive experience played a key role in starting Whitney on a career path that led him to founding Ten Fifty Entertainment. In the spring after attending Coachella, he transferred to the University of California, Berkeley. He always considered the hillside campus his dream school because of its track record for developing leaders. He soon discovered it was also the birthplace of the disability rights movement and home to an active disability community.

A class on the history of the disability rights movement helped Whitney understand how activists make the world a more accessible place. "If I'd been born 40 years earlier, my life would be totally different," he says. "People were experiencing widespread inaccessibility back then, and they said, 'We demand change.' That stuck with me."

His passion for live music grew as he

attended festivals while an undergrad, but the more he attended, the more he saw how little thought was given to accessibility. "I had shows where people had to put me on their backs and carry me down stairs," he says. "I had shows where I couldn't see a stage and couldn't use the restroom."

In his senior year, he got an internship with one of the Bay Area's leading event promoters. Being behind the scenes gave him a sense of what was needed to significantly improve accessibility. "When I first got started [in the entertainment industry] in 2011, I said, 'OK, I want to spend some time working on this problem because everyone should be able to enjoy these things," he says.

To develop the skills to help realize his goal, Whitney enrolled in law school at UC Berkeley in 2012. The following year, he got a chance to design his first ADA compliance operation at a Southern California festival called Lightning in a Bottle. He told the producers, "I think I can use my experience, and if you give me a tiny amount of money and a bunch of volunteer passes to give my friends, I can make your event more accessible." The producers agreed, and the show was a success, with noticeably improved accessibility.



Whitney didn't know it, but his name was making the rounds in the festival industry. Within a few months, he got a call from an event production company doing multiple shows a year, and he worked with them to help make their events more accessible. The realization he could work on multiple festivals at the same time motivated him to take the next step.

During the summer of his second year in law school, Whitney approached his college roommate, Oren Shani, with the idea of starting Ten Fifty Entertainment. Named after their Berkeley, California, address number, the project began as a nonprofit, but quickly split into the for-profit Ten Fifty Entertainment, providing accessibility services to event producers, and the nonprofit Accessible Festivals, focusing on getting people with disabilities to festivals.

#### AN INDUSTRY LEADER

Last year, Ten Fifty Entertainment provided accessibility services to 99 live events, including 70 of the 100 highestgrossing live music festivals in the country. Those events took place in 22 states, and Ten Fifty is branching out with international events in Mexico, Costa Rica, Canada and London.

They work primarily on music festivals but also manage accessibility at sporting events, conventions and municipal events. Ten Fifty's current clients include Coachella, Bonnaroo Music & Arts Festival, Rolling Loud, EDC, Formula 1 Las Vegas Grand Prix, the PGA Championship, Star Wars Celebration, and several of the nation's largest temporary events. Many occur in venues that rely on temporary infrastructure, including stages, viewing platforms, tents, concessions and restrooms, and regulations affecting access can vary by state. Because of that, Whitney and his team had to develop guidelines from scratch and refine them over the years. "One thing that attracted me to this space is that this is all temporary," he says, "which means if I work a show this year and I don't like a part of it, I have a blank canvas in 2024 and can start over." This results in ever-improving accessibility for attendees with disabilities.

While Ten Fifty Entertainment handles the logistics of staging events, Accessible Festivals works to address the more personal and cultural aspects of event accessibility. Whitney now serves as board chair, working with Executive Director Amy Pinder to grow the organization.

"I would say Accessible Festivals is like a big umbrella entity," says Pinder, who is also a speech and language therapist. "We have a lot of programs and projects in place that all support the idea of advocating for more accessible experiences in the music festival space." Whitney and the AF team give accessibility trainings to industry staff and have a consulting program for more in-depth projects.

Accessible Festivals hosts the Inclusion Festival, an annual three-day event in Pennsylvania with live music, immersive experiences, and both educational and recreational workshops. Pinder says the "sensory-friendly" event hosted about 1,000 attendees in the summer before the pandemic. "We like to see how we can go beyond ADA requirements," she says, citing technologies like vibrating backpacks



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so deaf concertgoers can feel the beat of music. These SUBPACs are available now at some of the larger festivals that Ten Fifty Entertainment supports.

#### SHARING THE EXPERIENCE

The Accessible Festivals project closest to Whitney's heart is the Dan Grover Memorial Ticket Grant Program, named after a music-industry friend of Whitney's who had muscular dystrophy and passed away in 2022. As part of this program, Accessible Festivals gives away festival tickets to people who haven't attended one since they became disabled. "I want to give something for people to look forward to, that would help them out at a time where they could really use some help," Whitney says, harkening back to his transformative experience at Coachella. "So, we built out this program, and I got most of the industry to participate in it, which is the cool part."

Kimmi Churchill attended a couple of music festivals a year before her T4 spinal

cord injury in a car accident in 2020. "I didn't really think that I would have any more fun, you know, in a wheelchair," she says. "That was, until I saw Accessible Festivals on Instagram. And I'm like, "They look like they are having fun, so it is possible to still be accommodated at a festival like that, or at a rave.""

Churchill signed up for the Dan Grover Ticket Program online and got a ticket for HARD Summer, a Los Angeles-based music festival. She ended up meeting several people and making "new wheelie friends" at the ADA platforms. "I just got more and more confident [from day 1 to day 3], came out of my shell more and all that," she says. "The experience got better and better as the weekend progressed."

She says going to HARD Summer "has been really great for my journey and recovery." It also rekindled her love of live music: After getting home, she bought tickets to the Jackpot NYE rave in Las Vegas and is back on track to attend two events a year.

Churchill is one of more than 20,000

disabled guests whom Ten Fifty Entertainment and Accessible Festivals work with every year. Whitney and staff say they get plenty of feedback in person and online, and they vow to continue improving. "I love my job because I get to see people enjoying the thing they like to do," he says. "It doesn't matter to me if it's a country show, if it's a motor vehicle race or a show with music that I like, a rock show. I just like helping people enjoy whatever they are into."

Whitney wants the industry to keep evolving with widespread accessibility and more cutting-edge services like those pioneered at Inclusion Festival. "I would definitely encourage people to go to festivals," he says, "because it's just gotten so much better and it will keep getting better."

If you're interested in applying for free tickets through the Dan Grover Memorial Ticket Grant Program, visit accessiblefestivals.com.

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## **REACHING** NEW HEIGHTS:

New Stair-Enabled Personal Exoskeleton Gives Individuals Living With Spinal Cord Injury New Options For Walking In Daily Life

or individuals living with spinal cord injury (SCI), a personal exoskeleton can be a transformational device. It offers a new option for wheelchair users that allows them to choose how they prefer to navigate tasks in everyday life, maintain an active lifestyle, and gain the health and wellness benefits of walking again.

And now, the team at ReWalk Robotics has expanded those possibilities even more with the introduction of its new Stairs-Enabled Personal Exoskeleton available in the U.S.

The new stairs-enabled exoskeleton is the only personal exoskeleton in the U.S. that allows paralyzed users to walk up and down stairs or over curbs that might otherwise have been challenging or inaccessible from a manual wheelchair. This can mean that everyday activities, such as being able to easily access private residences of friends or family members — which may have barriers like stairs at the main entrance — are now possible, allowing individuals living with SCI better access to these environments.

But it's more than a technological breakthrough. It's life-changing.

"The stair feature allows me to stop searching for a curb cut out and removes the barrier of steps or stairs altogether, whether in homes or out in the community. This truly opens the places I can go with family and friends in my exoskeleton!"

— Ashley Barnes, ReWalk user since 2015.





"The new Stairs feature opens the world to me in ways I didn't know possible. To have the option to sit, stand, walk and even step over curbs as a paralyzed individual is unimaginably rewarding. I'm in full control of the exoskeleton, and I am able to conquer stairs and other obstacles that may appear in my way. It's been life-changing for me."

— Simon Kindleysides, *ReWalk user since 2018.* 

#### The Life-Changing Benefits of Stair-Enabled Technology

In addition to creating a more accessible world, personal exoskeletons provide other benefits to those living with SCI:

• Increase freedom by lifting barriers: The stair capability allows users to walk up and down stairs and curbs as needed to gain easier access to homes and buildings.

• Improve quality of life: The ReWalk Personal Exoskeleton can help users to participate in more activities that they enjoy from an upright position, such as simply taking a walk with family or friends or accessing locations containing stairs or curbs.

• Reduce health risks: A ReWalk exoskeleton does more than put one foot in front of the other. By enabling walking in everyday life, exoskeletons have been shown to benefit many of the secondary complications of SCI. Clinical studies have reported improvements in GI function, reductions in pain and spasticity, and improvements in mental health following exoskeleton-assisted walking.

#### **How It Works**

The ReWalk Exoskeleton is powered by a series of motors and sensors that work together to mimic the natural gait pattern of the legs during walking and stair and curb navigation. When the user approaches an obstacle such as a stair or curb, the user selects the stair mode from their wrist-worn controls to initiate the command to ascend or descend the stairs or curb. The motors activate to power the exoskeleton's legs while the user maintains balance with their crutches or the stair railing.

ReWalk's stair-climbing feature has been rigorously tested and is safe and effective for use by individuals living with SCI. This feature has been available in Europe since initial CE Clearance, and real-world data from European users over a period of over seven years was collected to demonstrate the safety and efficacy of this feature and support the FDA submission.

#### The Future of ReWalk's Stair-Climbing Feature

The Stairs functionality is yet another example of the creative and groundbreaking innovation that ReWalk Robotics continually pursues — and it's only the beginning of these advancements.

If you are interested in learning more about ReWalk's stairclimbing feature, please visit rewalk.com/take-the-stairs to get in touch with your local ReWalk representative. " Our mission at ReWalk has always been to achieve widespread access to the health benefits of walking in everyday life for individuals living with spinal cord injury. The introduction of the Stairs-Enabled Personal Exoskeleton demonstrates this drive to create a more accessible world for paralyzed individuals by improving access to a broader range of activities in daily life, such as walking up the steps to visit a friend's home or stepping over a curb during a neighborhood walk. In parallel, our focus continues to be to broaden access to these life changing technologies through expanding payor coverage as we continue to work with Medicare to develop the pathway to reimbursement for medically-eligible individuals."

— Larry Jasinski, CEO, ReWalk Robotics



## AI IMAGE CONTEST DRAWS STRIKING ENTRIES But is it art?

We recently asked to see disability-related images you created using the mind-blowing advancements in artificial intelligence. We got the idea when Pete Aviles, a paraplegic business owner and designer, sent us some of his creations on the platform Midjourney. "You can make visionary art, or you can make it look like a real photograph," he says, noting that one of the biggest issues has been generating realistic wheelchairs. But AI has "learned" a lot in a few short months. "Now more of the wheelchairs actually do look right," he says.

While Aviles has found AI to be a boon to his creativity, some disabled artists who saw our call for entries were offended by the suggestion that AI images are "art."

"AI generated 'art' is theft," says Rus Wooten, a C6 quad whose cartoons and illustrations were featured in United Spinal's previous member magazine, *Life in Action*. "These apps steal art from actual human artists, then mash it together to create these images," he says.

AI image generators pull imagery from a vast number of online sources, and it's true that some images may be copyrighted. In artforms remixed by humans — such as collage and hip hop sampling — legal experts have struggled for years to define the line between violating intellectual property rights and creating a piece that is so altered that it is considered new work. AI complicates this conversation greatly.

"It amazes me the kind of power and ease that this technology has brought to generating images — it's like science fiction," says Srivats Shankar, who entered the contest but acknowledges that the use of AI raises questions about attribution and compensation. "I do hope it supplements the works of existing artists and authors rather than taking away from them."

Kary Pearson, another contest entrant, adds: "I know that AI and intellectual property and art styles is a hot topic, but AI has helped me get back into art after becoming disabled. I'm so grateful for that. Also, I think that a misconception about AI art is that it doesn't require effort. While you can roll the dice with a basic prompt and see what you get, you can also have a picture in your mind and put a lot of consideration into your description for the prompts."

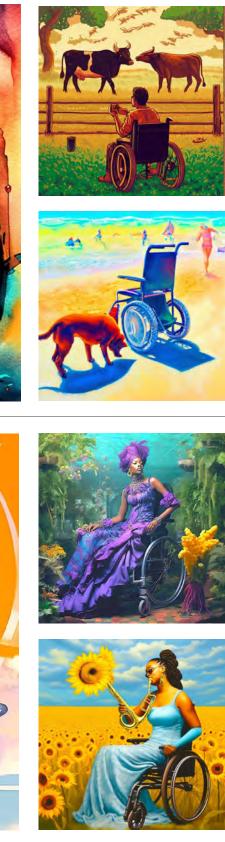
"I love, love love this invitation to remake the world," says contestant Akua Lezli Hope. "To envision and have images I've never seen of empowerment, energy and joy — I am lifted to just behold these images. Thank you for creating this occasion to dream."

So what is NM's bottom line? We think AI image generation has potential to be used responsibly by disabled content creators — another tool in the toobox — but we don't see it replacing art that taps into the authentic human experience of individuals. And ultimately, *that's* what we want to see in NEW MOBILITY. Submit your non-AI work here: newmobility.com/for-content-creators





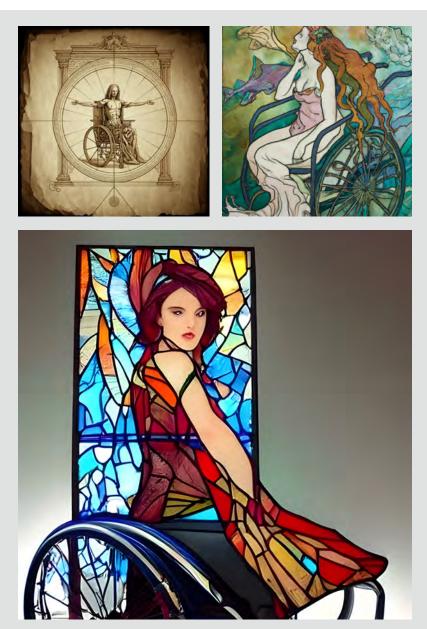
am paraplegic, an African American, an Afrofuturist, a creator who dreams dail without assistance in a place with no paratransit or support. I go hungry when imagining beauty, energy, agency, in a wheelchair-enabled body has been so a and was profoundly depressed for years because of all the things I loved that I co became too hard to play in the wheelchair. Now I'm working on my embouchure shout-out to Ukraine, because Ukrainian crochet designers inspired me, taught m ney back to an engaged and fulfilling art practice after becoming paralyzed. I mis to create a raised bed space to garden. I am limited to pots. So the regal woman i to my longing and reminds me to sit up straight.



y of a better life while struggling to create through pain the aide doesn't do her once a week shopping visit. So ffirming. I couldn't play my tenor sax in my wheelchair uld no longer do. Then I bought an alto sax, but it too for a new soprano sax. The sunflowers and blue are a ne and informed my crochet design, which was my jourss gardening and love plants. I've tried for over a decade n my favorite color surrounded by lush foliage speaks based the prompts for each of the images on feelings and thoughts I have had about what living life with a disability is like — especially about the people and things that are important to me. Some of the things that went through my mind were spending time with my family and friends, how my wheelchair and technology makes so much of my life possible, and the feeling that living in an accessible environment brings. The goal was to take these ideas and convert them to a form of expression that through the color and contrast could embody a sense of the beauties and difficulties of living with a disability. To that end I feel these images have been able to encompass these feelings in a unique way that feels like art but is something else.

I hope that this technology evolves from being a simple prompt-based form of image generation to one that builds upon tools like Photoshop, so that artists can continue to use the tools that they have always used but the AI can add an additional layer of "polish" to the artwork. I believe that this would greatly benefit all types of artists, particularly artists with disabilities who have trouble using certain types of tools.

— Srivats Shankar, AI platform: DALL-E 2



The stained glass woman is a reflection of me in that I feel like I'm learning to piece my life back together similar to how broken pieces of glass are joined together to create something new, and even beautiful. She is supported by her wheelchair, and even though she is fragile she can still move forward. "Vitruvian Man in Wheelchair" is also meaningful to me. In my previous life I was an artist, and I've noticed how few depictions of disability exist in art. I believe that disability representation should be in all facets of life, but art tends to last, that's why we still look at da Vinci's work. Maybe if art starts to represent disabilities, it will help break stigmas.

— Kary Pearson, Al platform: DALL-E



#### + POSTING FOR ACCOUNTABILITY

Disabled travelers are turning to the internet and social media to expose the negligence of the air travel industry and educate the general public and policy makers about the unequal treatment we regularly receive. Whether its videos of baggage handlers mishandling chairs, gate assistants dropping passengers and flight staff berating disabled passengers, or posts showing the extra lengths we go to for no guarantees, the accumulation of our stories is one of our best hopes for forcing the industry to change and make air travel more inclusive and equitable for everyone.

#### Ali Ingersoll @quirkyquad\_ali

"TSA destroyed my chair despite my best efforts to build and create a very secure system. Back to the drawing board on creating the best design for transporting power wheelchairs during flight. Thankfully I think most of the damage is cosmetic and the wheelchair is still driving, but many of my friends are not this fortunate. I did have my manual folding chair with me, which many do not, so at least I had a backup option."



# TAKING ON <sup>#</sup>UNFRIENDLY SKIES

#### BY KENNY SALVINI

Kelly Buckland faced a dilemma last December when planning a trip from his home in Washington, D.C., to his native Idaho. As a C4-5 quad, he could spend several days driving cross-country in his accessible van in the dead of winter, or he could book a one-stop flight with multiple transfers in and out of cramped, inaccessible planes, and get there in a day. "Every time I get on an airplane, I'm afraid," he says. "I figure I'm gonna get hurt. I'm gonna get COVID. And my chair is gonna get broken." For him, the choice was clear.

All wheelchair users face a similar predicament when deciding whether or not to fly. What makes Buckland's story unique is that he is the disability advisor for Secretary of Transportation Pete Buttigieg.

And so it went — the Department of Transportation's highest-level disabled appointee loaded up his adapted van and drove from Washington to Boise and back, braving multiple road closures, delays and detours due to severe weather. "Altogether, I drove 6,000 miles, just to avoid flying on an airplane," he says.

Like Buckland, I avoided flying for more than a decade after becoming a C3-4 quad, because of the horror stories I'd heard. When I finally did attempt braving the unfriendly skies, I had two power chairs destroyed by different carriers in less than a year. Forced into reluctant advocacy, I got to work. In a 2017 article in these pages, I chronicled the sad state of the airline industry, and



ROKEN

Feranmi Okanlami @okanlami "PSA: For all my wheelchair users out there, while flight attendants will often store their own luggage in these closets, the first priority is, in fact, your wheelchair." Okanlami demonstrated how he broke down his wheelchair and put it in a designated closet for mobility devices on his recent flight to Washington, D.C.



Gabrielle "GG" deFiebre @ggdefiebre "The flight attendant said 'We don't normally do this, but because it's not crowded, we will.' Then, on the flight back, I encountered similar resistance: 'Chairs are supposed to go underneath the plane, not the cabin,' 'We have to see if the plane has a closet and if it does, if the first class passengers want to use it, then you can't.'"



I've spent the last six years working my way behind the curtains of the notoriously inaccessible industry.

In researching the 2017 article, I discovered a record of negligence spanning three decades and fed by a vacuum of accountability due to outdated legislation and a confusing, inefficient system for reporting damages. While there were glimmers of hope on the horizon, the overall picture wasn't pretty.

Six years later, if possible, things seem even worse. Despite recent legislation and viral announcements claiming



As the Disability Advisor in the Office of the Assistant Secretary on Policy at the Department of Transportation, Kelly Buckland (right) has the ear of Secretary of Transportation Pete Buttigieg (left).

that a new age of air travel accessibility is on the horizon, the in-flight experience of wheelchair users worldwide remains largely unchanged. Even with the COVID-19 threat waning, more and more of us are, like Buckland, opting for road trips and/or smaller travel. To grasp why, I needed to understand the glacial pace of modern reforms and to plug myself into the loose network of like-minded advocates, influencers, engineers and policy wonks, who are focused on making the dream of truly accessible air travel a reality.

#### **EMPTY POLICIES AND BROKEN CHAIRS**

Before the COVID-19 pandemic wreaked its havoc on the entire travel industry, there was a palpable sense that advocates were making progress toward more accessible air travel. In 2017, Sen. Tammy Baldwin introduced the Air Carrier Access Amendments Act, aiming to bridge the sizable gap between 1986's Air Carrier Access Act and the 1990 Americans with Disabilities Act.

The ADA's crafters mostly left air travel out of the landmark civil rights legislation, under the assumption that the ACAA had the aviation industry covered. Their mistake became evident in retrospect. Unlike the ADA and most civil rights laws, the ACAA was not governed by the Department of Justice, nor did it include a private right of action — the ability to sue responsible parties for rights violations. Under the ACAA, our only recourse was to make a complaint to DOT through a confusing and convoluted reporting process that over the years led to infuriatingly little enforcement.

The Amendments Act called for a range of actionable accountability measures, such as mandating that all domestic carriers report data on mishandled wheelchairs

stored in the aircraft cargo compartment. In its first congressional session, the Amendments Act failed to make it out of Senate committee but succeeded in invigorating conversation around accessible air travel.

Many provisions from the Amendments Act were included in 2018's Federal Aviation Administration Reauthorization Act, including the establishment of an Advisory Committee on the Air Travel Needs of Passengers with Disabilities, and the drafting of an "Airline Passengers with Disabilities Bill of Rights" outlining the protections and rights afforded to people with disabilities in air travel. Despite the lofty title and 10 clearly stated rights, the exclusion of a private right of action made many advocates worry the bill had more bark than bite. "The bill of rights wasn't going to do anything," says WheelchairTravel.org writer and triple-amputee John Morris. "There were no new rights involved, and the key challenges that discourage people from flying were still in effect."

The Reauthorization Act also required DOT to commission studies reviewing air-carrier training policies related to properly assisting passengers with disabilities, and determining the feasibility of in-cabin wheelchair restraint systems. The biggest headlines would come from the bill requiring

#### Kelly Narowski @kellynarowskispeaks

"I recently took an international trip, and since I was traveling solo, it was even more imperative that the airline not lose my chair or leave it on the tarmac. So, I exercised my right, mandated by the Air Carrier Access Act of '86, to store my chair in the cabin on all four flight segments. On the fourth flight, my chair didn't fit in the cabin's closet and I asked to find another solution. Surprisingly, the frame of my chair fit in the overhead! Having taken hundreds of flights, that had never happened before. It was a Delta 737."



Karah Behrend @kindofaquad "Huge thanks to @american air for letting me try out the scooter on today's flight instead of using the aisle chair. Not everyone knows this or needs to know this, but as a survivor of military sexual trauma, having strangers touching me to DOT to finally start reporting the number of damaged wheelchairs and scooters by large domestic airlines.

DOT released the first numbers in March 2019, and they were not pretty. By the end of the year, media outlets had latched onto the fact that airlines had damaged more than 10,500 mobility devices, a whopping 29 per day. The numbers predictably plummeted with the onset of the pandemic but gradually rose again and even exceeded pre-COVID-19 levels, with 11,389 chairs lost or damaged in 2022 — more than 32 per day.

All told, the airlines have misplaced, damaged or destroyed more than 36,000 devices from January 2019 to May 2023. Staggering numbers, but Buckland is not surprised. He sees it as a by-product of a system that has been getting consistently worse



since he started flying 50 years ago. "At this point, I can't even count how many of my chairs have been destroyed," he says.

Considering the high likelihood of damaged equipment, it shouldn't be surprising that so few wheelers are choosing to fly. Full-time wheelchair users account for more than 1% of the U.S. population, yet we represented less than 0.1% of the nearly 2 billion passengers enplaned by reporting carriers between 2019 and 2021. But the threat of broken chairs isn't the only thing keeping us grounded.

#### **THE HUMAN COST**

Nothing illustrates the true risks that wheelchair users face every time they fly like the deaths of Gaby Assouline and Engracia Figueroa. Assouline, already a wheelchair user due to an extremely rare condition, was paralyzed in February 2022 when she hit a junction on a Southwest Airlines jet bridge, causing her wheelchair to flip. She sustained a cervical-level injury and never left the hospital until her death on Jan. 22, 2023. Figueroa's death on Oct. 31 followed a pressure sore and other related issues after her custom power wheelchair was destroyed by United Airlines on a flight home to California after she spoke at a rally in Washington, D.C.

The story of Nathaniel "NJ" Foster, a vent-dependent quad from New Jersey, has not received as much coverage. Foster was a 21-year-old college student in 2019 when he went into cardiac arrest after being improperly deplaned in an aisle chair. He went into a

vegetative state and remains unable to communicate today. The Fosters allege that staff "aggressively pushed" Nathaniel, making it difficult for him to breathe, ignored him saying, "I can't breathe," and recklessly disregarded an opportunity to have an available physician assist.

Nathaniel Foster, et al. v. United Airlines Inc., et al., was set to go to trial in the United States District Court for the Northern District of California when this story went to press. On his WheelchairTravel.org blog, Morris describes Foster's lawsuit as potentially pivotal, calling it "an important test case concerning the limits of an airline's liability for injuries caused to passengers with disabilities."

Adding insult to all the injuries and damage is the fact that

board me for a flight using the aisle chair is usually the abso-

lute worst part of traveling. This all ends today. I'm taking back my right to travel with dignity."



#### Cory Lee @curbfreecorylee

"I'm currently on a layover in Paris and flying to Cairo, Egypt, tonight. [The airport] staff has refused to bring me my personal wheelchair for this six hour layover, so I'm stuck in a manual airport wheelchair and have zero independence, can't recline to alleviate pressure, and there are no seatbelts on this chair. Also, I just found out that @delta/@airfrance forgot to load my shower & commode chair in Atlanta, so I won't have it for at least my first 24 hours in Egypt. No idea how I'll use the restroom without it. This is ridiculous and exactly why we need better accessibility on flights!" DOT has levied zero fines on carriers since the reporting on damaged devices began. The 2018 FAA bill tripled the previous maximum fine of \$40,000 per instance of damaged mobility aid. With 36,000 damaged devices at \$120,000 each, that's over \$4 billion in unlevied fines that might have helped incentivize change. "Without accountability, you don't have that change in behavior," says United Spinal Association's Director of Advocacy and Policy Steve Lieberman.

Still, the mounting bad press from obvious negligence — mixed with story after story of flight cancellations and other recent operational failures — had the industry in need of something positive to shift the narrative and public opinion. A Delta Air Lines subsidiary's June announcement of the Air4All, a prototype

seating arrangement that allows wheelchair users to fly while in their personal chairs, did just that (see sidebar, page 38).

#### A BETTER ALTERNATIVE

Michele Erwin has been leading the fight to allow wheelchair users to fly in their own chairs since she founded All Wheels Up in 2011. After years of raising awareness and funds to show that wheelchair users could safely fly in their chairs, AWU collaborated on the first independent crash testing of wheelchair restraints in 2016.

When the restraints held up, AWU reached out to airline and airplane manufacturer representatives, but Erwin and her team were largely stonewalled. "Nobody wanted to touch All Wheels Up with a 10-foot pole," she says. The allvolunteer organization continued to fight an uphill battle until the Transportation Research Board mentioned its work in a 2021 report on the feasibility of wheelchair-securement systems inside passenger aircraft. The report had a legitimizing effect that started opening doors. "This was no longer 'some crazy mom who has an idea," says Erwin. "This was

a respectable and viable project."

Advocating for wheelchair users to be allowed to fly in their chairs

is paying off for Michele Erwin and the organization she founded

12 years ago, All Wheels Up. At right: Erwin with her son, Greyson.

Their most recent working group, held at Seattle's historic The Museum of Flight in September 2022, brought together more than 100 stakeholders from 33 different organiza-

tions around the globe. "The interesting takeaway was that people who had not been working with us couldn't believe the incredible progress being made in this space," she says.

One of those wowed attendees was Buckland, who was appointed disability policy advisor to the secretary of transportation in 2021 after a career running the Idaho Centers for Independent Living and then the National Council on Independent Living. "They have found their niche, and are knocking the hell out of it," he says.

Building on that momentum, AWU held 22 meetings in three days with elected officials earlier this year to help craft the next wave of legislation, while fielding daily emails from equipment and airplane manufacturers, universities and others reaching out for some sort of help. "There is definitely

#### Sophie Morgan @sophlmorg

On the heels of launching her "Right on Flights" campaign to make airline travel more accessible for disabled travelers in the UK, Sophie Morgan posted a video documenting how she boards an airplane. It shows her transferring from her wheelchair to the aisle chair and workers strapping her into the chair before taking her to seat. "For people like me, this is how we board an aircraft. It's not easy but it's doable. Please don't let the bad news stories about flying put you off. If you are ABLE to fly, FLY. The reward is worth the risk. Things MAY get broken but they MAY NOT. We can only hope for the best and plan for the worst, I guess."



a heightened awareness of the problem, which is terrific," says Erwin.

Morris credits Erwin and AWU for laying the groundwork for Delta executives to greenlight the development of the prototype showcased in June. "The work that Michele has done over these last years has been tremendously important," he says.

The Air4All wheelchair securement space was created by a U.K.based consortium comprising advocacy group Flying Disabled, aviation design company PriestmanGoode, aerospace company SWS Certifica-



British media personality Sophie Morgan has been a relentless voice for making air travel more accessible for people with disabilities.

tion Services and wheelchair design company Sunrise Medical. The seat allows flight attendants to quickly convert a regular airline seat into a space for a wheelchair, with retractable tie-downs embedded in the cabin floor.

Over a few weeks, videos of Morris and British TV personality Sophie Morgan, a T8 para, found viral fame, catching the attention of major news outlets and sweeping through the feeds and inboxes of disabled travelers around the globe.

Morris had been vocal about his reservations prior to seeing the seat, but ultimately came away encouraged by what he saw. "Five years ago I said, 'Hopefully, in my lifetime.' So, I'm loving how the timeline is contracting."

### FROM FEASIBILITY TO IMPLEMENTATION

While the news was met with overwhelming enthusiasm from the majority of the disability community, others with long histories navigating an inaccessible world countered with cautious optimism. As the recently retired director of customer advocacy from Alaska Airlines, Ray Prentice is well-positioned to comment on the prototype's potential impact. "There is still a lot that has to be done in getting it certified on an airplane and integrated with the variety of power chairs (and) finding enough room in the cabin," he says. "All things that can be worked out, but ... there's a lot to discuss."

As an engineer at Boeing and a wheelchair user, Anthony

Anderson knows all too well that the path from feasibility to implementation can be a long and meandering one. A T8 para, Anderson started at Boeing in the months after the passage of the ADA, working on designs to help airlines meet new accessibility requirements for lavatories on twin-aisle airplanes. It took three years for the first models with accessible bathrooms to roll off the assembly line, and soon afterward Anderson could only watch as twin-aisle planes were phased out for single-aisle planes with inaccessible

bathrooms. Anderson sees a lot of upside to the Air4All prototype, but knows there are plenty of hurdles left to get to an



#### Emily Ladau @emilyladau

"Every time I go through security, I am essentially turned into a bit of a sideshow. And then I'll go through this invasive pat-down process with everybody watching. When they get ready to board, they say, 'first we have to get the wheelchair on,' as if I'm not actually a person. I'm just this big piece of inconvenient machinery that they have to get on the plane," says Emily Ladau in a Youtube video with VICE News. "I never feel quite so much like a burden as I do when I'm getting on an airplane. But even worse than all that's required to get on the plane can be what happens after landing." *During the flight Ladau's joystick was damaged and was unat-tached to the chair when she got it back*. "My chair is still not fixed, and it's been more than a month. I have been driving around with a broken wheelchair held together with duct tape and tire wraps for a month. There is no other method of transportation where I am asked to give up my wheelchair."



implementable design. "It is really tough to estimate time to certify something new," he says.

Keep in mind that airplanes are expensive and usually have long service lives. Even if the Air4All system or something similar were certified tomorrow, it would be years before they were widely available. And just because an accessible solution exists, until the government requires airlines to allow flyers to sit in their mobility devices, there's no guarantee they will undertake the costly endeavor of upgrading.

A study by All Wheels Up found that airlines are spending upwards of \$3 million a year on wheelchair repairs and replacements. While that may seem like a lot of money, consider that United Airlines alone made over \$48 billion in revenue in 2023. Compared to the cost of building and upgrading an entire fleet, \$3 million is pocket change. You can bet airlines will hold out on that endeavor as long as they can.

## AIR TRAVEL TIPS FOR WHEELCHAIR USERS

Flying with a disability comes with many challenges. However, advance planning and effective self-advocacy can make the trip much smoother. United Spinal Association's **Navigating the Skies** is a guide to accessible air travel for anyone with a spinal cord injury, physical disability or limited mobility who wishes to travel by air. It contains a complete list of the accommodations that can be requested, contact info of major U.S. airlines, forms for reporting damage to equipment and more. Here are a few tips to help make your next flight as safe and enjoyable as possible.

#### **BOOKING YOUR FLIGHT**

Find nonstop or direct flights to your destination. If no direct flights are available, include in your planning the time needed to deplane and travel to a new gate at your layover airport. If you're traveling to a faraway destination, consider breaking travel up into more than one day to allow your body to rest.

### REQUESTING ADVANCED ACCOMMODATIONS

Accommodation requests can be made online or by calling the airline directly. You can request assistance with getting through the airport, preboarding, sitting near a companion in a seat that suits your needs, flying with a service dog, etc. If traveling with a service animal, complete the U.S. Department of Transportation Service Animal Air Transportation Form to present to the airline on travel day.

Choose a seat that works best for what you need. The aircraft has designated aisle seats with removable armrests to allow easier transfers to and from an aisle chair. Bulkhead seats usually make up the first row of seats in each class cabin. They don't have removable armrests but offer more legroom and are favorable for traveling with a service animal.

### GETTING THROUGH SECURITY

Every traveler is required to go through the Transportation Security Administration checkpoint for screening. The TSA Cares helpline is available to assist travelers with disabilities in the screening process. It is best to contact the TSA with any questions at least 72 hours before traveling. They can be reached at 855/787-2227.

During the screening process, you can ask for a private screening with or without a companion, and request that the screening be completed in your wheelchair or scooter. Many wheelchair users apply for TSA Precheck to make the security process easier (see sidebar).

#### **BOARDING THE FLIGHT**

All airlines allow people with disabilities to board first. When you arrive at the gate, talk to the agent to let them know what assistance you require, and obtain a gate check tag to attach to your device if stowing it in the cargo compartment.

Be mindful of your bowel and bladder management in the days leading up to your flight, and use the bathroom before boarding the plane. Bathrooms on single-aisle aircraft are not accessible to wheelchair users.

Proceed down the jet bridge in your own wheelchair before transferring onto an aisle chair. If you're able, transfer into the aisle chair on your own. If you're unable to transfer without assistance, make sure you clearly communicate to the team assisting you the specific details on how to best transfer you to your assigned seat. You are in charge here, so don't let them transfer you until they're in position to do so safely.

### PROTECTING YOUR ASSISTIVE DEVICE

One of the biggest anxieties that wheelchair users face when flying is whether their equipment will be damaged. It is crucial to take steps to protect your devices and have a backup plan if damage occurs.

Familiarize yourself with the specifics of your assistive device, including weight, dimensions, battery type, etc. Notify your durable medical equipment supplier that you will be traveling by plane, and locate suppliers nearby your destination in the event your mobility device sustains damage.

Prepare an information sheet for airline personnel, with clear instructions how to care for your assistive device. Know how to disassemble any removable or fragile parts for stowage, and stow as much mobility equipment in the cabin as possible. Any mobility device stowed in the cabin will not count toward the carry-on baggage limit.

Take a photo documenting your device's condition before handing it over to airline personnel. If your device arrives damaged after the flight, you'll have proof of what went wrong. Document any damages, injuries or other issues incurred during the flight, and report them to the airline immediately. Follow up with the DOT within six months of the incident.

United Spinal, **Navigating the Skies:** united spinal.org/pdf/NavigatingTheSkies.pdf.

### AN IMPROVING FORECAST

Thanks to the growing chorus of advocates at home and abroad, key decision-makers finally seem to be paying attention. Sen. Tammy Duckworth was one of a handful of prominent legislators to introduce the Mobility Aids on Board Improve Lives and Empower All Act this June. In addition to requiring DOT to provide more details about the damage that airlines are doing to wheelchairs and scooters, the MOBILE Act could lead to an economic impact study finally revealing the true cost of sacrificing some seating and space to allow wheelchair users to sit in their chairs on board. Advocates like Erwin hope its provisions get rolled into the 2023 FAA Reauthorization Act. "We are going to put true economics on this," she says. "Because, first of all, they have to stop telling you every single flight is full. Give us numbers."

As the secretary of transportation, Pete Buttigieg would be the person responsible for implementing those requirements. Buttigieg has emerged as a vocal ally for making air

### **IS TSA PRECHECK WORTH IT FOR WHEELCHAIR USERS?**

If you're tired of extended, invasive pat-downs and long waits when you go through airport security, TSA Precheck could be the solution you've been looking for. With TSA Precheck, you can skip the long security lines for the much-faster TSA Precheck line. A Transportation Security Administration agent will still swab your chair for explosive chemicals, but, barring a positive test, you can avoid a full pat-down and having to take off your shoes.

To apply for TSA Precheck and receive a Known Traveler Number, you must fill out an online application with your place of employment, your primary residence dating back five years, and your criminal history. You will then schedule your interview with a TSA agent, where they will confirm the information you have provided and fingerprint you. If you are unable to utilize the digital fingerprint scanner, the TSA agent can assist, or you may have a personal care attendant to assist. The TSA charges \$78 for the background check. Within 60 days of your interview, they will let you know if you are approved. Your Known Traveler Number is valid for five years.

NEW MOBILITY columnist Teal Sherer was hesitant to apply for TSA Precheck but now can't imagine traveling without it. "I get through security faster, I don't have to do the pat-down, and I don't get asked to take off my shoes," she says.

If at any time you feel your civil rights and liberties are being violated or if you have been discriminated against during a previous interaction with a TSA Agent, you can file a complaint on the TSA website or call 855/787-2227. You can also call to request assistance during the screening process if you have specific needs that will not be met by the traditional screening. — HILARY MUEHLBERGER



### SEATING SOLUTIONS IN PROGRESS

While the Air4All prototype was touted in the press as a first-of-its-kind design, there are a number of innovative systems now in the works to allow wheelchair users to travel in their own wheelchairs on commercial aircraft.

**FREEDOM SEAT:** Colorado-based Molon Labe Seating designed an aisle-side seat that can slide over to create a space for a wheelchair user to park their chair and lock down. I had the opportunity to test the Freedom Seat in a mockup feasibility study at the Boeing 737 Configuration Studio in Renton, Washington, in July 2021. After some precise driving and a couple of attempts, I was able to back into a major carrier's current cabin configuration unimpeded and dock into a Q'STRAINT QLK personal docking system mounted to a piece of plywood in the vacant space below.

FLY YOUR WHEELS SUITE: Collins Aerospace teamed up with researchers and students at the National Institute for Aviation Research at Wichita State University to develop a concept that reengineers the cabin's front closet into a multipurpose module that can function as a safe parking berth for a wheelchair user in-flight. This design generated significant buzz last year because it effectively adds another paying customer without the need for drastic changes to existing in-cabin seating. The Fly Your Wheels Suite was shortlisted for a 2022 Crystal Cabin Award, along with the Air4All seat.

AIR4ALL: Delta-subsidiary Delta Flight Products' prototype is by far the most fleshed-out public concept. It features novel accommodations for adjustable armrests, and tray tables that can be customized to a wheelchair-user's height needs. Like the Freedom Seat, Air4All's original design incorporated the Q'STRAINT QLK docking system, but both have switched to the Q'STRAINT ONE retractable tie-down system as showcased at Aircraft Interiors Expo 2023 to allow for more universal access for all types of wheelchairs. Molon Labe CEO Hank Scott sees the ongoing work as a collective team effort rather than a competition. "The release by Chris and the DFP folks of their design recently has given the idea of flying wheelchairs a real boost to the momentum," he says. "This movement is more about collaborating and offering a worldwide solution. We have an aim ... and we will achieve [it] together with these advocates, partners and airlines."







## **MEET ATTO SPORT:** THE MOST PORTABLE MOBILITY SCOOTER

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### **ANNOUNCED IN JULY:**

## NEW RULE REQUIRES AN ACCESSIBLE RESTROOM ON SINGLE-AISLE AIRCRAFT DELIVERED AFTER 2035

The Department of Transportation announced a rule on July 26 that will require an accessible bathroom on single-aisle aircraft operating in the U.S.

The rule was finalized on the 33rd anniversary of the Americans with Disabilities Act, yet airlines will have a decade to comply with the new requirement. The rule applies only to new single-aisle aircraft ordered 10 years or delivered 12 years after the rule becomes effective. For as long as this time frame is, earlier drafts of the rule gave airlines 18 to 20 years to become compliant.

Double-aisle, wide-body aircraft — the larger planes that often fly transcontinental flights — are already required to have an accessible restroom. Single-aisle planes are used for most U.S. domestic flights, so the new rule has the potential to provide a significant accessibility upgrade to the flight experience of disabled Americans.

### WHAT DOES AN ACCESSIBLE RESTROOM EVEN MEAN?

The rule states that for single-aisle aircraft of 125 seats or more, an accessible lavatory "must permit a person with a disability and an attendant, both equivalent in size to a 95th-percentile male, to approach, enter, maneuver within as necessary to use all lavatory facilities, and leave, by means of the [portable aisle chair], in a closed space that affords privacy equivalent to that afforded to ambulatory users."

In layman's terms, the bathroom must have space for two full-sized adults plus an onboard aisle chair. There must be room to shut the door and transfer, with assistance if needed, onto the toilet, then get back through the door when done. How this will look in the real world is up to the airlines to figure out.

It's a fair bet that the bathrooms will look much like the accessible versions on current wide-body jets. John Morris of wheelchairtravel.org published an excellent article detailing the types of accessible bathrooms currently available. They vary in usability. Some offer enough



space to make a lateral transfer onto the toilet, while one of the most common configurations features a pull-down divider that turns two restrooms into one. Morris points out:

"Even with twice the space (and twice the number of toilets), the lavatory remains cramped. There is just enough room to perform an admittedly awkward transfer onto the toilet. You'll need to be patient and take your time to avoid mistakes or injury. It's not ideal, but this is considered accessible by many air carriers today."

Whatever the restroom layout, you will still have to access it via an aisle chair, or an "onboard wheelchair," as the DOT calls them. The rule mandates that within three years, all single-aisle aircraft of 125 seats or more need to have an onboard wheelchair. In the same time frame, they are also mandating that airline staff receive annual training on use and stowage of the onboard wheelchair, plus training in how to assist passengers to and from the restroom. DOT is also requiring airlines to have restroom accessibility features listed in the aircraft and on the airline's website.

### **MOVING FORWARD**

The new accessible-restroom rule is a major step forward. But the devil will be in the implementation and whether the DOT and Congress continue to mandate other airline accessibility improvements. In an

THE BATHROOM MUST HAVE SPACE FOR TWO FULL-SIZED ADULTS PLUS AN ONBOARD AISLE CHAIR. THERE MUST BE ROOM TO SHUT THE DOOR AND TRANSFER, WITH ASSISTANCE IF NEEDED, ONTO THE TOILET. HOW THIS WILL LOOK IN THE REAL WORLD IS UP TO THE AIR-LINES TO FIGURE OUT.

interview with longtime NEW MOBILITY writer Steve Wright, Secretary of Transportation Pete Buttigieg said that the DOT is working on a rule that would require better training of staff who operate aisle chairs and otherwise work with disabled passengers. "We see it in terms of dignity and safety. There are many clear cases where proper training would have made a difference [in avoiding serious injury]. We would like to get the notice of proposed rulemaking out this year," Buttigieg says.

The DOT finally has airline accessibility on their radar. Whether it stays there or not, and whether the government mandates other concrete improvements such as allowing disabled passengers to board and fly in their wheelchairs — will require continued, relentless advocacy from our community.

- SETH MCBRIDE WITH REPORTING BY STEVE WRIGHT

travel more accessible. He attended a meeting with disability rights leaders convened by Vice President Kamala Harris to discuss transportation accessibility at the White House in July. He told the attendees that DOT has "begun laying the preliminary groundwork for a rule that will make it possible for passengers to stay in their own wheelchairs when they fly, affording them the same dignity that so many Americans count on in other forms of transportation."

Days later, on the 33rd anniversary of the ADA, Buttigieg announced a new rule requiring airlines to make lavatories

on new single-aisle aircraft large enough to permit a passenger with a disability and attendant (see sidebar). "We are proud to announce this rule that will make airplane bathrooms larger and more accessible, ensuring travelers in wheelchairs are afforded the same access and dignity as the rest of the traveling public," said Buttigieg.

From boarding to bathrooms, there are plenty of other issues that matter to people with mobility disabilities, beyond being able to remain in their mobility devices. But Prentice and other insiders I spoke with pointed to Air4All as evidence that the accessibility discussion may have turned a corner. "This shows how one major obstacle was already overcome when smart people get the go-ahead to solve issues," Prentice says. Anderson urges patience. "Yes, it's taking forever," he says. "But when you're making a huge paradigm shift in thinking and design, unfortunately it takes time."

The sense that things are changing and a window for real reform may be opening is part of the reason the 70-year-old Buckland signed on as a DOT advisor, with a key factor being the recent \$1.2 trillion infrastructure bill that has made massive financial commitments to updating and overhauling the country's airports, roads, bridges and rails. "We have an opportunity right now to make a once in a generation difference in the built environment," says Buckland.

As a high-level quad who flies on a regular basis, it's disheartening to be asked for more patience when our rights continue to be violated and our lives are at stake. And though little seems to have changed for current flyers, what has changed is the groundswell of voices pushing to bring down one of the last major walls of exclusion from equal access to modern mass transportation since the ADA was passed 33 years ago.

What I have come to learn over the past six years of studying the disability rights movement is that true progress is a product of successive waves of activism that incrementally alter the landscape of society over time. Progress will come so long as we all stay engaged and sustain our momentum.

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f you tell a multitattoo owner that you're thinking about getting one, they always say the same thing: "Be careful, they're addictive." Truer words have never been spoken. I have 14 tattoos scattered around my forearms, lower legs and midsection. But as the saying goes, you never forget your first.



Mine is innocuous enough. It's a little gecko on my lower abdomen that I got while attending the University of Florida's homecoming in my freshman year of college. There is no particular meaning attached to it other than I was having a really good time with great friends. Subsequent tattoos, however, are a different story. Deeper meanings and intense memories became prerequisites for any new ink, including reflections of my children, being an active-duty Air Force officer on 9/11, and my passion for travel.

Once relegated in Western culture largely to rock stars, sailors, gang members and prisoners, tattoos now are as common as pierced ears. But tattoos have been a significant part of many cultures for centuries, including the Maori in New Zealand and numerous tribes across Africa. In addition to serving as a rite of passage into adulthood or memorializing family ties, tattoos have a unifying effect. For example, many U.S. Marines have tattoos of the "EGA," or the eagle, globe and anchor, which is a primary symbol of the service. Tattoos can symbolize membership in a club, whether it's a motorcycle gang or fans of a football team.

Another such "club" is the disability community. We get tattoos, like everyone else, but because of our various physical conditions and disabilities, getting one as a wheelchair user can present unique challenges. Still, many disabled enthusiasts will tell you: Tattoos are a great way to celebrate and commemorate your life on wheels.

### **OWNING IT WITH INK**

Jesi Stracham is an athlete, model and disability rights advocate who began using a wheelchair after a motorcycle accident in 2015. She got her first post-injury tattoo shortly afterward, at age 22. It reads, "Feed me to the wolves and I'll lead the pack," a philosophy she's followed ever since. "I got into this crazy accident where I died twice and came back, and I was leading the pack," she says. She describes her other tattoos as images of things or concepts that are near and dear to her heart. People with tattoos often have interesting stories related to them, and Stracham is no exception. "I broke my foot waterskiing a year into my injury and went to the same hospital I was taken to after my accident," she

says. "That was when I met the emergency-room nurse who was on duty the night I was resuscitated, and she remembered me from my (pre-injury) tattoos." Stracham believes that tattoos give the disability community a sense of being in this together. "Many of us have tattoos of wheelchairs, and it's typically our way of saying, 'I'm owning this, I'm living it, and I'm using it to my advantage.""



Erika Bogan is an athlete, travel consultant and former Ms. Wheelchair America. Like Stracham, she uses a wheelchair because of a spinal cord injury and enjoys having multiple tattoos. She says, "My tattoos represent chapters in my life, and are all very symbolic of things that have happened to me as part of my journey." As a victim of domestic violence, Bogan is particular when selecting who does her ink. "I'm weird about who touches me," she says. "This is why I've had only two tattoo artists, because they're people I've built relationships with and trusted."

Finding an artist you trust is essential, and finding



Erika Bogan by BAW Photography

one who can comfortably accommodate you can be tricky as well. "My friend who does my tattoos had a shop, and because the place wasn't accessible, I would have to go through the back door just to get inside," says Spencer Blomquist, a vacation consultant who has used a wheelchair for 14 years due to an SCI from a bullet wound. "And none of the rooms inside the shop were accessible, either." The solution? His friend would let him in on Sundays when the shop was closed and set up everything for him to get tattooed in the lobby.

Accommodations often go beyond simply getting in the door. Bogan's hip flexors have major muscle contractures that shorten her leg muscles and prevent her legs from fully extending. She can't lie on her stomach, so for her back tattoo, she had to sit in her wheelchair with the brakes on and lean over for the tattoo artist. Cory Lee, an accessible travel blogger, has spinal muscular atrophy and uses a large power wheelchair. "It's difficult for me to easily transfer over to a table, so that's why most of my tattoos are on my arms," he says. He only has one tattoo on his right ankle because he's limited in how he can position his legs.

### **SCI ISSUES**

People with higher-level spinal cord injuries also must be aware of potential issues with autonomic dysreflexia, as the stimulation of the needle below your level of injury can cause discomfort that triggers an abnormal overreaction of the involuntary nervous system. Symptoms range from goose bumps to excessive sweating and high blood pressure. Left unchecked, high blood pressure combined with a very low heart rate can lead to a stroke, seizure or cardiac arrest.

Blomquist makes sure his tattoo artist is aware of the potential for AD and is careful to sit up and let his blood pressure go down if he starts feeling any symptoms. For Greg Traynor, a quadriplegic who has used a wheelchair since 1999, relieving AD can be as simple as reclining in his wheelchair. If symptoms do not go away after taking a break or making adjustments, you should consider stopping the session. There are also drugs like nifedipine and topical nitroglycerin paste that can quickly lower your blood pressure in case of an emergency, but you should consult with your doctor before considering them.

One tattoo enthusiast who is uniquely aware of all these considerations is Nathan Galman, one of a handful of wheelchair users working as tattoo artists. Galman, who lives in Chicago, started out as a body piercer, but the people he was working with saw his artistic talent and asked if he wanted to try his hand at tattooing. Galman has autism, which he credits for making him a quick learner, and has been a successful tattoo artist now for nine years — eight of them as a part-time wheelchair user who has also experienced AD.

"Autonomic dysreflexia can be a really big situation for us because, obviously, you have extended periods of sitting, and being in one position too long can be make or break," he says. "AD can hit randomly, so I can be in the middle of a tattoo session, and my leg will feel like there's fire running through it." He has also had a client with AD. To prevent any issues, she would stay in her power wheelchair so she could recline during the tattooing session if needed.

Instead of trying to make a standard tattoo parlor meet his accessibility needs, Galman retrofitted his home to create an accessible studio where everything he needs is within easy reach. When he was still using a wheelchair full time, he used a raised massage table for clients to lie on so he could roll underneath. Tattooing in his chair made him mindful of pressure points on his body when leaning over for long periods of time.

He acquires all of his clients through his website and Instagram, and they know about his disability. "I've never had any clients show any kind of prejudice, but I've been to tattoo conventions in certain parts of the country where people have been more ... closed-minded," he says. "They might see me and expect lower quality work, but that ends up not being the case. If anything, that becomes interesting to them instead of being a reason to second-guess."

To wheelchair users thinking about getting their first tattoo, Nathan says the most important thing is to communicate clearly with your tattoo artist about your expectations and what you want. He also says that if you have issues with spasticity or sensitivity in parts of your body where you want to get a tattoo, it's best to choose a design that doesn't require straight lines or fine detail.

### YOUR PERSONAL BILLBOARD

Despite the wide range of disabilities, personal experiences and tattoo styles among the wheelchair users I interviewed, all of them agreed that tattoos are a great way to bring together the disability community, and serve as excellent conversation-starters. Galman believes that tattoos announce who you are. "Getting a tattoo is like a billboard," he says. "People who don't know your story can get a brief look."

Bogan says, "Almost everyone in the (tattooed) wheelchair community (whom) I've met ... has at least one that represents their disability. That's absolutely beautiful because it puts more representation of our lives out there." She says people without tattoos often approach her to ask what her tattoos mean. "I look at that as a great educational opportunity."

In my 18 years of being part of the disability community, I have found that just starting a conversation can be the most challenging, rewarding and wonderful experience that people with and without a disability can have with each other. If that can be brought about by the simple act of inking some permanent art on our skin, then put me at the front of the line at a wheelchair-accessible tattoo studio so I can start working on number 15.

# READER TATS

### *Clockwise from top left* ⊳

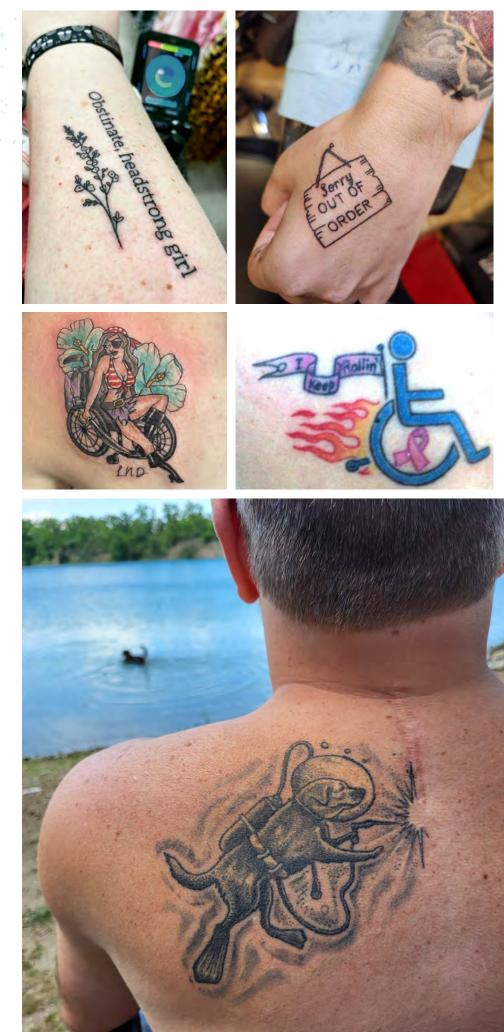
**SARA NURRENBERN:** "I have ALS. This is a favorite Jane Austen quote. Below is a sprig of heather which represents good luck and reversal of fortune. I have defied the odds and survived six years with ALS and am even suspected to be in the 1% experiencing a regression! This tattoo reminds me daily to keep fighting."

**JAMES LEE:** "The sign is super disarming and leads to laughs and new friends."

JENNIFER WYNVEEN: "My tattoo sums up my life. I have been paralyzed for 32 years. The pink ribbon signifies my being a 15 year breast cancer survivor. The banner says it all: 'I keep rollin!' This design was also on my graduation cap when I graduated with my bachelors in psychology."

**BRIAN ELLIOTT:** "Had a diving accident in 2005 and a year or two afterwards got a Labrador Retriever that became my best friend and helped with my overall recovery. Always wanted a tattoo and thought my first should mean something special to me. Scuba diving Labrador welding my SCI scar is what I came up with, as it brings it all together for me."

**BETHANY VENTRONE:** "This is a female pirate in a wheelchair. I got it a couple of years ago after I had been doing adaptive CrossFit for 3 years. It just represents the strength and overcoming adversity I've learned from life and not giving up even when I feel like I can't go on I've learned from CrossFit. The letters LND at the bottom of my tattoo stand for Leave No Doubt which is a CrossFit and life motto."



## Wheelchair-Accessible Autonomous Vehicles Are Here. Now What?

BY CHERYL ANGELELLI



AND THE COMPANY PLANS TO EXPAND TO OTHER MARKETS. ust 42 miles away from the Detroit factory that produced the first Ford Model T — which changed the way Americans lived, worked and traveled another Michigan company is hoping to once again revolutionize transportation.

Founded in Ann Arbor, Michigan, in 2017, May Mobility is a leader in the development of autonomous vehicle technology and accessibility. In collaboration with Toyota Motor Corporation and BraunAbility, May Mobility has launched a fleet of modified Toyota Sienna minivans with rear-entry ramps and May Mobility's AV technology. The accessible AVs are currently on the road in three of the company's 10 test markets, serving users of all abilities. The rides are free in some cities, and others charge a nominal fee set by the municipality.

"We're passionate about making transportation better for everyone, and providing innovative, accessible transportation solutions to rural communities is a key step in that journey," says CEO Edwin Olson. May Mobility believes AVs can be a viable transportation solution for underserved communities, including people with disabilities.

Currently, accessible AVs are available in Ann Arbor, Michigan; Grand Rapids, Minnesota; and Arlington, Texas. Thirty percent of May Mobility's active commercial fleet is wheelchair accessible, and the company plans to expand to other markets. n communities where May Mobility has launched accessible AVs, riders like Myrna Peterson are already enjoying the benefits. Peterson, 73, is a disability advocate and quadriplegic who uses a power wheelchair and owns a wheelchair-accessible van, but needs a driver to take her places. She has used May Mobility's wheelchair-accessible AV almost every day since the service launched in Grand Rapids, Minnesota, in October of 2022. She says it gives her gives her the freedom and independence to move around her community.

"I go to worship twice a week, I go downtown for city hall meetings and to go to restaurants or a movie," says Peterson. "I'm able to go to Target, see my grandkids play sports at their school, and get to my work."

Before May Mobility, Peterson's options were limited. Local ADA bus service through Arrowhead Transit only runs until 5 p.m. and is not available on weekends. There are no accessible taxis in her community, and medical transport is too expensive, especially for those with limited income.

Peterson books her rides on her phone using May Mobility's free app. Minutes later, an AV arrives with an Autonomous Vehicle Operator on board. Currently all of the company's AVs, including their wheelchair-accessible ones, have an AVO. The AVOs monitor the vehicles and do a manual takeover should there be a safety issue. For passengers with disabilities, AVOs provide assistance entering and exiting, and with securing mobility devices. They are more than faceless operators — Peterson knows all the AVOs in her area by name, and looks forward to their daily conversations as she cruises about town.

There are still plenty of hurdles to overcome if May Mobility is to fully realize the potential of accessible AVs. The biggest obstacle by far is going truly autonomous. That means moving past AVOs and figuring out a way for wheelchair users to independently enter and exit vehicles and secure their own chairs.

May Mobility's stated goal is to be completely driverless by the end of 2023, although their wheelchair-accessible AVs will continue to have AVOs on board to provide assistance. But the company is one of many interested parties working on an independent wheelchair-docking station and an automated beltdonning system that would replace AVOs.

> Users can indicate the need for a wheelchairaccessible AV on the app.

Along with the University of Michigan Transportation Research Institute, United Spinal Association, BraunAbility and others, May Mobility was selected to participate in the U.S. Department of Transportation's Inclusive Design Challenge to meet these goals.

The company has plans to enhance the AV's interior accessibility features with speakers and a video display to help passengers with hearing and/or visual impairments to see and hear key journey moments such as arriving at a stop, or when doors are opening and closing.

No one knows how these future improvements will change the AV experience, but May Mobility can take encouragement from strong positive feedback by early testers. In five years, May Mobility has provided more than 320,000 rides, and since debuting in Ann Arbor last December, that market has around 85% repeat ridership.

Peterson estimates she has put about 12,000 miles on her power wheelchair just getting to places in her community. She says having access to an accessible AV now makes it safer for her to go out, and she doesn't have to be out in the frigid cold during Minnesota's harsh winters.

"I have a master's degree in educational technology, so I've always been interested in what technology can do to make everybody's life easier, especially people with different abilities," she says. "AV technology is just so visionary, not only opening up the world and creating opportunities for people with disabilities but for (also) those who can't or choose not to drive."

### I Got To Test One of the First Wheelchair-Accessible AVs ... Here's What Happened

On a crisp, sunny day in Ann Arbor came my chance to ride in one of May Mobility's wheelchair-accessible AVs.

> Driving into the city in my personal vehicle, it was easy to spot the Toyota Sienna vans with giant logos and roof-mounted cameras, navigating the streets. My excitement was building. I didn't know what to expect. Secretly, I envisioned KITT, the talking, self-driving Pontiac Trans Am from the popular '80s sci-fi TV series *Knight Rider*, pulling up, asking me to get in, and off we'd go fighting the injustices of the world. Even though my ride would lack a glamorous Hollywood storyline, it was still pretty cool.

Upon arriving in Ann Arbor, the next step was to go to May Mobility's mobile app to book my free, on-demand ride. Rides can also be booked by phone for those who do not have a smartphone. In Ann Arbor, there are 19 pickup and drop-off locations established, based on popular travel patterns and community input, to easily connect residents and visitors to restaurants, pharmacies, grocery stores, churches and more.





Using the app, I provided my current location and booked a ride to the University of Michigan's campus. I also indicated I needed a wheelchair-accessible AV, as well as the number of passengers in my party. I received a confirmation text, followed by text updates on when my AV would be arriving.

Six minutes later, my green-and-white hybrid AV arrived with an AVO on board. My AVO was very knowledgeable about how the technology worked, and happily answered questions and demonstrated the vehicle's many capabilities.

Once we were ready to roll, my AVO attached straps to the front of my manual chair that automatically pulled me up the

ramp and into the vehicle. As a C6 incomplete quad, I was grateful for the powered assist. Once inside, the AVO used the Q'STRAINT manual securement system to strap down my chair, and provided me with a lap belt and shoulder belt. I definitelv felt secure.

The interior of the wheelchairaccessible AV was spacious and could



Left: In the future, accessible AV providers hope to develop independent wheelchair-docking stations. For now, May Mobility has Autonomous Vehicle Operators to help wheelchair users enter and strap into the vehicle. Below: Angelelli found the inside of the vehicle spacious and felt secure while riding in it.

accommodate one rider in a manual or power wheelchair and two non-wheelchair users. My chair was locked down in the middle of the vehicle so I had a full, unobstructed view out the front windshield. The only negative was I could not see out the side windows. The right window was completely blocked by a seat folded to make room for my wheelchair, and the small left window was too high to allow a view. Once I was secured, the AVO climbed behind the wheel, and as we pulled safely out into traffic, he put the vehicle in self-drive mode.

AVs are equipped with a series of sensors, radars and cameras working together to create a 360-degree view of the world around the vehicle. Then there is May Mobility's proprietary autonomy technology, called Multi-Policy Decision Making. MPDM imagines thousands of real-world driving scenarios every second. It looks at the most likely scenarios and the highrisk scenarios, and in milliseconds, the vehicle decides what to do.

I had a chance to experience firsthand how the AV's self-drive mode reacted to situations in real time. On my 15-minute ride, it knew when to stop for pedestrians crossing the road. It saw construction barrels in the road and moved out

of the way, and it knew when the speed limit changed and adjusted its speed. I hate flying because giving up control to someone else causes me anxiety, but I never felt anxious or nervous while riding in the AV. The ride was smooth, there was never any hard braking for a traffic light or stop sign, and the vehicle slowed to a comfortable stop every time.

All in all, the experience was really enjoyable. I drive my own modified vehicle, but if I did not have access to a car or public transportation, I could definitely see myself using this service. I would also use the service if I was headed somewhere that had limited ADA parking or no on-site parking. M

> About 2 minutes. Key moments: 00:33 Is it driverless? 00:56 Wheelchair tie-downs 01:04 Safety newmobility.com/wheelchairaccessible-autonomous-vehicles

### UNITED SPINAL'S ASSOCIATION'S ADVOCACY FOR ACCESSIBLE AVS

United Spinal believes autonomous vehicles could be life-changing for people with disabilities and has been working to ensure that accessibility is integrated throughout AV design and implementation.

"For tens of millions of people with disabilities and seniors, and those in transportation deserts, we are starving for the safe, on-demand, accessible and reliable transportation AVs can deliver," says Kent Keyser, public policy fellow at

United Spinal. "I say 'starving' because for untold millions, we don't have the luxury of transportation alternatives.

"Transportation brings all that the world has to offer to our doorstep. That includes health care, education, employment and living our lives to the fullest by engaging in the communities in which we choose to live and thrive. ... United Spinal is advocating for AVs to get us to wherever, whenever we want to go, at an affordable price."

Keyser cites a recent study that found "mitigating transportation-related obstacles for individuals with disabilities would enable new employment opportunities for approximately 2 million individuals with disabilities, and save \$19 billion annually in health care expenditures from missed medical appointments alone."



May Mobility and United Spinal share a mission to ensure autonomous vehicles are accessible.



<image>

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## IN THE MEDIA

By Teal Sherer

### **DISABLED WRITERS AND ACTORS STRIKE FOR A BETTER FUTURE**

Hollywood is at a standstill. The Writers Guild of America, the union that represents 11,500 screenwriters, and the Screen Actors Guild - American Federation of Television and Radio Artists, representing 160,000 actors, are both on strike against the Alliance of Motion Picture and Television Producers. These are the writers and actors who make your favorite TV shows and movies, like Ted Lasso, Oppenheimer and countless other productions, yet the vast majority of them are living from paycheck to paycheck.



Jamey Perry, Shea Mirzai and David Radcliff chair the Disabled Writers Committee for the Writers Guild of America.

The WGA and SAG-AFTRA are fighting for many of the same issues. They seek protections against rapidly developing artificial-intelligence technology and are trying to ensure living wages for their members. With the explosion of streaming services, the writers and actors have seen their paychecks and residuals dwindle.

The WGA has been on strike since May 2, and SAG-AFTRA since July 14. I chatted with WGA members David Radcliff and Jamey Perry, both wheelchair users, about why the strike is important to disabled writers. Perry is vice chair of the WGA's Disabled Writers Committee, which works to advance the visibility and employment of disabled writers. Radcliff is the DWC's co-chair, alongside fellow co-chair Shea Mirzai.

TEAL SHERER: David, weren't you working as a staff writer on the new CBS show *Tracker* when the WGA strike started? DAVID RADCLIFF: Yes, we were literally plotting my episode. The way our writers' room is set up is, whoever's episode is being worked on is leading the room that day. Our last day was a weird experience, because I knew everybody was thinking about the strike. We'd anticipated a strike was coming, and nobody wanted to think about Act 3 of my episode, or a twist because we were all waiting for the twist in real life of, "Ha, you don't have a job anymore."

## **TS:** How has the rise of streaming affected the writers?

**DR:** With the rise of streaming services, money earned from creative content isn't trickling to the actual creators of the content. For many years, it was very possible for a writer to work consistently, year after year after year, on network shows and get residuals. There used to be 20 or 22 episodes a season.

I remember X-Files was doing 24, 25

episodes a year — and that show went for nine years. Now you have a show on Netflix and your season is eight or 10 episodes long, no real residuals, and you're probably going to get cancelled after two seasons.

JAMEY PERRY: Writers' rooms have also become smaller. There is an abuse of something called "mini rooms," which consist of small groups of writers to work out a whole season of a series before that show is even officially (greenlighted). Because these rooms are smaller, and aren't officially rooms, they can be held for cheap, and tend to leave out a lot of newer talent. There is really no longer a middle-class TV writer or screenwriter in our industry. There are people at the very top. And then there's almost everybody else just absolutely scrambling at the bottom.

#### TS: What impact is this having on disabled writers?

**DR:** These issues impact underrepresented communities to an exponential degree. Of the few disabled writers who are working, we tend to end up at the lower levels, and then just stay there for a while, even if we're lucky. I'm doing a staff writer



More than 100 people turned out for the Disability Writes picket in June on the Sony lot.

Photo by J.W. Hendricks

job for the third time — that's almost 38 episodes of television at an entry-level job. It's hard to point to disabled folks who are at the upper levels — upper-levels being the folks who make big decisions about story and about casting and about everything. So much of this is intersectional too. If you're a Black disabled woman, your odds of being in a writers' room are even less.

JP: It also makes it even harder for disabled talent to break into the field. Smaller writers' rooms mean showrunners are less likely to take chances on new talent. We are also battling ableism. Though around 25% of Americans identify as having a disability, we're less than 1% of the Writers Guild. That is clearly a result of systemic ableism. To believe otherwise would be to believe that disabled people can't write, don't have any stories to tell, or are not good in a writers' room.

**TS:** You both have been active on the picket lines, and you all organized the Disability Writes picket in June at the Sony lot. How was that?

**DR:** Energizing. There were over 100 people there. There was something kind of powerful, having low-vision people, people in wheelchairs, neurodivergent people, and people who are Deaf all in one space. There were SAG-AFTRA disabled actors there, supporting us, even before their own strike. We've already had requests to do another picket and would love to plan a joint event with SAG-AFTRA, now that both guilds have struck.

JP: One of the coolest parts about the picket was that Margaret Nagle, a nondisabled WGA member who's a real ally, helped sponsor an accessible bathroom truck from (Californiabased nonprofit) Momentum. ... Their trucks are specifically made for the entertainment industry because, as we know, accessible bathrooms aren't always on sets. I have had to crawl up steps to use a bathroom. This truck costs \$2,900 a day. That's like the bagel budget of a big-budget show. So, here's your reasonable accommodation.

### **TS:** Why should people with disabilities support the strike? How can they help?

**DR:** The outcome of this strike sets a direction for labor in other industries too. We're aiming to build a more equitable industry that has room for a broad spectrum of voices and pays them fairly. To grow careers, we need a healthier industry that fosters space and opportunity. Otherwise, disabled people will likely be among the first to be squeezed out, and potentially to be replaced by artificial intelligence that will work for cheap.

JP: A big part of any strike is the public relations battle, and that is happening on social media. So, you can post positively about the guild, or you can amplify what other people are sharing and retweet. You can also donate to Entertainment Community Fund, which gives financial support to striking writers and actors, or to the World Harvest Food Bank, which is providing free groceries to striking writers and actors in Los Angeles. And anybody can come out and picket with us. Nobody is going to look at you weird — you'll just get high-fives all day.

You can follow the WGA on Instagram at @writersguildwest. To learn more or donate to Entertainment Community Fund and World Harvest Food Bank, visit entertainmentcommunity.org and worldharvestla.org.

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## Vicair AllRounder Strap-On Cushion Reviewed (Mid-September)

Years of battling pressure wounds have left Tim Gilmer's skin easily susceptible to reinjury. To safely make transfers onto a variety of surfaces — including an old golf cart he uses to check the crops on his farm —he tried out a unique cushion from the Netherlands. It's filled with tiny air packets and straps onto your backside, so it goes where you go.

## A Wheelchair User's Guide to Fall and Winter Clothing (Late September)

Check our website this fall for a cold weather clothing guide for wheelchair users, including adaptive options and ways to make existing, mainstream options work for you. From jackets to underlayers and accessories, we've got you covered when the thermometer starts to dip.

### Fire Through Dry Grass Documentary (Mid-October)

During the height of the COVID pandemic, a group of wheelchair users began documenting the deplorable conditions that they faced at Coler Nursing Home in New York City. They've just released a powerful feature length documentary, premiering on PBS, which exposes the brutal reality of trying to fight back when the systems you rely on deem you expendable.

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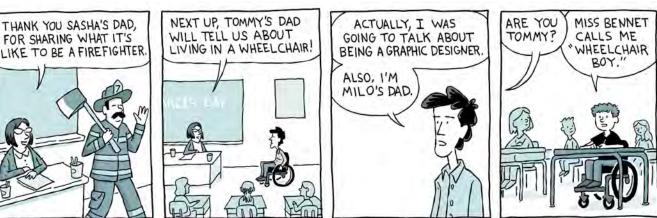
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Meme by @adam\_lucio

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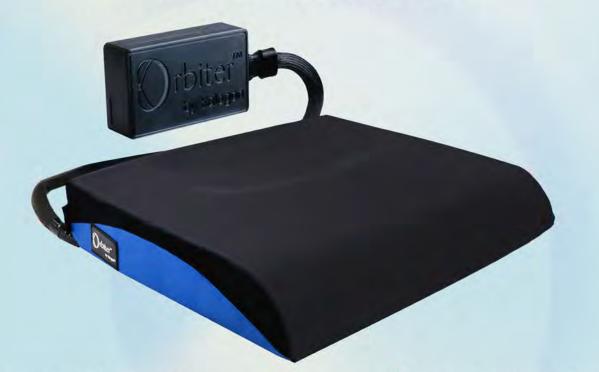








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