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OF UNITED SPINAL ASSOCIATION

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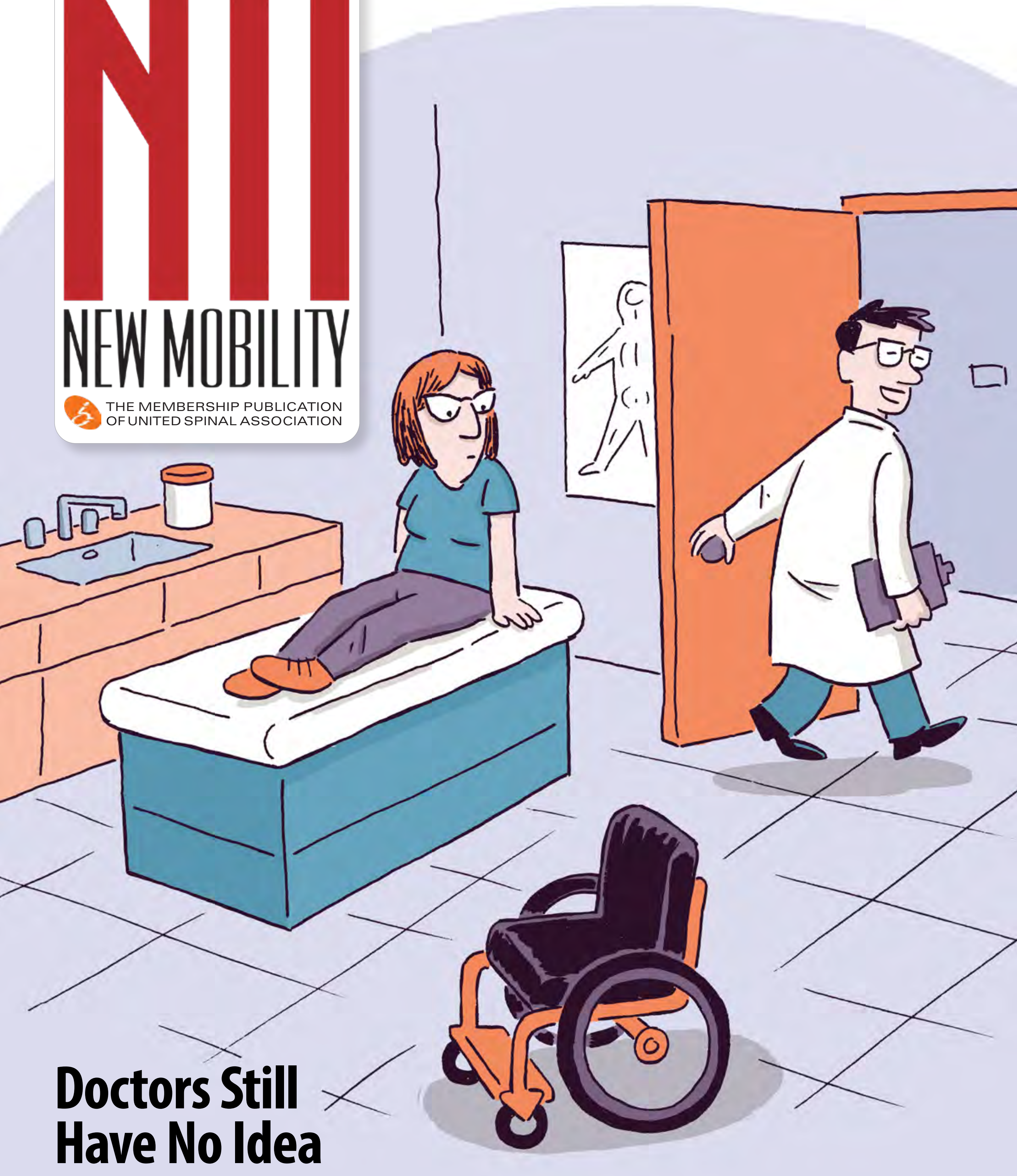

Doctors Still Have No Idea How to Treat Us

newmobility.com JUL-AUG 2023

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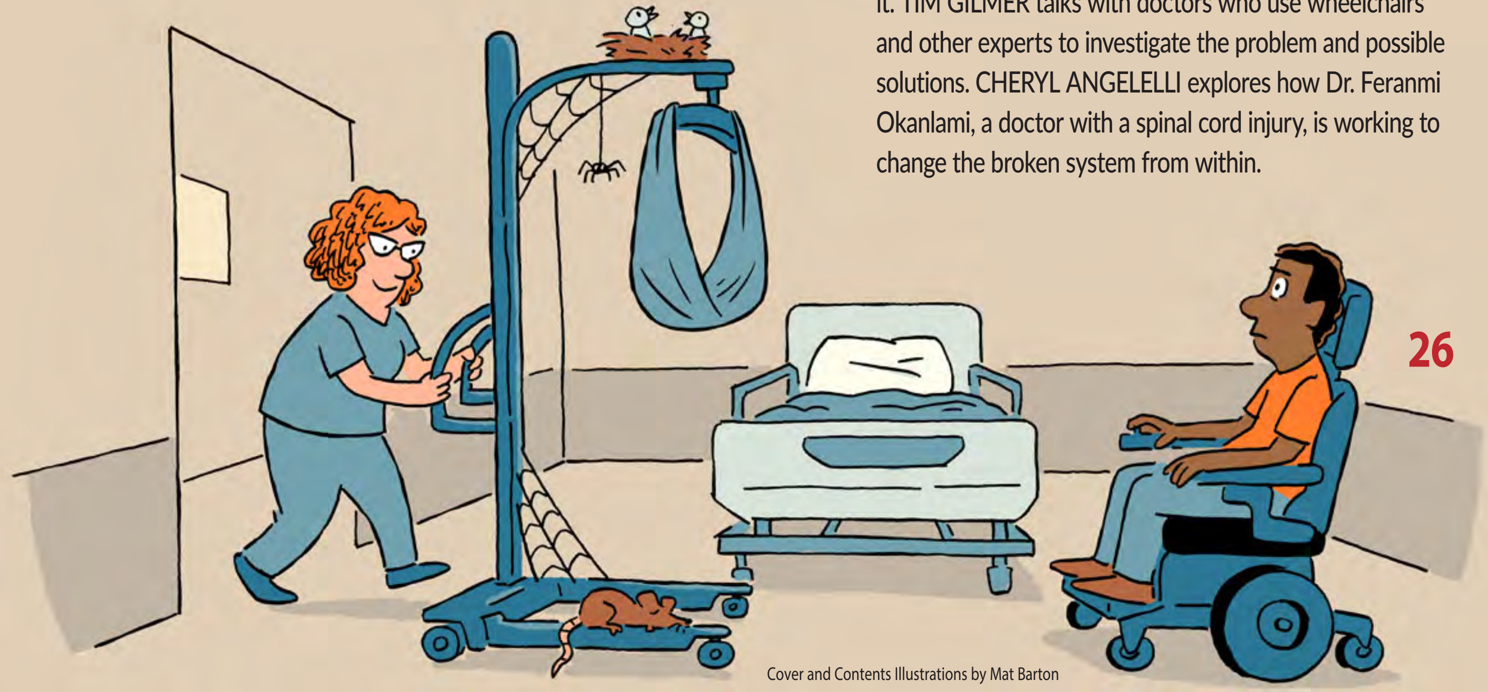
Issue 349 - July/August 2023

COVER STORY

DOCTORS STILL HAVE NO IDEA HOW TO TREAT US

Every wheelchair user has a horror story about a bad interaction with medical professionals who just don't get it. TIM GILMER talks with doctors who use wheelchairs and other experts to investigate the problem and possible solutions. CHERYL ANGELELLI explores how Dr. Feranmi Okanlami, a doctor with a spinal cord injury, is working to change the broken system from within.



Cover and Contents Illustrations by Mat Barton

FEATURES

DEPARTMENTS

NEW MOBILITY

United Spinal Association

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BULLY PULPIT

By Ian Ruder

WHEN AN ACCESSIBLE RESERVATION ISN'T A RESERVATION AT ALL

After nine hours of driving across the Southwest in my packed minivan, I could almost feel the hotel mattress by the time I rolled into the lobby of the Phoenix Hampton Inn. My achy shoulders and rumbling stomach subsided, knowing that after a week and almost 2,000 miles of driving, it was time for my Arizona vacation to begin. Five days in the sun, six baseball games and no responsibilities — I'd been looking forward to my first post-pandemic trip since I booked everything almost four months earlier.

I handed the receptionist my ID and credit card to confirm the reservation and watched her face change as she stared at her computer screen. I could feel my stomach and shoulders starting to groan again. Something was wrong.

"I'm sorry sir, but we don't have any rooms with roll-in showers available."

"But I reserved one almost three months ago. I have the confirmation number right here. I even called to double-confirm it two days ago."

"Our rooms with roll-in showers are occupied tonight, so …"

"That's why I reserved one three months ago. I have a five-night reservation and I can't shower without a roll-in."

"I'm sorry, but we can't hold those rooms as we have to give them out if people need them."

"I don't think you understand what a reservation is," I said, my frustration fully visible. The next ten minutes felt like a humorless *Seinfeld* sketch. I tried to explain what I thought was a simple concept and she looked at me like I was from another planet.

If you've traveled at all as a wheelchair user, chances are you've found yourself in the same situation: denied the accommodations you need despite going beyond the letter of the law. Embarrassing, dehumanizing and rage-inducing don't begin to describe the mixture of emotions swirling through your brain because you know that despite having the moral and rational high ground, ineptitude and ableism are going to leave you with nowhere to stay and no satisfactory resolution.

I kept trying to explain how unacceptable the situation was in hopes she would at least help me find somewhere to spend the night. A small part of me also wanted to make her feel the same hurt I did. When it became clear neither was attainable, I simply gave up.

Frustration

Finding an affordable room with a roll-in shower for an extended stay is never easy. Doing so at 9 p.m. in a town full of spring breakers and elderly sun chasers adds a whole other level of intrigue. It's exactly why I'd reserved the room months earlier. I ended up having to split the nights between two different hotels and paying almost $700 more than I had planned.

When I finally got home, I vowed to do anything I could to ensure no other disabled person had to endure what I did. My first call was to the property manager. She tried to give me the same spiel the receptionist had and eventually hung up on me. I calmly called back and explained I simply wanted to help her fix the problem. She gave me an 800 number and promised they had the power to address the situation. The number was dead.

Hampton Inn is one of Hilton's many hotel brands, so I submitted a formal complaint through the company's website and blindly emailed several Hilton employees I found on LinkedIn. None of the LinkedIn inquiries received responses, but I did receive well-formatted emails from Ankit, Mohit and Jaishiv in Hilton's complaint response team apologizing but telling me they were unable to call me to discuss further.

One person who did return my phone

call was Assistant U.S. Attorney Lauren DeBruicker. We've profiled DeBruicker in New Mobility before, and she is one of a handful of wheelchair users kicking ass and taking names in the Department of Justice. She turned me on to the DOJ's revised ADA regulations around accessible lodging, which clearly laid out exactly the arguments I'd futilely made to the receptionist and manager. Most significantly: *When a reservation is made for an accessible guest room, the specific accessible guest room reserved must be held for the reserving customer, and the room must be removed from the reservation system.*

As simple as that seems, Hilton properties have a history of struggling to comply. In 2010, in response to a DOJ complaint that around 900 of their properties had failed to meet ADA standards, Hilton agreed to physically bring these properties up to ADA standards and fix their reservation system so disabled guests could actually get the rooms they reserved.

I'm happy to acknowledge that Hilton has made lots of progress around accessibility in the last 13 years (we recognized its Home2Suites brand as the best chain for wheelchair users), but my experience — and the similar experiences I've heard from many others — shows how much work remains to be done.

Resolution

After a month of emails and calls producing no results, I was on the verge of giving up. The fading prospect of corporate accountability was losing to the daily demands of quad-life. Then, while I was about to dig into my Sunday breakfast, my phone rang with an unknown Texas number.

On the other end was an executive ambassador from Hilton's customer relations team. Over a 15-minute conversation she apologized for what I had gone through and relayed conversations she had with the regional director of sales who oversees the Hampton Inn I stayed in. She explained that through the conversation the director of sales discovered an issue in their inventory and reservation system that prevented them from appropriately reserving rooms with specific accessible features. She promised me the issue was being fixed and would not affect any future disabled travelers.

Without booking another room at the same hotel, there's no easy way to see if these promised changes have been implemented. The optimist in me hopes so. And the pessimist in me takes solace in knowing that by speaking up about the issue, I prevented the local operators from sweeping it under the rug with no accountability.

As disabled people, we shouldn't have to do extra work for the same access and benefits the rest of society enjoys, but unfortunately, we are often faced with doing that or accepting discrimination. If a hotel or other business has discriminated against you, or you think they are in violation of the ADA, I encourage you to submit a claim at ADA.gov.

DeBruicker knows how hard it can be to find the time and energy to pursue complaints, but she assures me the complaints are seen by the DOJ and often lead to investigations and lawsuits. "It's a pretty simple way to say something," she says. "Honestly, if all of us reported everything, it would probably flood the system, but it would make an impact."

NEW MOBILITY

SHARE

> “May Judy rest in love and power. What a legacy of strong women!”

Judy Heumann
Mother of the Disability Rights Movement

69

11 shares

MAY-JUNE 2023

Judy Heumann Mentored the Next Generation of Disability Advocates

Rest in Power: This is just a wonderful and uplifting reflection. May Judy rest in love and power. What a legacy of strong women!

Donna Thomson
NewMobility.com

For Wheelchair Users, Finding Attendants Has Gone From Crisis to Catastrophe

Could Happen to Anyone: Excellent and comprehensive explanation of the problem. I could very easily be one of the stories if it weren’t for my incredibly supportive family.

Georzetta Lynn Ratcliffe
NewMobility.com

Unsafe and Stuck: I’ve been waiting for accessible housing and a carer for four years now living with someone who wants me out of their home. I’m working with a program TCLI in my state. I’ve even been approved, but the government placed a hold [and] won’t place me, saying ONLY those from care homes and nursing homes would get placement. I was supposed to be placed in one, but I fought it with a hospital case worker. It’s been unreal! Now I’m in a situation that’s unsafe for me — THEY know it and they WON’T budge. I need care and they won’t GET IT.

@chronicallyaskew
Instagram

Turnover Trouble: It is so bad, at one point I went through four attendants in six months. They just sat around while I worked. So, I quit having one. Now I’m needing one on a permanent basis and am afraid to look.

@susanhemann
Instagram

No Nursing Home for Me: This is in fact a crisis. I just did a virtual advocacy day with the Reeve Foundation asking our senators and congressman to have town hall meetings to deal with the caregiving crisis. I wake up worrying that I will no longer be able to afford my care after 40 years of being a quadriplegic. My husband and I separated in a nursing home. Quite frankly, I would rather die before going to a nursing home. There have to be solutions.
We need to band together and fight. The Medicaid model is outdated. I am a successful attorney who earned an income and pay my taxes and contribute to society. Why should I need to be broke and on Medicaid to qualify for caregivers who may not even be available? We need a village. Please join us! Thank you for amplifying this issue, New Mobility.

@happyonwheels
Instagram

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

Lasting Rewards: I had to comment on the article on wheeler/teachers since I was one for 24 years. I taught chem and sponsored the Drama Society. I retired 11 years ago, but missed the kids. So, I volunteered and then subbed up until the pandemic. Now I’m just volunteering again. I wish I’d known these other wheeler/teachers when I was teaching. It would have been nice to have a group to chat with. Nowadays I could see these people in a monthly Zoom meeting. What a great support group that would make!
Just one short story: When I thanked my new state rep for an item in his newsletter, he responded within hours with “No, thank YOU Mr. Bronstein. I met my wife in your chem class.”
Yes, teaching does have its rewards.

Alan Bronstein
Via email

Testing Abilitease Gripping Aids as a C5-6 Quad

Affordable Solutions: Thank you for this article. Very interesting. As a C5 quad, incomplete, I am always experimenting with different tools to help support my grip. Interestingly, I have had great success with using and adapting tools originally developed for toddlers.
I have found that young children’s products are often less expensive than adaptive equipment for adults.

Asch
NewMobility.com

BEHIND THE STORIES

With Ian Ruder

Editor Emeritus can be a lovely honorary title to thank someone for years of service without actually expecting or requiring much in the way of new work. Rest assured that is not the case with New Mobility Editor Emeritus **Tim Gilmer**, who may be the hardest-working editor emeritus out there. In addition to living up his retirement, he finds time to chip in with editing and consulting on most of the content that graces our magazine and website. In this issue, he keeps his writing chops sharp with a powerful look at how and why so many in the medical profession are failing our community. "I don't know about being the hardest-working emeritus editor," he says, "but NM will always be near and dear to my heart."

It's hard to believe it has been nine years since Tim Gilmer introduced cartoonist **Mat Barton** to New Mobility readers in our May 2014 issue. I remember editing the story and familiarizing myself with Barton's work, while at the same time, wondering how we could work with him going forward. Almost a decade later, he is a beloved favorite of NM readers and one of our go-to artists for spot illustrations, comics and more. This May we used one of his panels for our first-ever cartoon caption contest. Predictably, we were inundated with responses. "Now readers get a chance to see how difficult my job really is," Barton says with a laugh.

When I realized that I have yet to highlight **Cheryl Angelelli** in this space, I went back and double-checked every issue from the last two years because I couldn't believe it. With her professional approach to reporting and her nose for a good story, Angelelli has quickly become an NM mainstay. She's already covered Ms. Wheelchair America, para dance and a quad chef, with more already in the pipeline. In this issue she profiles Craig H. Neilsen Visionary Prize-winner Dr. Feranmi Okanlami. When she's not on the beat for NM, Angelelli works as a communications manager at Rehabilitation Institute of Michigan and competes in para dance sport. "I love being able to share the diverse, lived experiences of real people and topics that make an impact on our community and connect us to one another," she says.

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.

The Porsche of Outdoor Wheelchairs?

Auto giant Porsche wants to help wheelchair users explore the great outdoors and has partnered with a Swiss organization to upgrade the Protrek, a single-wheel, all-terrain chair that is pulled and lifted over rough terrain by front and rear guides. Porsche engineers are teaming with mobility experts from Alber and Procap, a Swiss self-help organization, to improve the chair's auxiliary electric drive.

The collaboration isn't Porsche's first foray into disability mobility. A Porsche subsidiary designed the suspension of the Alber Adventure A10 power wheelchair, produced from 2003 to 2014, and they developed a prototype chair similar to the Segway called the P'GASUS.

"The P'GASUS is a project close to my heart. I was fully involved in its development," says Maic Grabert, a development engineer at Porsche Engineering Services GmbH and a wheelchair user. "It lets wheelchair users suddenly do completely obvious things like look their companions in the eye — or hold hands with them. I view the Protrek in a similar light. It lets you get out to places in nature that are otherwise hard to access — and gives you marvelous experiences." Read more at tinyurl.com/2s3c555z.

Back on the Mound

An Alabama wheelchair user is back on the mound after an ill-conceived attempt to ban him from pitching for safety reasons. Chase Carnley made the news in April when officials from the 8-and-under softball league he coaches in asked him to stay in the dugout instead of pitching to the girls on his team. A local attorney lodged an ADA complaint, leading the league to devise and implement a new set of rules for wheelchair-using coaches. Carnley took the mound again a few days later, saying it felt good to be back on the field. "It's all about making them happy," he said. "If I can make them happy by being their pitcher, I'll pitch out there to the best of my ability."

More than a Makeover

Almost four years after the Fab Five made over Kansas City's Wes Hamilton, *Queer Eye* rolls to the rescue of another wheelchair user in the new season of *Queer Eye: More than a Makeover*. This time Karamo and crew work with Ray "Speedy" Walker, a burgeoning TikTok star who was paralyzed in 2020. Tune in on Netflix to see Speedy get hooked up with a new wardrobe and set up in his new accessible apartment. He even gets to meet up with Hamilton.

Better Beach Access

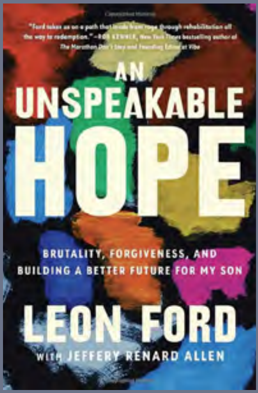
If you're planning your next international vacation and seeking some accessible beach sun, you may want to add Greece and Italy to your itinerary. Thanks to government funding, more than 200 beaches will be outfitted with wooden walkways allowing wheelchair users access to a Seatrac chair, a remote-controlled solar-powered recliner that rides a track into the shallow water. The setup allows users to avoid sand and get in the water with ease. The Seatrac was designed by a Greek company in 2012 but has seen a limited rollout until the last two years. To find out more, visit seatrac.gr/en.

WHAT TO READ

SUMMER IS FINALLY HERE, AND THERE'S NO BETTER TIME TO ENJOY THAT STACK OF BOOKS YOU'VE BEEN MEANING TO READ. TO HELP GET YOU STARTED, OUR NM STAFF SHARED A FEW PICKS FROM OUR LISTS.

TRUE OR FALSE: A CIA ANALYST'S GUIDE TO SPOTTING FAKE NEWS & **AT THE SPEED OF LIES** BY CINDY OTIS

AS THE ONLY NM CONTRIBUTOR I KNOW WHO ALSO WORKED AS A CIA ANALYST, OTIS HAS SKILLS IN ALL TYPES OF DIFFERENT AREAS. THE JUXTAPOSITION OF THESE TWO BOOKS IS MORE PROOF. *TRUE OR FALSE* IS A MUST-READ NONFICTION GUIDE TO THE ALL-TOO-FICTITIOUS WORLD WE LIVE IN, WHILE *AT THE SPEED OF LIES* IS HER FIRST FORAY INTO YOUNG ADULT FICTION (AND FEATURES A COOL DISABLED PROTAGONIST). — *IAN RUDER*



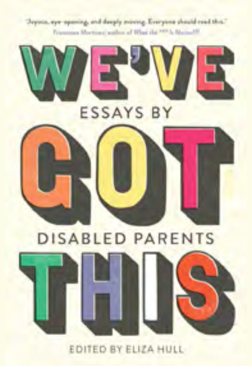
AN UNSPEAKABLE HOPE BY LEON FORD

LEON FORD BECAME A WHEELCHAIR USER IN 2012 WHEN HE WAS SHOT BY A PITTSBURGH POLICE OFFICER IN A RACIALLY-PROFILED CASE OF MISTAKEN IDENTITY. SINCE THEN, FORD HAS BECOME A POWERFUL SOCIAL ACTIVIST DEDICATED TO BRIDGING THE GAP BETWEEN THE POLICE AND THE COMMUNITIES THEY ARE SUPPOSED TO SERVE. HIS NEW MEMOIR IS AN HONEST REFLECTION ON PROCESSING TRAUMA, FINDING FORGIVENESS AND WORKING TOWARD A BETTER FUTURE. — *SETH MCBRIDE*

ACCESS YOUR DRIVE AND ENJOY THE RIDE

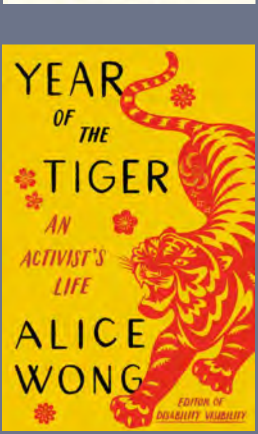
BY LAUREN "LOLO" SPENCER

ACTRESS, MODEL, AND DISABILITY LIFESTYLE INFLUENCER LAUREN "LOLO" SPENCER GIVES US A CANDID LOOK INSIDE HER LIFE WHILE PROVIDING A GUIDE TO HELP OTHERS ACHIEVE THEIR DREAMS. SPENCER'S ENGAGING PERSONALITY SHINES THROUGH FOR AN INSIGHTFUL AND DELIGHTFUL READ. — *TEAL SHERER*



WE'VE GOT THIS: ESSAYS BY DISABLED PARENTS BY ELIZA HULL

PARENTS WHO IDENTIFY AS DEAF, DISABLED OR CHRONICALLY ILL DISCUSS THE HIGHS AND LOWS OF THEIR PARENTING JOURNEYS AND REVEAL THAT THE GREATEST OBSTACLES LIE IN OTHER PEOPLE'S ATTITUDES. I LOVE THAT IT NORMALIZES THE DISABLED PARENTING EXPERIENCE, WHICH IS OFTEN A TABOO TOPIC.
— *SHANNON KELLY*



YEAR OF THE TIGER: AN ACTIVIST'S LIFE BY ALICE WONG

DISABILITY ADVOCATE ALICE WONG REFUSES TO SHY AWAY FROM THE HARD TRUTHS AS SHE LOOKS BACK ON HER PREVIOUS WORKS AND DIVES DEEPER INTO THEMES LIKE ACCESS, POWER, CARE, THE PANDEMIC AND MORE WITH NEW ORIGINAL ESSAYS. STARTING WITH HER ORIGIN STORY, WONG'S BOOK EXPLORES HER LIFE AS AN ASIAN AMERICAN DISABLED ACTIVIST AND THE UPS AND DOWNS OF HER ONGOING BATTLE AGAINST ABLEISM.
— *HILARY MUEHLBERGER*

UNITED SPINAL

By Shannon Kelly

United Spinal Joins Lawsuit Against California's Assisted Suicide Law

United Spinal Association joined a coalition of leading disability organizations to file a complaint against the state of California, declaring the state's assisted suicide law unconstitutional. The law, known as the End of Life Option Act, went into effect in 2016 and allows terminally ill patients to request medication that can be self-administered to end their lives.

The lawsuit claims the law is discriminatory on the grounds that disabled people's lives are not treated as being worthy of protection in the same way that nondisabled people's lives are. The lawsuit argues that people who are suicidal receive radically different treatment responses from their physicians, depending on whether the person has what the physician deems to be a "terminal disease" — which, by definition, is a disability under the Americans with Disabilities Act.

"Nondisabled people present symptoms of depression, and they are diverted to suicide prevention. And people with substantial impairments present to say the exact same thing and they can — depending on the doctors' estimation of quality of life — be given a prescription to end their life," says United Spinal Association General Counsel James Weisman.

Instead of helping disabled people die, United Spinal believes physicians and the state of California should help them live. United Spinal believes disabled people deserve help dealing with the symptoms and practical necessities that come with living with a disability, including access to mental health care, customized mobility devices, affordable housing and adequate caregiving. "We know there's life after disability, meaningful life. You don't just live, you love people and they love you. Life is fulfilling if you let it happen. Doctors may not know that," says Weisman.

United Spinal's Resource Center offers information and support for wheelchair users and their families. Call 800/962-9629 or visit unitedspinal.org/spinal-cord-resources.

From Injury to Independence with the Help of Technology

United Spinal Association's Injury to Independence project helps newly injured individuals at Touro Rehabilitation in New Orleans find independence through technology. Program manager Tyler Schrenk meets with participants to develop creative tech solutions for their everyday needs.

Schrenk, a C1 quad, knows the impacts of technology firsthand. "After my spinal cord injury, I struggled with social anxiety and depression. I had little interest in doing anything at all," he says. "One day, a friend of mine from Microsoft donated me a Microsoft Surface tablet I could control by voice. All I did at first was look at baseball blogs, but it was something I could do independently, which was huge."

Thanks to funding from Consumer Technology Association, 10 participants receive $1,000 each. Common uses are Amazon Alexa, Amazon Fire TV Cubes or Bluetooth-enabled lightbulbs. One participant purchased a voice-activated GPS to help their travel to and from work. Once the technology arrives, Schrenk schedules training sessions for installation and use.

Meet New Member John Moralez

C3-7 Incomplete SCI, Age 54 from Hudson, New Hampshire
Volunteer peer visitor at local rehab hospital

Why did you join United Spinal?

I joined because I was interested in learning more about my condition, resources and finding support.

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

My AFO brace has helped me tremendously with keeping my drop foot upright while learning to walk and with getting in and out of my wheelchair.

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

Having power assist on manual wheelchairs would make getting around much easier. It would take the strain off of shoulders and help people maneuver around without much need of assistance from other individuals.

How to Help Improve Air Travel

Every five years, Congress must renew authorization for the Federal Aviation Administration. The renewal gives federal lawmakers an opportunity to examine the airline industry and see if any reforms or updates need to be made.

To improve safety, accessibility and accountability in air travel for disabled people, United Spinal Association is urging Congress to pass the Air Carrier Access Amendments Act. Members of our community too often face damaged wheelchairs, injuries and even death. If passed, the ACAA would be implemented and enforced by the FAA.

The bill includes the following provisions:

- Establishes a private right of action, allowing passengers with disabilities to sue airlines for damages in civil court.
- Requires the Secretary of Transportation to create new standards for safe and effective boarding and deplaning, seating accommodations, accessible lavatories and stowage for mobility devices.
- Requires the Secretary of Transportation to issue fines to airlines that violate the laws protecting people with disabilities in air travel.

Now is the time for our community to take action. Please contact your members of Congress today and urge them to support the Air Carrier Access Amendments Act. Find out more and get involved at unitedspinal.org/advocacy-action

Schrenk

Celebrating our Capstone Students

Since welcoming its first two students in 2019, United Spinal Association's Capstone Program has grown into an in-demand opportunity for Occupational Therapists in training. Working hand-in-hand with a nonprofit allows students to gain a different perspective of their field, while also offering them an array of connections that might not otherwise be available to them.

"The Capstone students provide perspective into OT best practices and are able to interact with our members and learn from individuals with lived experience," says Abby Ross, chief operating officer. "It is a win-win arrangement and we hope it continues to grow with new universities and schools participating in the future."

For Rachel Buckley, an OT student at the Katz School of Health and Science at Yeshiva University, the Capstone Program has been eye-opening. "The biggest takeaway I have learned while working at United Spinal is the importance of having representation and individuals living with SCI involved in all the decision making, planning and the advocating process," says Buckley.

Lindsey Elliot, United Spinal's director of member initiatives, says the organization benefits as much as the students. "Through the work of our capstone students, we are able to enhance much-needed information and resources to better serve our members," she says. "The capstone students bring a new and fresh perspective and are able to help us bridge that working relationship between community organizations and clinicians."

Here's how this year's students connected with members:

RACHEL BUCKLEY, KATZ SCHOOL OF HEALTH AND SCIENCE AT YESHIVA UNIVERSITY: Buckley created a toolkit to provide primary care physicians more knowledge about SCI/D to help them better serve the community and their patients. The toolkit includes questions for individuals with SCI/D to ask before committing to a PCP, a client intake form, an accessibility page, a clinician checklist and a resource page.

SARAH INGRAM, MURPHY DEMING COLLEGE OF HEALTH SCIENCES: Ingram, a student at Murphy Deming College of Health Sciences, focused on making fashion and beauty products more accessible for wheelchair users. She interviewed members of the disability community to learn what problems they face and to devise solutions. "As apparel impacts mental health, self-image and employment, I hoped to provide resources to support individuals in accessing desired, functional clothing and beauty products," she says.

JONAH ECKERT, HUNTINGTON UNIVERSITY: Eckert harnessed the power of personal narratives to stress the importance of mental health awareness for people with spinal cord injuries. He interviewed members about their recoveries post-SCI and compiled the responses in "My Spinal Cord Injury Perspective," three articles currently available on United Spinal's website. He is an occupational therapy doctoral student at Huntington University.

DATA SECURITY EXPERT AND PILOT

Ashwini 'Ash' Ahuja

After flying for 13 years, Ashwini "Ash" Ahuja finally found a plane accessible enough to purchase, but there was only one way to get it from Florida to his home in California — fly it cross-country.

Preparing for Take-Off

When you ask Ahuja what city he grew up in, he can't tell you. That's because his father was a pilot for the Indian Air Force, so he grew up an army brat on bases all over India. Having grown up around planes all his life, Ahuja planned to follow in his dad's footsteps and become a pilot. But after becoming paralyzed at age 11 from an unknown virus, he put his dreams of flying on hold.

In 2010, well after immigrating to America and establishing a fulfilling career in data security in Connecticut, he found Philly Sport Pilot, a New Jersey flight school owned by a wheelchair-using pilot. Ahuja learned how to fly with factory-built hand controls on a Sky Arrow 600, a tandem two-seater aircraft. Ahuja was the school's first wheelchair-using student. He graduated with his pilot's license in three months.

"If you compare hand controls in a plane with hand controls in a car, there are more things in the plane that you are constantly doing all the time, especially during take-off and landing, so the hand controls must be configured in such a way that you can do all the things required to fly a plane without taking your hands off the controls," says Ahuja.

After learning on and flying Sky Arrows for many years, Ahuja mastered the complicated stickwork needed to make that plane soar, but he eventually felt the need for something new. "I liked the Sky Arrow, but I didn't own it, it was too small to fit my wheelchair and I wanted to actually go places. I was only borrowing it when I wanted to fly, but I needed something of my own that was more practical," says Ahuja.

Three years of internet research and talking to other wheelchair-using pilots around the globe led him to a Paradise P1 for sale in Florida. Ahuja lives in San Francisco. Thankfully, the owner of the company selling him the plane not only agreed to install the hand controls, but fly back to California with him.

"I could've just hired someone to fly the plane for me, but I wanted to experience flying from coast to coast myself, and surprisingly, not a lot of people have done that because in flying, any flight over 50 miles is considered a cross-country flight," he says.

When you're a pilot and a wheelchair user, such flights can be extra tricky. He tried to plan a route that would allow him to stop

MOST ACCESSIBLE PLACE YOU'VE BEEN: In the U.S., Cincinnati or the Midwest. Outside of the U.S., Barcelona.

WHAT ACCESSIBILITY LAW DO YOU WANT CHANGED? The idea that buildings can be grandfathered as inaccessible as heritage buildings.

at airports with more services and staff that could help him, but that wasn't always possible. Not every airport they flew into during the journey had an accessible bathroom or an accessible way to travel from the airport once you land.

"Finding an accessible washroom is definitely an issue, and there were some airports we landed at that didn't have Uber or Lyft in the area. When you land at airports like that, some of them have crew cars for pilots to use, but many are trucks that I can't get into. So if I was by myself, I'd have to think about how I could go get food or go to a hotel," says Ahuja.

Ahuja enjoyed the experience and hopes it motivates others to push the limits. "I fly to actually reach new heights and break new ground, but I also fly because as a pilot I can go anywhere," he says. "I'm not restricted by cars, roads or the earth itself, and when I'm flying, I'm no different than any other pilot in the sky. It's the same freedom I experienced when I first started driving, but increased tenfold."

Managing Mindset

Ahuja explains how the power of his father's belief in his capabilities allowed him to resist internalizing the belief of many in India that people with disabilities will never amount to anything.

> "The whole mentality of people in India is if you're in a wheelchair, you're an invalid and you need to be pushed around by somebody else. That's how most people think. Growing up in a place like India, I have to give full credit to my parents, my dad especially. There was nothing that he would be like, 'You can't do that.' Anything I wanted to do, he would say, 'Of course' and would carry me sometimes up three to five flights of stairs just to get me to places. It was like, 'Oh, you want to go there? Sure, I'll take you there.' He did that all the time and helped shape my mindset.
>
> Also in India, very rarely would you find a person in a wheelchair driving a car. I was driving a car and being independent, and I think that changed me the most. Luckily, I had a friend who used a wheelchair who was driving and encouraged me to drive and get hand controls. I was driving in India for five or six years before I came to the U.S.
>
> I visited England when I was 16 with my dad and that's when I realized how different the mindset is in some of these developed countries compared to India where they're constantly staring at you, asking you weird questions and people are more interested in watching you than helping you."

ADAPTIVE TECHNOLOGY THAT CHANGED YOUR LIFE?
The two I use a lot are the SmartDrive and Freewheel.

WHAT DO YOU GET OUT OF YOUR UNITED SPINAL ASSOCIATION MEMBERSHIP?
New Mobility magazine.

GEAR HACKS

By Kary Wright

BUILDING A BETTER BLADDER SOLUTION

Having to ask for help draining a leg bag can be one of the most frustrating and embarrassing everyday tasks of life as a higher-level quadriplegic. As soon as I was paralyzed in 1986, I was on a mission to come up with a better solution to independently manage my bladder. Almost 40 years later, I'm still tinkering. Here are three solutions I've found along the way.

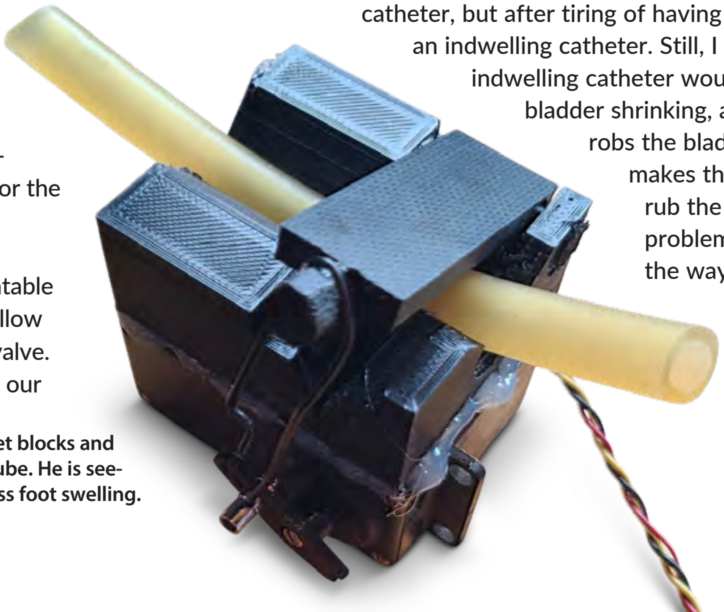
A Leg Bag Drainer

Back in the '80s, the only option I could find for a leg-bag-drainer was an electric 24-volt valve that connected to your wheelchair batteries. It cost over $400. I sprung for the unit and enjoyed the freedom to be alone for most of the day — but within a year it quit working.

If only I'd had my beloved 3D printer. Ever since I got my first little Anycubic in 1997, I've used it to print simple, affordable solutions. Instead of wasting a lot of money on an imperfect product, my friends and I work to identify a problem, brainstorm a solution and then print it, right in my own home. Sometimes it takes a few iterations and some tinkering, but time and again, we've come up with unique products that worked better than anything I had seen for sale. That's exactly what happened once I decided to devise a better leg bag drainer.

I wanted the drainer to be easy to use and reliable. I'm nervous about fire hazards, so I focused on a solution that would be manually operated instead of tapping into my wheelchair's batteries. Instead of inventing a new valve, I searched the internet. I found a cheap manual plastic fuel valve for about $10, and scrolling down farther on the website there were 20 valves for $20. I didn't really need 20 of them — but coming from a long line of professional hoarders, I figured there'd be a use for the other 19 at some point, right?

After some tinkering on Tinkercad.com, I had a 3D-printable design that would house and allow me to operate my $1 bargain valve. My buddy Dave came over for our weekly "tinker-frick-day," and in about an hour he had it glue-gunned together and mounted. The main housing that holds the valve is printed thick and solid, with the valve glue-gunned in place. A lever is attached to the valve, making opening and closing of the valve easy. I needed a way to open and close it, a string would work for pulling the lever up, but after extensive testing we realized string isn't very good for pushing. A glance around the room revealed a broken fishing rod. Attaching it to the lever proved that it worked great for pushing and pulling the lever. Now after a couple of years of flawless operation, it appears that I have a lifetime supply of plastic fuel valves.



This computerized gadget blocks and unblocks Wright's drainage tube. He is seeing less sediment and less foot swelling.

Dealing with Bladder Sores

A few years ago, I was at my yearly urologist checkup, and he was explaining what he saw in my bladder as we watched it onscreen in real time.

"What are the red spots on the bladder wall?" I asked.

"Those are sores, your catheter touches the wall and rubs on it, making a sore," he replied.

I use an indwelling catheter and was previously advised that it wasn't the best for long-term health. "Is there a solution?" I asked.

"Intermittent catheterization is better — then there won't be sores."

I enjoy being relatively independent during the day, and having to rely on an attendant to catheterize me every few hours had always been unappealing. I used a condom catheter, but after tiring of having accidents, I switched to an indwelling catheter. Still, I understood that using an indwelling catheter would eventually lead to my bladder shrinking, as the constant draining robs the bladder of its elasticity and makes the catheter more likely to rub the bladder walls and create problems. So, I figured mimicking the way my bladder was designed to work — allowing urine to build up before draining en masse — made sense. Dave and I got to work brainstorm-

> "I'm not a medical expert, just a guy living in a partially functioning body trying to increase my quality of life and extend my visit to this planet."

ing a solution that would do just this. We found a simple hose clamper that I could manually block and release the flow from my catheter. I clamped it off for an hour or so at a time. My bladder tells me when it's getting full with mild tingles up my neck. Then I open the clamp. I did this daily for the next year, about two to four times per day, or whenever I remembered. My bladder infection frequency reduced from every couple of months down to a couple of times per year. The next year I went for my bladder check. We once again looked at the computer screen in real time.

"How long have you been on an indwelling catheter?" asked the urologist.

"About three or four years," I said.

"Your bladder looks perfectly normal, no sores or anything," he said.

Sure enough, there were no red sores. I told him what I was doing.

"I don't recommend that," he said. "But based on the way it looks, I think, keep doing what you're doing."


Wright's friend Dave solders the tiny wires that control the clamping mechanism.

Computer-Aided Drainer

I did, until recently when my friend Landon, also a quad, got me interested in Arduino computer boards. They are programmed from a PC and can take inputs and send a result to outputs. At my age, without programming experience, learning C++ (computer language) is a bit of a stretch, but fun. After realizing that these can run a servo, the hamster in my head started running on its wheel.

I programmed an Arduino on Tinkercad.com's Arduino simulator to make a servo turn its motor to a specified degree of rotation and hold the position for a set time. You know where I'm going with this: I started thinking of building an Arduino-controlled clamp that would allow my bladder to fill, then empty, all automatically. In my thinking, the faster fluid flow should reduce bladder sediment buildup; mimicking normal bladder behavior should help with sores and improve overall bladder health.

I bought an Arduino, and Landon suggested an Arduino Micro Pro for the finished product. Some radio-control enthusiast friends donated servos. With the 3D printer, I designed a servo-operated pinch valve and set up the Arduino to open and close it. After some tweaking, it blocked a rubber tube on command, and opened it. It is powered by a USB and uses about 1 amp for the servo. I turned it on and programmed it to open and close every 10 seconds for a few days to test reliability. We had to glue a pin that worked loose, and Loctite a screw on the servo, but it otherwise proved durable.

On our next "tinker-frick-day," Dave soldered the wires to a Micro board, and we loaded the code into it. We made a power cord out of a high-speed USB cable and soldered it to the board, powering the servo directly as the board isn't designed to power more than a few milliamps. We plugged the USB into a phone-charger-battery and let it run for a day. The unit used very little power and seemed reliable.

I'm the Guinea Pig. I've been blocking my bladder for 15 minutes and letting it flow for 15 minutes in the evenings. After a few days of use there seems to be much less sediment, and I drain a lot of fluid during the day and have less foot swelling. Long term? I don't know yet, but it would seem mimicking normal bladder function should be good, and hopefully there'll be long-term benefits. I will keep testing and monitoring for infections. If nothing else, we created a first-class computerized plant waterer and learned some new programming skills!

Now remember, don't ever take any medical advice from me (I wouldn't), and I don't give any. I'm not a medical expert, just a guy living in a partially functioning body trying to increase my quality of life and extend my visit to this planet.

ADAPTIVE RIDERS

JOIN THE COMMUNITY AT THE WORLD'S LARGEST MOUNTAIN BIKING FESTIVAL

BY SETH MCBRIDE | PHOTOS BY JOE STONE

I STARTED ADAPTIVE MOUNTAIN BIKING seven years ago. At the time, I was riding a traditional recumbent handcycle with no motor — it was better than nothing, but still a poor approximation of the nondisabled experience. How quickly times change. Today, adaptive mountain bikes can take you places that a traditional handcycle never could, and the sport is quickly being integrated into the broader mountain biking community.

In April, I went down to the world's largest mountain biking festival, the Sea Otter Classic, in Monterey, California, to see what this integration felt like and what was driving it. There are many reasons for the sport's advancement — but they boil down to the bikes and the riders. All the adaptive sit-down riders at this year's event were riding Bowhead bikes, which have a unique, articulating front end that allows you to ride dirt at speeds that no other adaptive mountain bike will let you. The bike was designed by wheelchair user Cristian Bagg and has unleashed a host of mountain sport athletes — many of whom participated in or were injured in adrenalin-fueled activities — to keep charging hard after SCI. They're surprisingly quad-friendly too — fully adaptable for low-quads, with some power chair users finding ways to ride them as well.

As a company, Bowhead has been working to integrate its brand and adaptive riders, into the scene since it first attended Sea Otter in 2019. They've succeeded. A big part is the people running the event just seem to get it: Disabled or nondisabled, people just want to have fun riding bikes. As Sarah Timlick, the expo sales director for Sea Otter, puts it, "It really is just this massive, joyful festival that celebrates everything bicycle and cycling related."

Photo by Seth McBride

At Sea Otter, adaptive divisions were incorporated into the racing schedule, using the same courses as everyone else. There was plenty of accessible parking and a number of accessible porta-potties. Adaptive riders had our own tent area to leave wheelchairs and any other gear when we were out riding. We had our own space, but it never felt apart — we were right in the middle of it all.

▲ Racing is fun, but most of what draws people to adaptive mountain biking is the chance to be active outside, exploring beautiful areas that they wouldn't be able to otherwise. Here, Lisa Franks checks out the rolling hills — still green in early April — that surround Monterey, California.

◀ Another driving force behind the visibility of adaptive mountain biking in the broader mountain biking world is Martyn Ashton (right), seen here discussing the downhill course with Pierre Bergman. Ashton is a para and former world champion in trials — which consists of jumping mountain bikes up, over and off all sorts of obstacles. He's now a presenter on Global Mountain Bike Network, the world's largest mountain bike channel, which has 1.9 million subscribers on YouTube. Ashton is on GBMN all the time, sometimes talking about standup mountain bikes, sometimes talking about and riding adaptive mountain bikes. He's got an easy-going, self-deprecating style, which quickly dispenses with any "isn't it nice that the wheelchair guy can ride a bike," vibes. Ashton makes adaptive mountain biking look fun and normal, and millions of people get to see it.

Photo by Seth McBride

▶ Wufke Crosby is the kind of guy who will drink Champagne out of his shoe to celebrate a third-place finish. I guess it's not as gross since his feet don't sweat. Or maybe it is. Either way, Crosby likes to go fast. Sometimes this goes well. Like last year when he won both the downhill and the dual slalom at Sea Otter. Sometimes it doesn't. This year he charged full throttle into a section of muddy ruts at the bottom of the downhill course, rode his left wheel up a chain link fence and flipped on his head. Don't worry, Crosby was fine — and still stoked on the weekend.

Photo by Seth McBride

◀ The Sea Otter Classic is the largest mountain biking festival in the world. It spans four days —10,000 racers, 74,000 fans and around 750 brands that set up booths in the expo center. There are professional races. There are amateur races. There are children riding bikes, people riding unicycles, adults riding tiny bikes or jumping electric unicycles. There are many, many people on e-bikes. Increasingly, there are wheelchair users — nearly 20 attended this year, the biggest field ever. Most of us are here to race, but just being here is important. The Sea Otter Classic is where everybody who's anybody in the mountain biking world comes to see and be seen. "When we first started coming here, we were the weird little guys, and the only people who came to our tent were the other weird people," says Christian Bagg, the founder of Bowhead. " But now we're not the weird little guys anymore."

◀ Over the course of my 20-plus years as a wheelchair user, I've met a lot of impressive quads but none who live closer to my ideal than the ones I met at Sea Otter. Lisa Franks is a Canadian multiple Paralympic gold medalist in wheelchair racing. She made a good living as a mechanical engineer, until corporate downsizing took her job. Now she lives on public speaking gigs and spends her winters wandering around California in her van — surfing, riding her Bowhead, catching up with friends and doing it all independently. She raised her bed so she can fit her bike underneath and she gets to "cuddle with my surfboard every night." Sounds like the good life to me. For a full tour of her van, check out: tinyurl.com/yvmwrfeu

◀ Gustavo Ortiz, a Chilean former mountain bike World Cup downhill racer, won the adaptive downhill at Sea Otter. Ortiz is fast and smooth and makes things that are very hard look easy. Ortiz got second in the adaptive dual slalom race, and during practice laps he was beating nondisabled racers down the course. Top riders like Ortiz and former motocross racer Cole Bernier (who won the dual slalom) are pushing the boundaries of the sport every time they get on their bikes.


17”
TURNING
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ABLE BASICS

What is the purpose of an ABLE account? To save money or grow financial assets tax-free, while maintaining benefits like Medicaid and SSI.
When does the age restriction change? January 1, 2026.
Who will be eligible? Anyone who acquired their disability before age 46.
What is the savings limit? $100,000.
What can you use the money for? A wide variety of quality-of-life purchases.
How is the account structured? Like a traditional retirement account (deposits made with after-tax dollars), but you can withdraw penalty-free at any time.
Is there any risk? There are options for risk-free savings and investment accounts with market risk.

HOW TO Make THE Most OF AN ABLE Account

BY STEVE WRIGHT

Dante Allen used his savings to pay for an upgrade to his everyday wheelchair. Valerie Crisci is saving money to cover costs related to her service dog. Gayle Stanford used her savings to pay off her home mortgage so she could better afford recurring medical expenses.

Disability life is expensive. There are a thousand potential costs that nondisabled people rarely have to think about. "Achieving a Better Life Experience" accounts offer an easy, tax-advantaged way to save for disability-related expenses, plus they let you save without violating draconian disability benefits asset limits. Thanks to a recent federal law that expanded ABLE age limits, more people than ever will soon be eligible for these accounts.

We talked with experts and wheelchair users in a variety of financial situations to find out more about the best-kept financial secret in the disability community. The consensus: If you're eligible, there's no reason not to open an ABLE account.

Eligibility

Mark Raymond Jr. of New Orleans serves as national outreach lead for ABLE Today, the National Association of State Treasurers Foundation's campaign to promote awareness of ABLE accounts. An enthusiastic advocate, Raymond, a C5 quadriplegic, knows the benefits of an ABLE account as well as anyone, but is ineligible to open one. Thankfully, that's about to change.

When Congress created ABLE accounts in 2014, they restricted them to people who acquired their disabilities before the age of 26. Raymond was paralyzed in a diving accident at age 27. Fortunately, in December 2022, Congress passed an adjustment that raises the eligibility age to 46. Raymond will finally be eligible when the new rules take effect Jan. 1, 2026.

"A tax-free savings account — you bet I will open one

Thanks to the recent ABLE Age Adjustment Act, Mark Raymond Jr. will finally be able to open an ABLE account.

the day I'm eligible. I have expenses that would be nice to cover with ABLE account savings," Raymond says. "Home renovations could be saved for and funded. One time my (wheelchair) armrest broke and it cost $2,000 to fix it — not covered by insurance, so again, ABLE savings would help."

Under the amended law, it won't matter how old you are when you want to open an ABLE account, just how old you were at the onset of your disability. Otherwise, all you need is a doctor's signature that you have "severe functional limitations" lasting longer than a year. If you're a wheelchair user, you're almost certain to qualify.

Eric Ochmanek, program director at the National Association of State Treasurers, is promoting ABLE accounts through ambassadors and the abletoday.org website. He says opening an ABLE account takes about 20 minutes online. You have the option of creating a savings account, which pays low interest but protects every dollar contributed, or an investment account, which comes with potentially higher growth but also the risk of losses if stock markets decline like they did in 2022. "ABLE allows people with disabilities to accumulate wealth," he says. "It gives them choice for financial inclusion and empowerment, all while maintaining their Medicaid and [Supplemental Security Income] benefits."

ABLE accounts are structured like individual retirement accounts. You put money in them after taxes, and don't have to pay taxes on any investment profits. Dante Allen is a wheelchair user and the executive director of the board at California Achieving a Better Life Experience, the organization that runs California's ABLE program. Through CalABLE, Allen owns an ABLE account and sees it as a useful financial tool, even though he has a good job and does not qualify for government benefits.

"It is a great way to grow money long term … better than a Roth IRA or other IRA. An IRA has a significant penalty if you withdraw money before you are 59 ½ years old," he says. "But you can withdraw ABLE account money for any qualified expense at any age."

The definition of a qualified expense is quite broad. Virtually anything that maintains or improves the health, independence and quality of life of a person with a disability is a qualified expense — so it is not limited to medical copays and home accessibility modifications.

Allen says he uses relatively small withdrawals to pay out-of-pocket costs. He has good insurance, but it only pays for a basic wheelchair. To upgrade to a titanium frame, his out-of-pocket cost was about $900. He used his ABLE account to cover it.

Help Avoiding the Benefits Cliff

As an undergraduate student at The City University of New York School of Professional Studies and a recipient of SSI, Valerie Rose Crisci finds her ABLE account is the perfect way to save wisely without losing benefits that keep her active and in school. Crisci uses a power wheelchair due to a progressive neurodegenerative disease and is legally blind due to optic nerve atrophy.

She has saved $1,330 with her CalABLE account. It's money she plans to put to good use. "My current service dog, Cleo, is getting up there in age. Canine Partners for Life requires their recipients to donate at least $1,000, and there is the price of traveling to and staying in Pennsylvania for three weeks during team training," she says. "CalABLE offers a Visa card that can be used much like a typical debit card in order to spend the money that has been saved. I plan on using this method when it's finally time to go to Pennsylvania."

She created the website *Respect the Vest* to raise

Valerie Rose Crisci (with Cleo) is using her ABLE account to save for future service dog training.

awareness of service dogs and would like to create a nonprofit to do the same. “Trying to save the money for how much it costs to start a nonprofit is one of the reasons I opened my ABLE account,” she says. “Without having a CalABLE account, I had to worry about saving money — because if I were to save money, I could lose my government benefits. With a CalABLE account, I am able to save up to $100,000 without that worry.”

Monthly SSI benefits peak at $914 for an individual and $1,371 for a couple, barely enough for many to pay rent — let alone cover food, transportation and other daily expenses. On top of that, if you save more than $2,000, you risk having SSI cut off. “SSI is poverty, being constantly at the brink of ruin,” Allen says. “ABLE is a way of supporting people with disabilities, a group that is quite chronically underserved.”

Gayle Stanford, a wheelchair user with cerebral palsy, works part time at Columbus Speech and Hearing in Columbus, Ohio. She’s on Medicare and receives small Social Security Disability Insurance payments. Stanford says her medical expenses — including things not covered or only partially covered by Medicare — were growing and crowding out what she had left to make house payments.

> **WITHOUT HAVING AN ABLE ACCOUNT, I HAD TO WORRY ABOUT SAVING MONEY — BECAUSE IF I WERE TO SAVE MONEY, I COULD LOSE MY GOVERNMENT BENEFITS. WITH AN ABLE ACCOUNT, I AM ABLE TO SAVE UP TO $100,000 WITHOUT THAT WORRY.**
>
> ”

“I pulled about $45,000 out of my ABLE account to pay my house off. That way, I could focus my earnings on paying medical expenses and not worry about falling behind on the mortgage,” she says. “I still have about $20,000 left in my ABLE account. I have about one-third in high-risk, one-third in medium-risk and one-third in low-risk growth.”

Even if you don’t have the financial resources to save for big-ticket items, ABLE accounts can still be a useful option. Stanford says that family and friends can make gift contributions into your ABLE account. Similarly, if you ever raise money through crowdsourcing, you could put those funds into an ABLE account to save or grow them further.

Presently, 46 states and the District of Columbia offer ABLE accounts to their residents. If you live in one of the four states that don’t have ABLE programs — Idaho, North Dakota, South Dakota and Wisconsin — you can still open an account through any of the 30 states that have programs available to outside residents. The ABLE National Resource Center has a helpful list with details and contact information for all the state programs: ablenrc.org/select-a-state-program.

UNITED SPINAL HELPS SECURE ABLE AGE ADJUSTMENT ACT

Last year, United Spinal Association government relations and advocacy staff pushed strongly for passage of the ABLE Age Adjustment Act, along with the National Association of State Treasurers and the disability community at large. They met with key members of Congress to answer questions and secure their support. United Spinal advocates included Shelley Jaspering of Ames, Iowa, who testified before the U.S. Senate Committee on Aging in support of the bill.

Dante Allen uses his ABLE account to pay for out-of-pocket costs on mobility equipment, like upgrades on his wheelchair.

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paralysis

John Martinson's spinal cord injury didn't keep him off his Harley. Instead, he took that hog to his state capitol, crafting legislation to speed curative therapies.

Hear from John and other SCI advocates who are revolutionizing the research landscape at **U2FP's 18th Annual Science & Advocacy Symposium on October 20-21, 2023 in Minneapolis, MN.**

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Doctors Still Have No Idea

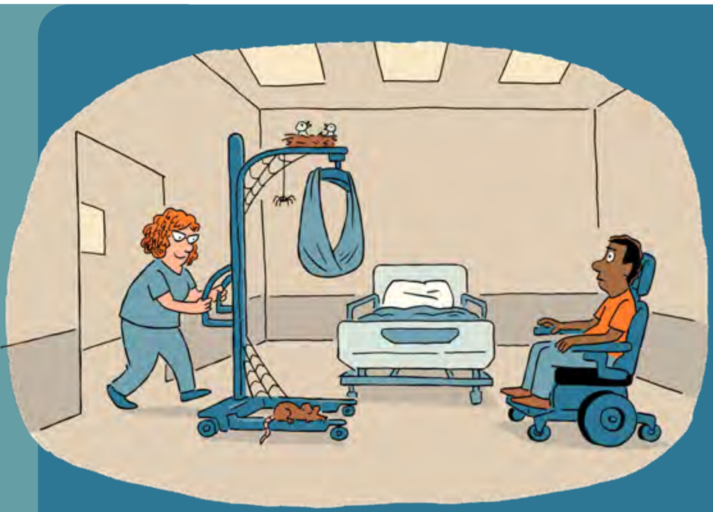
HOW TO TREAT PEOPLE WITH DISABILITIES

BY TIM GILMER

Over and over again I hear from fellow wheelchair users, "My doctor knows little or nothing about spinal cord injury." Or, "It's really hard to find a urologist who has any real understanding of SCI." We talk among ourselves about how important it is to have a doctor with experience treating chronic SCI, cerebral palsy, multiple sclerosis or whatever condition we may have. But finding that doctor can seem nearly impossible at times.

Dr. Lisa Iezzoni, Harvard Medical School professor and a respected public health care researcher, knows this better than anyone. As a doctor with MS and a wheelchair user herself, she has talked to more than 300 people with significant mobility disabilities and conducted studies documenting disparities in medical care for 25 years.

Her most recent series of studies found that a shockingly high percentage of doctors are ill-prepared to treat us. More importantly, she uncovered specific underlying causes why. Not only are most doctors undereducated about patients' disabilities, but they also know little about the Americans with Disabilities Act and how to accommodate patients with disabilities. Bias and negative attitudes toward disability can also be factors. Some doctors are so reticent or fearful to offer treatment that they find ways to discharge disabled patients from their care or avoid accepting them altogether.



THE MEDICAL ASSISTANTS WHO SUPPOSEDLY PASSED TRAINING ALMOST DROPPED ME FROM A HOYER LIFT. THEN, WHEN THEY PUT ME BACK IN MY WHEELCHAIR, I WAS HALF DANGLING OFF THE SEAT.

KATHLEEN DOWNES

INACCESSIBILITY AND BIAS

Iezzoni shared her shocking findings on NPR's *Science Friday*, including that only 22% of surveyed doctors routinely weighed patients on wheelchair-accessible scales, and nearly 60% do not use accessible exam tables and chairs. Host Ira Flatow said, "I can imagine if someone tries to visit an office and they can't get the services that they expect, it's got to be pretty discouraging."

"Yes. Well, it's not just discouraging," Iezzoni said, "it's bad quality of care, and it leads to risk of disease not being diagnosed until later stages, which could put people's lives at risk." And that is precisely the point of her decades-long research, demonstrating that disparities in medical care are a real life-and-death problem that is pervasive and resistant to change.

It is not simply an accessibility problem. There is a deeply held, often-hidden bias driving the obvious inequities in medical care: 82% of doctors surveyed believe patients with disabilities have lesser quality of life than nondisabled patients, even though studies show that those with disabilities feel their quality of life is as good as, if not better than, those without disabilities.

It all came to a head for Iezzoni during the pandemic, when ventilators and other medical resources were in short supply. She heard many stories of people with complex disabilities who had to go to the back of the line or do without the care they needed. This took the life of Michael Hickson, a Texas quadriplegic with a wife and five children, who was refused treatment for suspected COVID-19 while hospitalized. A recording by his wife, Melissa, captured her conversation with her husband's doctor.

On the recording, the doctor justifies his decision to withdraw life-sustaining treatment like tube-feeding and water by stating his preference for treating ambulatory patients who can communicate clearly, and adds that her paralyzed husband has little or no quality of life. When challenged by Melissa, he says that he would withhold lifesaving treatment in similar circumstances from any of his own family members. Melissa says, "That's a lie," and now questions his ability to make that decision. He replies that she doesn't know him, and knows nothing about him. To which she says, "And you know nothing about me." Her implication is clear: How can a doctor assess her husband's daily quality of life without knowing anything about him beyond his medical charts?

Six days later, Michael Hickson died.

ILLUSTRATIONS BY MAT BARTON

CHANGING THE CULTURE OF MEDICINE

Tara Lagu, a health care researcher and professor of medicine at Northwestern University Feinberg School of Medicine, focuses on health care disparities and co-authored the recent study about doctor's attitudes toward disabled patients with Iezzoni. In a *New York Times* article on the research, she bluntly states what must be done to correct the underlying bias and obvious disparities: "We have to change the culture of medicine."

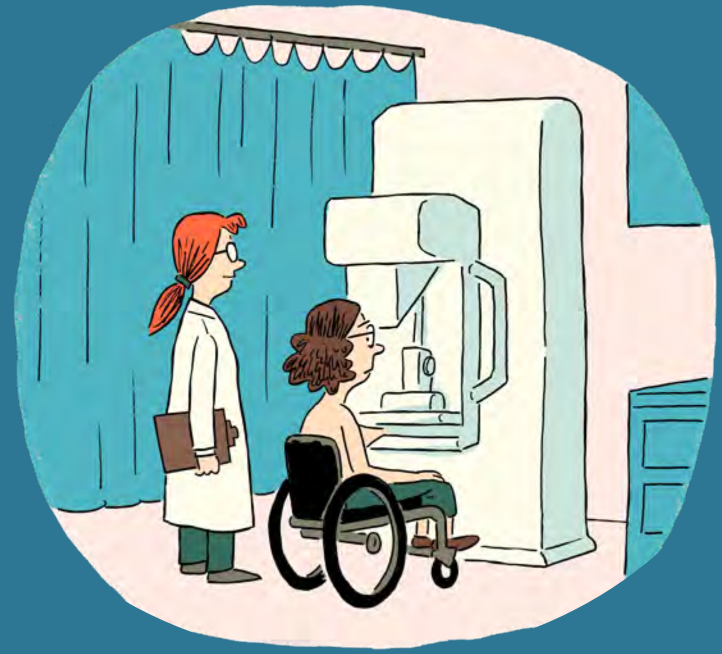
Lagu focuses on culture because in spite of 50 years of successful disability civil rights legislation, disabled Americans still experience profound differences in care. Laws can have an impact on policies and budgets, which are the building blocks of access, but they don't change people's perceptions and/or long-entrenched biases. Iezzoni also argues for a broader human rights approach that would "maximize the health and dignity of disabled Americans and support their full participation in the community." In recent decades, people with disabilities have made progress in pushing society to move

IT WAS MY ANNUAL CARDIOLOGY VISIT, NOT A BIG DEAL, SO I WAS ALONE. THE NURSE BROUGHT ME IN AND DID HER WORKUP WHILE I SAT IN MY WHEELCHAIR. WHEN THE DOCTOR CAME IN, I TRANSFERRED OVER TO THE EXAM TABLE. THE CARDIOLOGIST MOVED MY CHAIR (WITH PERMISSION) ACROSS THE ROOM SO THAT HE COULD MOVE AROUND THE TABLE EASIER. THERE WERE NO MAJOR FINDINGS IN MY EXAM SO WHEN HE FINISHED HE SAID, "GREAT, SEE YOU BACK IN A YEAR," AND LEFT THE ROOM. I WAS SITTING COMFORTABLY ON THE TABLE, BUT MY CHAIR WAS ABOUT THREE STEPS AWAY. I WAITED A MOMENT TO SEE IF HE OR A NURSE WOULD COME BACK TO HELP ME. THEY DID NOT. TOO EMBARRASSED TO CALL OUT FOR HELP, I LOWERED MYSELF TO THE FLOOR, SLID ACROSS THE LINOLEUM TILES AND CLIMBED BACK UP INTO MY CHAIR. WAS IT SAFE? NOT REALLY BUT IT WORKED.

KATHLEEN M.

MY SON, WHO HAS CEREBRAL PALSY, HAD AN EXTENSIVE ORTHOPEDIC SURGERY IN 2007. WHEN HE WAS GETTING READY TO BE RELEASED, HE WAS STILL IN A FULL-BODY SPICA CAST. WHEN WE ASKED FOR MEDICAL TRANSPORT TO GET HIM HOME, THE DOCTOR SAID HE COULDN'T WRITE AN ORDER FOR THAT BECAUSE HE COULDN'T JUSTIFY THE NEED. I ASKED THE ORTHOPEDIC SURGEON WHO PERFORMED THE SURGERY HOW I WAS SUPPOSED TO TRANSPORT HIM HOME IN MY TOYOTA COROLLA. JOKINGLY I SAID, "WHAT AM I SUPPOSED TO DO, STICK HIM OUT THE SUN ROOF OR PUT HIM ON TOP ON THE ROOF RACK AND STRAP HIM DOWN LIKE A SURFBOARD?" I ENDED UP REFUSING TO TAKE HIM HOME UNLESS THE DOCTOR WROTE THE ORDER. A DAY LATER THE DOCTOR WROTE THE ORDER. BUT WHEN IT CAME TIME TO GO BACK TO THE HOSPITAL TO REMOVE MY SON'S CAST, I HAD TO GO THROUGH THE SAME ARGUMENT WITH THE SAME DOCTOR ALL OVER AGAIN.

JUDY WAITE



THEY COULDN'T FIT ME IN THE MAMMOGRAM MACHINE THE RIGHT ANGLE, SO THE TECH LEFT THE ROOM IN FRUSTRATION AFTER ABOUT 20 MINUTES.

SUSAN VANCE

beyond a medical model of disability — viewing disability as something to be treated or cured — and toward a social model where people with disabilities are equal members of society.

Sadly many doctors remain rooted in the medical model and are arguably among the ADA's worst offenders. In a 2021 study, Iezzoni writes, "More than 30 years following the ADA, most physicians still do not use accessible equipment for routine medical care for patients with mobility disability." They see people with disabilities through the only lens they have been trained to use: the medical model, based on the idea that disabled patients are broken and that their job is to fix them.

"Any budding medical student thinks disability is a pathology," says Dr. Feranmi Okanlami. Okanlami is a doctor, wheelchair user and associate professor of medicine at University of Michigan, where he is director of Services for Students with Disabilities. "Most people would think that we're supposed to go into medicine to cure the world of illness, to then make sure that we eradicate these things that we see as sort of a scourge on society."

But most doctors also say they have neither the time nor the specific education to provide quality health care to people with disabilities. Iezzoni's research shows that only 40.7% of doctors said they were "very confident" that they could provide the same quality of care to disabled patients as they do to their nondisabled patients.

Other telling stats shed light on doctors' lack of confidence on the basics of providing access: 35.8% of physicians reported knowing little or nothing about their legal responsibilities under the ADA, and 71.2% responded incorrectly about who determines reasonable accommodations for patients with disabilities. No wonder they fear ADA lawsuits. As a whole, doctors get a failing grade not only in disability health, but also in disability law.

Which leads to another main cause of inequitable health care: a medical school culture that is sorely lacking in disability competency curricula.

THE MED SCHOOL CHALLENGE

According to Okanlami, doctors are plagued by fears that arise from their lack of specific knowledge and experience with disabilities. Okanlami was a medical student himself when he sustained a cervical SCI. He is uniquely positioned to speak from personal experience about the med school experience. He openly admits that prior to his injury, he held some of the same misconceptions and fears that lead to substandard treatment for disabled patients. In his frequent talks to med school students and professors at universities, he begins with his own confession, establishing an atmosphere of humility and grace, and putting his listeners at ease by relieving their fears and feelings of guilt.

"Doctors are used to being in control and knowledgeable," he says. "Not knowing what to do in an unfamiliar situation [with a patient] exposes their ignorance and feeds their fear. They don't want to admit their lack of knowledge about ADA accommodations because that would be an acknowledgement that the [medical] system is inaccessible."

He advocates embedding more disability information into medical school training "to equip them, give them language and knowledge of how to treat people with disabilities successfully. We need to provide the tools for medical schools. Every single patient has some kind of disability, or will have. But to focus on only the most disabling conditions [like quadriplegia] misses the point, which is to treat every patient the same."

He discusses what he calls "the plague of lower expectations" — the longstanding bias of the medical model that pervades mainstream attitudes toward disability. Medical students and professors "need to be exposed to the social model: If [disabled people] are given access, we can demonstrate success. 'Special needs' is not what we are talking about," he says. "I don't think our needs are special. Needs are the same for everyone, but how [doctors] provide access may vary from individual to individual."

When he speaks to others, he is careful not to focus exclusively on his own experiences as a wheelchair user. "I introduce them to other accommodations that people with different disabilities use, like eyeglasses, doctors using high-powered microscopic tools, or stools to sit or stand on. There are also neurodiverse ways of thinking, processing and learning. I am trying to normalize the fact that everyone is different, that we are all individuals, no different from broader disability issues."

Okanlami wants students and professors alike to adopt a new way of thinking about not only patients, but humanity at large, and to acknowledge that humanity is not perfect, including doctors. From his work, he now has mentees at numerous medical schools who are also opening up conversations about disability, including The Ohio State University, Yale University, Penn State University, Stanford University, Johns Hopkins University, Duke University, The University of Texas and, of course, University of Michigan.

Okanlami has shared many discussions with Susan

UNITED SPINAL SUPPORTS HEALTH EQUITY FOR WHEELCHAIR USERS

United Spinal Association has been advocating for several years to enforce standards on accessible medical diagnostic equipment. In 2017, the U.S. Access Board issued technical criteria to ensure that medical diagnostic equipment — including examination tables and chairs, weight scales, mammography and other imaging equipment and more — is accessible to individuals with disabilities. However, without any directives from the Department of Justice, the Access Board's final standards have no enforcement mechanism for implementation.

With that in mind, United Spinal and other leading disability organizations have met to coordinate strategy for engaging with both the Department of Justice and the U.S. Congress to ensure enforcement of accessibility in health care. United Spinal continues to discuss this important issue with the Department of Health and Human Services as well as health care providers, physicians and disability advocacy organizations, and is working on providing best-practice documents and guidance for individuals with disabilities and health care providers regarding their responsibilities to the disability community.

United Spinal also works closely with the National Council on Disability, an independent federal agency charged with advising the President, Congress and other federal agencies regarding policies, programs, practices and procedures that affect people with disabilities. NCD released a health equity framework in February 2022 focusing on five key components, which United Spinal supports:

- Designating people with disabilities as a Special Medically Underserved Population under the Public Health Services Act.
- Designating people with disabilities as a Health Disparity Population under the Minority Health and Health Disparities Research and Education Act.
- Requiring comprehensive disability clinical-care curricula in all U.S. medical, nursing and other health care professional schools, and requiring disability competency education and training of medical, nursing and other healthcare professionals.
- Requiring the use of accessible medical diagnostic equipment.
- Improving data collection concerning healthcare for people with disabilities across the lifespan.

In February 2023, NCD released an update detailing the progress that has been made in the year since the framework debuted: ncd.gov/sites/default/files/Documents/NCD_Health_Equity_Framework_Progress_Report.pdf

TELL YOUR SENATORS TO SUPPORT THE HEALTH EQUITY ACT

In April, United Spinal endorsed the Health Equity for People with Disabilities Act for the second Congress in a row. The bill provides funding to ensure that more than 17,000 Federally Qualified Health Centers in the U.S. are prepared to serve people with disabilities.

The bill provides these community health centers with quality improvement grants to strengthen staff skills and ensure that settings and equipment are accessible to people with disabilities. Tell your senators to support this important piece of legislation: tinyurl.com/3z9484w9

Havercamp, a health care researcher at The Ohio State University Nisonger Center, who has identified core disability competencies for med students and professors as part of the Alliance for Disability in Health Care Education. The alliance's mission is to integrate disability content and experiences into health care education and training programs. These core competencies include situating disability within the broader context of human diversity, collaborating across disciplines to better serve disabled patients, assessing the functional needs of individual patients, teaching doctors' legal responsibilities under the ADA, and more. Successfully integrating them into med school curricula would help bridge the knowledge gap that keeps many doctors from providing quality care to people with disabilities.

THE IMPORTANCE OF FILING AN ADA COMPLAINT

The U.S. Department of Justice offers resources for people with disabilities to understand their rights and for medical to providers to comply with their legal obligations under the Americans with Disabilities Act. These resources include an ADA phone line staffed by specialists who can answer questions, and easy-to-understand publications explaining the basics of ADA-compliant medical care. But DOJ's most valuable resource when it comes to ADA enforcement, says Lauren DeBruicker, an assistant U.S. attorney in Philadelphia and a C6 quadriplegic, "might just be you."

Anyone who thinks their (or someone else's) rights under the ADA have been violated can report incidents to DOJ by phone, mail or online, for potential investigation. You'll be asked for basic information like the date and place of the incident, the names of the people or facility involved, and a short description of what happened. Teams that specialize in handling your type of issue will review it, determine next steps, and get back to you. Possible outcomes include DOJ following up with you for more information, starting a mediation or investigation, directing you to another organization for further help, or informing you that DOJ cannot help. "While not every claim gets investigated, reports from the community about potential ADA violations are a vital part of DOJ's enforcement process," says DeBruicker.

DOJ investigates and prosecutes ADA violations in a wide range of health care settings — from individual doctor's offices to large hospital systems, and from general primary-care practices to specialists. DOJ's Civil Rights Division recently sued and settled with a group of eye care facilities in Arizona that had refused to transfer patients with physical disabilities onto surgical and exam tables, and had forced some patients to hire medical transport services to bring them into the office on gurneys so that the facility's personnel wouldn't have to assist with transfers. In Philadelphia, DOJ recently settled a similar allegation against an outpatient imaging center that refused to transfer someone with cerebral palsy onto a table for a DEXA scan. "Both of these cases were brought to DOJ's attention by someone willing to share what happened to them," says DeBruicker, whose office was involved in the Philadelphia case.

* Submit a complaint online: ada.gov/file-a-complaint
* DOJ's ADA Information Line: 800/514-0301; 833/610-1264 (TTY).

HOW TO START CHANGING THE SYSTEM

Iezzoni is convinced that pushing ADA compliance for medical equipment is achievable in the short term. She urges advocates to "put pressure on the Department of Justice to declare the ADA guidelines for accessible medical equipment as enforceable law — and enforce it! Let's go full-bore on equipment to let providers know this will help them."

The approved guidelines, gathering dust since the Trump Administration shelved them in 2017, already have the force of law. All that is needed is for the current Department of Justice to take the reins and do so, and it has been moving in that direction: The DOJ recently issued a notice of proposed rulemaking that would have the effect of making these guidelines enforceable (see sidebar).

Changing the culture of medicine will require

IEZZONI PROPOSES HOLDING DOCTORS ACCOUNTABLE: "UNLESS YOU HAVE SOME DISABILITY COMPETENCY TRAINING, YOU WILL NOT GET YOUR LICENSE RENEWED."

RESOURCES

- **"Equal Health Care: If Not Now, When?" New Mobility, 2013 cover story: newmobility.com/equal-health-care-if-not-now-when**
- **Health Affairs "Disability and Health" issue: healthaffairs.org/disability-and-health**
- **"'I Am Not The Doctor For You': Physicians Attitudes About Caring For People With Disabilities": bit.ly/43EBd99**

Dr. Lisa Iezzoni

longer-term thinking. Iezzoni suggests advocates put pressure on Congress to ratify the 2006 U.N. Convention on the Rights of Persons with Disabilities, which was signed but never ratified by the U.S. The convention situates disability within a human rights rather than a civil rights framework. Pushing to finally ratify this important treaty — the U.S. is one of only eight countries in the world that have yet to ratify it — could create an opportunity and momentum to push policy grounded in a more inclusive, social model of disability. "It could also energize efforts to improve the health, daily lives and dignity of Americans with disabilities," Iezzoni says.

Forcefully advocating for med school core competencies is every bit as important. Iezzoni also suggests holding doctors accountable with licensure requirements for annual recertification. "They must have continuing education requirements and documentation to have their license renewed. Unless you have some disability competency training, you will not get your license renewed. Continuing ed is especially important since it includes risk management quality-of-care issues."

Our most important tool, though, may be our own stories. Lagu has direct experience in the broader arena of pushing a national agenda. "We have done it before," she says. "Take a look at LGBTQ+ people — the culture and attitudes have changed tremendously in the last 20 years. Back then you would not 'come out' on an application. In 20 years, I've seen it go from fear and rejection to acceptance. All kinds of changes, big and small. When we see images and hear people's stories, it can change the way we feel about people."

Lagu says we must get our first-person stories into the hands of people who are making decisions. "With disability, we are 'othered.' It is our job to advocate for acceptance and respect. We also need to address physical barriers, adequate medical training, all of this is needed. Tools plus empathy. … The idea of universal care can help remove the stigma of otherness — and we all need quality health care."

AS A DOCTOR WHO USES A POWER WHEELCHAIR, I WILL SOMETIMES HAVE PATIENTS OR STAFF BE FASCINATED WITH AND ASK QUESTIONS ABOUT MY CHAIR. ONE NEGATIVE INTERACTION STICKS OUT FROM MEDICAL SCHOOL. WHILE ROUNDING ON ONE OF THE MEDICAL FLOORS WITH THE FULL MEDICAL TEAM, A HOSPITAL STAFF MEMBER NOT AFFILIATED WITH OUR TEAM MADE THE COMMENT, "LOOKS LIKE THEY ARE TAKING PATIENTS ON ROUNDS NOW." HE ASSUMED THAT I WAS A PATIENT BECAUSE I WAS IN A WHEELCHAIR — NOT A MEDICAL STUDENT, SOON-TO-BE PHYSICIAN. I WAS QUITE MORTIFIED BY THE COMMENT IN THE MOMENT, AND NO ONE ON MY TEAM CORRECTED THE STAFF MEMBER AT THE TIME. LATER MY ATTENDING [PHYSICIAN] PULLED ME ASIDE AND APOLOGIZED FOR THE STAFF MEMBER'S BEHAVIOR.

JEFF MAHLUM

NURSE: "PLEASE GET ON THE SCALE."
ME, FROM MY WHEELCHAIR: "HOW?"
NURSE: "WE NEED TO WEIGH YOU."
ME: "UMMM, I CAN'T WALK."
I DON'T EVEN KNOW WHAT TO SAY. MY PHYSICAL THERAPIST DOESN'T HAVE AN ACCESSIBLE SCALE. MY GENERAL PRACTITIONER DOESN'T HAVE AN ACCESSIBLE SCALE. AND MY NEUROLOGIST DOESN'T HAVE AN ACCESSIBLE SCALE.

MISSY MORRIS

Dr. Feranmi Okanlami:

FIGHTING FOR ACCESS AND EQUALITY IN THE HOSPITALS AND ON THE COURTS

BY CHERYL ANGELELLI

Feranmi Okanlami knew he wanted to be a doctor at a young age. "I was always interested in science and how the body worked. In medicine you have a unique ability to use your hands or your mind and effect change in someone else's life," he recalls.

Growing up as the son of two Nigerian immigrants, he had lots of role models. Both of his parents were doctors and he had countless aunts and uncles in the medical field. Being a doctor was practically in his DNA.

In 2013, Okanlami was in the final stages of realizing his dream. He was working as a surgical resident when he sustained an incomplete spinal cord injury diving into a pool. "I never thought, I can't be a physician anymore," he says. "The question was, 'How can I be a physician?'"

Finding the answer to that question led Okanlami on an eye-opening journey into disability, discrimination and more, and helped mold him into the thoughtful, passionate leader, affectionately known as "Dr. O." As a speaker, educator and member of key national and regional committees, Dr. O has emerged as a respected advocate for rethinking the prejudices inherent in our medical system and creating a more inclusive world for people with disabilities.

FAMILY FIRST

Okanlami, 37, was born in Lagos, Nigeria, to his mother, Bunmi, a pediatric critical care physician, and his late father, Femi, a neonatal critical care physician. They named their son Feranmi, which translates to "God's love." Lured by the American dream and opportunities to further their graduate medical education, Okanlami's parents moved the family, which also includes his older sister, to the United States in 1988 when he was almost 3 years old. They settled in Maryland, before establishing roots in Indiana.

Okanlami's parents knew he was destined for something special at an early age. "When Feranmi was really young, he was a very quiet child, but someone who was older than his chronological years. He was kind and thoughtful. You could put him in a room with anyone and he was comfortable among people of all ages. He was quiet but when he spoke, you took notice, and people would say "who is this kid?" says Bunmi. "You had this feeling he was going to be somebody, but whom, we didn't know."

He grew up in a community with other Nigerian families that celebrated Nigerian and American culture. "All of the kids from those families were like brothers and sisters," he says. "We had our Nigerian community, we had our Christian community, we had the schools we went to, and so I saw people that we were all different, in different ways. It wasn't until later in life that I would experience discrimination."

Okanlami says Nigerian culture is often seen as being strict, but he never felt family life to be oppressive. Education and hard work were emphasized. "My parents instilled in us the importance of education," he says. "They told us education is the one thing that nobody can ever take away. They demonstrated that hard work was the thing you could do to make sure that you gave yourself the best opportunity. We were taught compassion, empathy, integrity, to put others before yourself and to have respect for everyone."

All of those lessons paid off throughout Okanalami's childhood. He eventually graduated from high school as a four-sport athlete and class president, all the while excelling in the classroom. Upon graduating from high school, he was accepted at Stanford University. In addition to knocking out the prerequisites for medical school while earning an undergraduate degree in the Humanities, Okanlami served as the captain for Stanford's track and field team during his last two seasons and achieved Academic All-American honors. By all accounts he was living his best life, the American Dream his parents had envisioned when they first came to this country.

FORGING A NEW PATH

After receiving his degree from Stanford in 2007, he attended medical school at the University of Michigan, earned his M.D. in 2011 and was accepted into an orthopedic residency surgery program at Yale that same year. In 2013, in his third year of residency at Yale, he broke his neck at a July 4 pool party, resulting in an incomplete spinal cord injury.

Okanlami used the injury as fuel. "What I was going through was hard, but I never got down or sad or depressed. I'm not saying that I am better or stronger than anybody else, it just didn't happen for me," says Okanlami. "And while I wasn't negative about things, there was still uncertainty, like, 'How is this going to be possible?' 'How am I going to define myself?' 'How are people going to look at me?'"

Over the next two years, Okanlami focused on regaining function and earning a master's degree in Engineering, Science, and Technology Entrepreneurship from Notre Dame. He regained more function in his lower limbs but still used a wheelchair for community mobility and navigating his busy life. From 2015-2017, he worked as a physician in a family medicine residency at Memorial Hospital in South Bend.

Working in family medicine exposed him to more aspects

Photo by Leisa Thompson

> IT WASN'T UNTIL MY INJURY THAT I TRULY FELT DISCRIMINATED AGAINST. I'M NOT BELITTLING MY BLACK EXPERIENCE, BECAUSE YES, I HAVE EXPERIENCED RACISM, DISCRIMINATION AND STEREOTYPES — BUT IT PALES IN COMPARISON. I WAS THE SAME PERSON, BUT PEOPLE SUDDENLY STARTED TREATING ME DIFFERENTLY, LOOKING AT ME DIFFERENTLY, INTERACTING WITH ME DIFFERENTLY, AND EXPECTING LESS OF ME.

of medicine, and helped grow his perspective on the state of the field. "As a family medicine physician, I had an opportunity and a platform to talk about medicine and disability in a way I may not have been able to as an orthopedic surgeon," he says.

LEADING BY EXAMPLE

Okanlami didn't realize how ableist and inaccessible the world was for disabled people until he started living life on the other side of the stethoscope as a person with a spinal cord injury. "It wasn't until my injury that I truly felt discriminated against," he says. "I'm not belittling my Black experience, because yes, I have experienced racism, discrimination and stereotypes — but it pales in comparison. I was the same person, but people suddenly started treating me differently, looking at me differently, interacting with me differently, and expecting less of me."

In hopes of effecting change, he coined the catchphrase, "disabusing disability," to demonstrate that disability doesn't mean inability. "We all have our unique contributions we can make," he says. "Instead of being limited based on what we cannot do, we need to be given the access to show what we can."

With this sentiment in mind, Okanlami has dedicated his life to becoming a disability advocate and creating an accessible and inclusive health care system for patients and providers with disabilities.

He returned to the University of Michigan in 2018. He now serves as the Director of Student Accessibility and Accommodation Services and oversees the office of Services for Students with Disabilities, two testing accommodation centers, and the Adaptive Sports and Fitness program. In addition, he is an assistant professor in the Departments of Family Medicine, Urology, and Physical Medicine and Rehabilitation. As if that isn't enough to take on, in 2021 he was appointed adjunct assistant professor of orthopedic surgery at UCLA's David Geffen School of Medicine, where his responsibilities include working with the department on efforts of justice, equity, diversity and inclusion as well as participation in the development of an adaptive sports medicine program.

Okanlami and his colleagues in Michigan's Department of Family Medicine are working to raise awareness about doctors with disabilities. More than 20% of Americans live with a disability, but recent studies show only about 3% of them are practicing physicians. Okanlami is proud of the work he and his colleagues are doing at Michigan to close that

FROM THE HOSPITAL TO THE COURT


Photo by Leisa Thompson

In addition to parsing his time between all his responsibilities in the medical world, Okanlami has consistently made time to fight for accessibility in the other world he is passionate about: sports.

Okanlami got his first taste of adaptive sports when he was a patient at Shirley Ryan AbilityLab. He later became a coach/player for the River City Rollers wheelchair basketball team in Indiana and has played wheelchair rugby, sled hockey and wheelchair tennis. "I didn't know what my life was going to look like living with a disability, but getting a chance to play sports again absolutely opened up my world," he says. "Recognizing how inaccessible the world is for individuals with disabilities helped guide my future in medicine and advocacy. Once I saw the inequity that existed with respect to access to sport and fitness for individuals with disabilities, it became my passion/focus to provide that access."

In 2018, he helped create Michigan's Adaptive Sports and Fitness Program to address the inequitable access to physical activity opportunities, competitive and recreational, for students and community members with disabilities. The program, which he still leads, has brought national attention to the university and has enabled the Wolverines to become a force in the collegiate adaptive sports scene.

Okanlami is a hands-on leader, often getting directly involved with student athletes. Caiden Baxter, 22, is one of many Okanlami mentees. Now a nationally ranked wheelchair tennis player, Baxter, who has a T12 SCI, credits Okanlami with introducing him to adaptive sports. "I was an athlete before my injury, so when I was injured, I honestly thought that part of my life was over," he says. "Thanks to Dr. O, I've learned to be comfortable with the fact that I have a disability and I've learned to continue to push myself despite my disability. Despite how busy he is, he has a personal relationship with every one of us, and we can pop into his office anytime to talk about anything."

Okanlami's work in adaptive sports affords him similar opportunities to help others and build a more inclusive world. "I don't think this is the work I would be doing had I not had my accident, so I feel blessed to have this opportunity," he says.

gap, including making changes to the technical standards used for admission. Many medical schools require physical aptitude, which can inadvertently exclude applicants with disabilities.

Dr. Philip Zazove is one of many colleagues with high praise for Okanlami. "Dr. O has had a huge impact in many ways," says Zazove, an emeritus professor of family medicine at Michigan. "In our department of family medicine, we have a focus on improving health of people with disabilities, and there's nothing like having faculty with disabilities as role models and who live the experience. For example, I am deaf. He brought expertise around mobility disabilities that we did not have."

Nationally, Okanlami serves as the Disability Issues representative on the Steering Committee for the Group on Diversity and Inclusion at the Association of American Medical Colleges, while also sitting on the National Medical Association's Council for Medical Legislation. He was also selected by the White House Office of Public Engagement to participate in the Health Equity Leaders Roundtable Series dedicated to exploring perspectives around access to care.

To honor his collective efforts in medicine and his recent work in adaptive sports (see sidebar, page 34), the Craig H. Neilsen Foundation selected him as one of three recipients of its 2022 Visionary Prize award. The award is presented annually to influential voices whose contributions have improved the lives of those affected by spinal cord injuries. Friends, family and Foundation members surprised Okanlami live on national television last fall with news of his selection and the $1 million prize check.

"The Craig H. Neilsen Visionary Prize celebrates individuals who are not afraid to take bold risks, show a potential to enrich, expand, and advocate for new ideas. This is Dr. Okanlami," says Kym Eisner, the foundation's executive director. "He is an out of the box thinker and a thoughtful mentor, who leads by example."

With everything that is on his plate, you might wonder when Okanlami sleeps. He says he only gets a few hours of sleep a night. There is always more to do. "I feel like to whom much is given, much is expected," he says. "I've been blessed with a lot of opportunity throughout my life, and I feel the desire, the need, the want, to pay it forward."

BALANCING WORK AND FAMILY LIFE

While the list of titles Okanlami holds is long, his favorite and most important title is dad. Okanlami lights up when he talks about his 11-year-old son, Alex, whom he co-parents with Alex's mom. Alex was born the same day Okanlami graduated from medical school and the two share a special bond. "My son is amazing," he says. "The beautiful thing about children is that they know no limitations themselves, so to Alex I am the coolest dad in the world."

The two share a love of sports, watching movies and playing cards and board games. They've traveled together to Nigeria twice and last year they vacationed in Spain. In addition to getting to try his hand at all the adaptive sports, Alex is receiving a firsthand education in disability. "He has had an opportunity to see disability through a different lens," says Okanlami.

BEHIND the LENS

WHEELCHAIR USERS TELL THEIR STORIES IN ACCLAIMED DOCUMENTARIES

BY STEVE WRIGHT

A GROWING NUMBER OF WHEELCHAIR USERS are getting behind the camera and creating documentaries that are airing on PBS, winning at film festivals and even earning Oscar nominations.

New, more affordable technology, expanding media outlets and a content-craving public are a few of the reasons why documentary filmmaking has become more accessible than ever. We spoke to three wheelchair-using filmmakers with varying degrees of experience who aim to entertain, educate the masses, and motivate others with disabilities to tell their stories and bust myths held by nondisabled viewers. Disclaimer: No cringeworthy inspiration porn was created in the making of these films.

DANI IZZIE, PRODUCER, *DANI'S TWINS*

Dani Izzie knew there was an audience for her story and genuinely believed others could benefit from seeing it documented on film, but she also knew how easily it all could go wrong. "I have a sensational story, like the greatest clickbait: 'Quadriplegic woman gives birth to twins,'" she says. "But I don't want it to be sensationalistic. I want to combat the bias against women with disabilities becoming parents. … We have to break through this ableism."

Izzie, a C5-6 quadriplegic, had been approached by a casting director of reality TV shows and offered a handsome sum of money to document her pregnancy in exchange for relinquishing the exclusive rights.

"They are my children. I want some ownership. You can't just buy me," she says, explaining why she rejected the offer. "There was no guarantee that they were going to get the disability narrative right. I was worrying, from what I've seen on TV and film, they were going to really fuck it up."

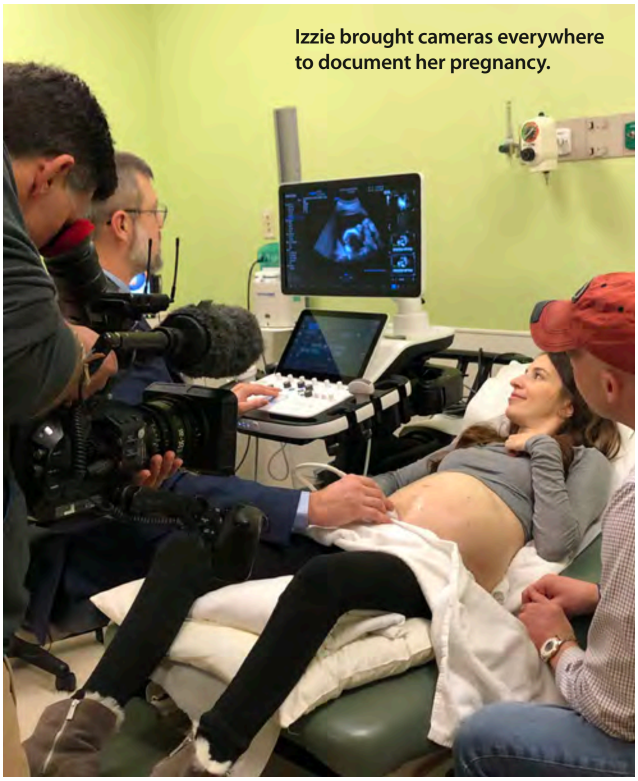
Izzie held out before eventually deciding to make *Dani's Twins* with a filmmaker known for documentaries with a social impact. It helped that he was a personal friend and promised her the freedom to tell her story her way.

As Izzie's pregnancy progressed, cinematographers began filming her and her husband, Rudy, in their West Virginia home. Then came Covid. No one wanted to travel, and no one wanted to expose Izzie to increased health risks during her pregnancy. "The pros did a shoot before my baby shower, then everything shut down. It was in the middle of the pandemic. We couldn't even do fundraising," she says.

Because there's no pause button on pregnancy, Izzie and her husband became the camera crew, using smartphones and a digital camera. Izzie evolved from being the subject of the film to its producer.

Despite having no experience as a filmmaker, the change came naturally to her. Being behind the camera made it even easier for Izzie to ensure her story emphasized the normalcy of living life with a disability and avoid the "overcoming all odds" storyline that nondisabled filmmakers fixate on in movies about disability.

"I focus on concrete solutions and figure it out like any other new parent," she says. "With a spinal cord injury, I honestly think it makes me a stronger parent. I know how to prepare for massive challenges. What matters is what you can give your children emotionally, physically and mentally."



Izzie brought cameras everywhere to document her pregnancy.

The 40-minute film tackles many issues unique to disability and pregnancy, while also covering hospital trips, the pandemic and, of course, the eventual birth of Izzie's two healthy girls, Lavinia and Giorgiana. It premiered in May 2022 at Mountainfilm Festival in Telluride, Colorado, and has been on the film festival circuit while the team searches for a distributor.

Izzie encourages people with disabilities to try documentary-making. She says the key is to reach out to people in the industry, ask questions and start telling your story. She hopes that the film, and her prominent role in making it, will help educate others. "I did this to amplify disabled parenting," she says. "Pregnant disabled women are subject to hate speech. A lot of times people are judgmental or biased against people with disabilities having kids."

KELSEY PETERSON, CO-DIRECTOR, *MOVE ME*

Kelsey Peterson's full-length documentary, *Move Me*, provides a candid look at a number of raw subjects: her father's terminal illness, his struggles with her C6 spinal cord injury, her research into invasive but possibly life-enhancing medical procedures, and her choreographing and performing in a dance project for the stage.

Through sweat, tears and a lot of earthy language, the film moves between all of these topics while also exploring Peterson's evolving relationship with her own disability. Since being released in fall 2022, the film has played at eight film festivals and aired as part of PBS' prestigious *Independent Lens* series. These are heady accomplishments for a first-time co-director, and even more so when you consider how different the final product is from what Peterson started in 2017.

"I had no intention of making this film. I filmed some of it, then saw the footage wasn't good enough and realized that I needed production professionals to tell the story," she says. After a rotating series of assistant filmmakers and do-it-yourself filming funded by Kickstarter contributions, she eventually brought on award-winning co-director/producer Daniel Klein. She credits Klein for creating a "container of trust" that allowed her to be her vulnerable, truest self.

The team applied to an open call for documentary submissions from nonprofit Independent Television Services and received $350,000 in funding plus a pipeline to PBS. ITVS funds and presents documentaries on public television, new media projects on the internet, and the weekly Independent Lens on PBS. Peterson said the support from ITVS turned her project from a personal endeavor to a high-caliber film.

Filming the documentary helped Peterson rediscover the internal artist and storyteller she had lost post-SCI. She was a successful dancer prior to her injury and loved expressing herself through dance. She says her "internalized ableism" made it difficult for her to see herself as a dancer after her injury.

“The artist in me came out in documentary form, and it felt like a reblooming of myself. I could feel it in post-production and the editing room. This beautiful unraveling. Being able to translate myself.”

Listening to Peterson discuss the filmmaking process, it’s clear the experience had a profound effect on her. “When I started, I wasn’t even comfortable with the word ‘disability,’ or claiming it,” she says. “I learned the importance of storytelling for your own personal growth.”

> ***“My story is about self-discovery. It’s a wild thing to discover that while you’re in a wheelchair, you still have internalized ableism from our culture.”*** *KELSEY PETERSON*

Peterson advises would-be documentarians in the disability community to “be brave” and reach out to experts in production, funding and broadcasting. She suggests working with grant writers, or at least finding multiple good editors to review grant applications and deliver quality feedback. “Fundraising is challenging enough as it is, and you don’t want to put in all this effort and wish that you could’ve done more, or feel like you wasted your time,” she says.

Peterson’s film happened so organically that, looking back, she wouldn’t do much of anything differently. “My story is about self-discovery. It’s a wild thing to discover that while you’re in a wheelchair, you still have internalized ableism from our culture,” she says. “I love my body,” she adds. “I don’t need to be fixed. But I’m really interested in possible recovery and if it could give me different kinds of pleasure or give me more time.”

JAMES LEBRECHT, CO-DIRECTOR, *CRIP CAMP*

If there was a Mount Rushmore of disabled filmmakers, James LeBrecht would be on it. The longtime disability rights activist and founder of Berkeley Sound Artists has done sound design work for over 145 films — including as re-recording mixer for *Move Me* — with a particular focus on documentaries. The New York native, who has spina bifida, co-directed *Crip Camp*, the award-winning 2020 documentary about the birth of the disability rights movement.

LeBrecht’s passion for film and documentaries inspired him to co-found Filmmakers with Disabilities — Documentary, a nonprofit that seeks to increase visibility, support, access and opportunities for deaf, disabled and neurodiverse filmmakers. FWD-Doc is modeled after successful startup film advocacy groups launched by and for women of color.

LeBrecht said that FWD-Doc, funded by the Ford Foundation, Perspective Fund, Field of Vision and Jonathan Logan Family Foundation, has created a private database of people with disabilities who work in many aspects of filmmaking. The database allows productions that want to be inclusive to get referrals for hiring industry professionals. In association with filmmaking nonprofit Doc Society and supported by Netflix, FWD-Doc published *“A Toolkit for Inclusion & Accessibility: Changing the Narrative of Disability in Documentary Film,”* available as a free download on its website.

FWD-Doc is also thinking beyond the filmmaking process, pushing for more accessibility at film festivals, from screening facilities to after-parties. LeBrecht notes that deals for financing, distribution and collaboration get done at festivals, and if they are not accessible to all, the playing field is not level for disabled documentary makers. To this end, FWD-Doc created a Film Event Accessibility Scorecard, a handy checklist to steer film festivals away from private screenings that are inaccessible, or after-parties held at lounges that are downstairs, upstairs or are otherwise inaccessible.

With personal memories of how things were, he appreciates the progress the industry has made on including people with disabilities. “Thank goodness there are easier entry points than there were 30 years ago. Being able to use an iPhone, being able to do a podcast, being able to do edits — the price points are much lower than they used to be,” he says.

Obstacles remain when it comes to disabled technical talent progressing on the film career ladder. “Entry-level positions in film are on-set production assistant(s). If you don’t have endurance and agility, it is an absolute deal breaker. The attitude is ‘if you’re not willing to sleep under your desk, I don’t want you here because you’re not dedicated.’ That kind of pressure will kill people,” LeBrecht says. “Only

LeBrecht appreciates how the film industry has evolved. "Thank goodness there are easier entry points than there were 30 years ago."

wanting people who can do a coffee run for 12 people and work 10 days straight — that's impossible for a single parent, for economically disadvantaged people — it's bullshit. It has nothing to do with your true value."

LeBrecht wishes more industry leaders appreciated the value people with disabilities bring to their work. "As a person with a disability, if I limit my time, it's not limiting my creativity," he says. "I can manage time really well. The industry has to change to create openings for all people with imagination and dedication and creativity."

Knowing that *Crip Camp's* success opened doors, LeBrecht has leveraged his renown to grow FWD-Doc. By partnering with companies like NBCUniversal, he hopes to keep the industry headed in the right direction.

"NBCUniversal is trying to develop some shows about disability. We're working with them and trying to get studies to understand that disability is a part of diversity, equity and inclusion — that you must add an A for 'Access' to DEI," LeBrecht says. "Because mainstream films still have a hard time seeing beyond the tropes, I think there is a great need for independent films made by people with disabilities. You simply have to tell your story from an authentic viewpoint."

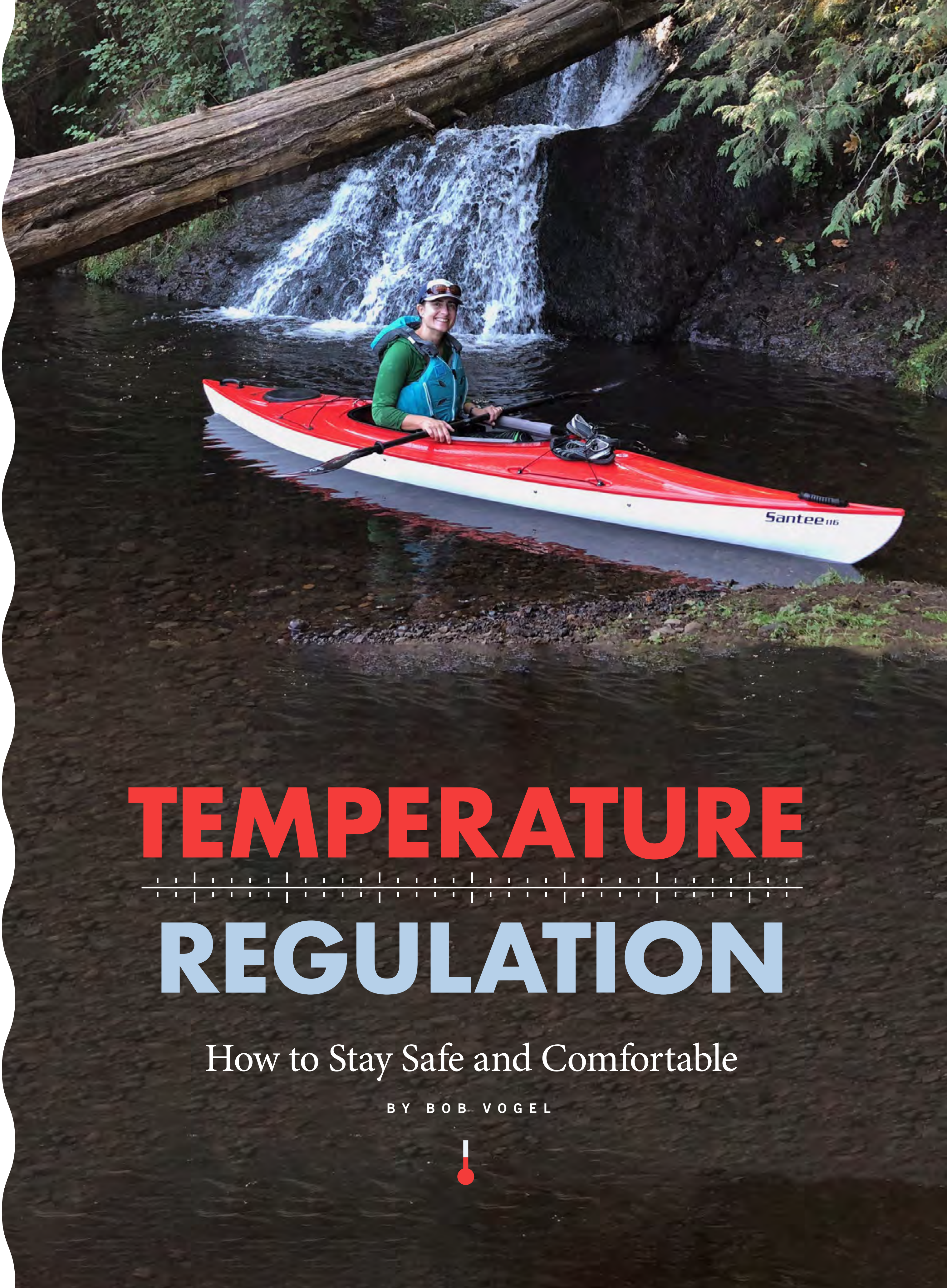
RESOURCES

Dani's Twins
danistwinsfilm.com, IG: DanisTwinsFilm

Move Me
movemedoc.com, IG: movememovie

Crip Camp
cripcamp.com, IG: CripCampFilm

FWD-Doc
fwd-doc.org, IG: FwdDoc



TEMPERATURE REGULATION

How to Stay Safe and Comfortable

BY BOB VOGEL

AMONG THE MANY WAYS our bodies work differently with a spinal cord injury is temperature regulation, in part because SCI impedes our ability to sweat below our injury level and compromises blood flow in the legs. This makes it tougher to remain cool when it's hot, and difficult to stay warm when it's cold. Compromised temperature regulation can quickly become uncomfortable and dangerous, ranging from overheating and heat stroke to hypothermia — harmfully low body temperature.

Here are some tips and tales from veteran wheelchair users on how to stay comfortable and safe when the mercury rises or falls outside the norms.

Opposite: Arwen Bird cooly enjoys nature. Above: When a spray bottle won't cut the heat, Jarred Evans breaks out instant ice packs for an emergency cooldown.

STAYING COOL WHEN IT'S HOT

The body compensates for heat by producing sweat and triggering vasodilation, which directs warm blood flow toward the skin to cool down. However, SCI impairs this process below the injury level and makes us more susceptible to hyperthermia — body temperature that is too hot. The higher the SCI level, the less we're able to cool. And the higher the body temperature, the greater the danger. The stages of hyperthermia are:

- **Heat Cramps**, with symptoms including painful muscle spasms and muscle tightening.
- **Heat Exhaustion**, with symptoms like blurred vision, dizziness, headache, nausea and muscle cramps.
- **Heat Stroke**, which is a life-threatening condition that occurs when body temperature rises to 104 degrees or higher and causes confusion, slurred speech, altered mental status and/or loss of consciousness.

Overheating is an emergency, and immediate cooling is a must. This means get out of the sun, take off things like compression hose, and apply cold, wet towels. If you know you are going to be in the heat, have options ready to help cool you down.

During summer months, Jarred Evans, 43, a C6 incomplete quad for 18 years, carries an emergency cooldown kit in his car that has instant ice packs — the kind where you break the tab and shake for instant cold. Dan Gibson, a 63-year-old C5-6 quad, says you don't have to overthink it. "When I need to cool down, I go for the obvious — dump a lot of cool water on my head and put a cold, wet towel on my neck and body."

If overheating is not addressed in a timely manner, it can quickly become dangerous. "I've had probably 10 times when I've gotten so hot I can't think straight," says Todd Wolfe, 54, a C5-6 incomplete quad for 18 years. The worst incident was when he overheated and passed out on a summer outing while in inpatient rehab. He woke up after clinicians had moved him to the shade, doused him with cold water and placed cool, moist towels on him.

The best way to deal with overheating is taking steps to avoid it in the first place. Stay hydrated and stay out of the sun. "When it's hot, I move like Luxor, my service dog, and we go from one shade patch to another," says Wolfe. His "super-go-to" for staying cool is a straw lifeguard hat from Walmart. Keeping a handheld umbrella in your car or on your chair is a great way to create your own shady spots and avoid burns.

Another tip is to keep a mister bottle on hand. Add ice for extra cooling. At less than $10, Wolfe suggests loading up. "I always buy two mister bottles because they are affordable, but it seems the lid tends to come off when it's really hot, so it's good to have a backup."

Gibson and Wolfe both rely on cheap cooling neck wraps available at most stores. "They are only about $9 and they really work. I have a bigger one for my head, and a skinny one for my neck. I usually stick the bigger cooling towel under my hat and let it drape over the back of my neck for cooling and sun protection combined," says Wolfe. When it gets very hot, Evans adapts. "When I'm playing rugby, my core really heats up, so I put ice packs between my chest strap and stomach to keep me cool," he says.

For more extreme cooling, Evans turns to an AlphaCool ice vest ($69-$500). The lightweight vest offers extra cooling, thanks to a battery pack that circulates cold water. Should you choose a more affordable one, he adds a word of caution about use of refreezable ice packs: "I use ones designed to stay at a temp of 40 degrees or higher, because ones that get below freezing can cause frostbite and skin-freeze damage on areas with no sensation."

STAYING WARM WHEN IT'S COOL

A primary reason why SCI makes it difficult to stay warm when it's cold outside is because of reduced blood flow in the legs. Typically, flexing leg muscles act like a second heart, pumping blood up to the body. Because SCI inhibits or halts muscle-flexing in the legs, blood flow becomes greatly reduced, and the stagnant blood remains at the surrounding temperature. As the cooler blood from the legs circulates into the rest of the body, it makes us colder, and that is exacerbated when we lie down.

Besides being uncomfortable, coldness can lead to hypothermia when the body temperature falls below 95 F. Symptoms include shivering, a feeling of exhaustion or extreme fatigue, and confusion. If not addressed, it can be fatal.

The simplest way to avoid hypothermia is to limit your time in the cold, and dress warmly. Wear a warm hat and scarf, and warm socks in shoes or boots. Layer up as much as you need, and avoid using any type of artificial heating below your level of sensation. If electric socks or blankets malfunction, you won't feel it, and they can cause severe burns. "I've been severely burned by putting a heating pad on a body part that doesn't have sensation, like my legs," says Gibson.

Warming up can be as simple as getting out of the cold and adding more clothing or a blanket. A quicker way is to take a warm shower or bath, or wrap yourself in a warm, moist towel, because moisture better transfers the heat. Also, drink warm liquids. As a para who loves the outdoors, I can attest to the warm shower or tub. There are times I've come in from a day of sailing or skiing and my legs feel frozen. My only hope of warming them is to soak in a warm bath or shower.

Gibson's wife makes "corn cuddler" heating pads from dry corn kernels or dry rice sewn inside a cloth pad. "You heat them in a microwave to a temperature that you want, but not too hot," he says. When it's really cold outdoors, he puts them in his shirt and on his shoulders for hours of warmth. "I will also put them on my legs when I lie down. It's important to make sure they are not hot — just warm to the touch — so you don't get burned." Corn cuddlers can be purchased online for $10-$20.

For Wolfe, wearing the right clothing goes a long way toward staying warm. He favors a Filson hunting hat with a short bill and a warm flap for his ears and neck, or a wool Stetson hat ($175) that keeps him warm and blocks snow and rain from going down his neck. He also had a friend sew a warm poncho that he can wrap around his legs along with a small woolen blanket. "This really comes in handy when I'm watching my son play a full game of outdoor ice hockey," he says.

Jason Fowler, 49, a T5-6 for 32 years,

HYDRATION MATTERS

“AN IMPORTANT COMPONENT FOR BOTH COLD AND HOT TEMPERATURE REGULATION IS TO STAY HYDRATED. IT HELPS WITH COOLING IN THE HEAT AND HELPS KEEP SKIN FROM DRYING OUT AND CRACKING IN COLD, DRY AIR,” SAYS DEBBIE SHULTZ, ADVICE NURSE FOR CRAIG HOSPITAL. IDEALLY, DRINK 8-12 GLASSES OF WATER A DAY AND ADJUST FOR INTERMITTENT CATHETERIZING AND BLADDER/FLUID OUTPUT. AN EASY WAY TO TELL IF YOU ARE PROPERLY HYDRATED IS URINE COLOR. URINE IN THE CLEAR-TO-STRAW COLORED RANGE SUGGESTS OPTIMAL HYDRATION; DARKER COLORED URINE AND/OR LESS OUTPUT IS GENERALLY A SIGN YOU NEED TO DRINK MORE WATER.

BURN DANGERS IN WINTER AND SUMMER

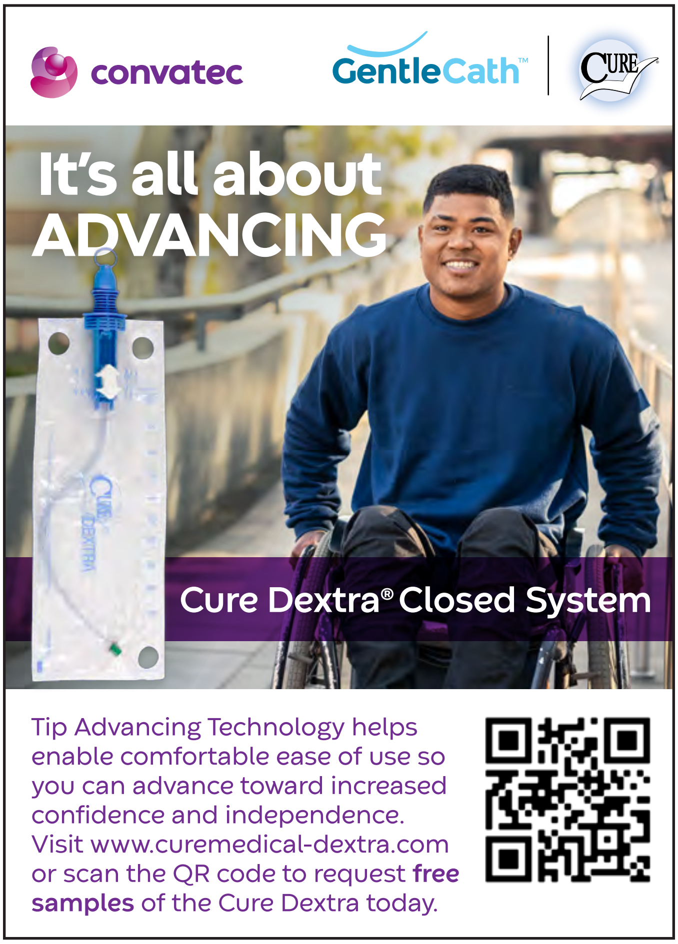
Summer or winter, it's important to take precautions to avoid burns with SCI-compromised sensation.

Summertime burn dangers include severe sunburns, especially on areas like exposed knees when wearing shorts — I wear longer shorts that go over my knees, or drape a towel over them — and also burns from objects that have been heating in the sunlight. Wolfe learned this the hard way at a summer tennis clinic. "I transferred into a tennis chair, and the ratchet strap that goes over your legs was black and had been cooking in the sun," he says. "I ratcheted it over my legs and didn't think about it until I removed it, and there was a nasty burn on my thighs where the strap had been." Gibson's lesson came when he leaned against his van on a hot, sunny day. "I was resting part of my arm that doesn't have sensation against the van and didn't realize how hot it was in the sun. When I got home, I saw I had a bad burn on my arm," he says. Other potential burn dangers are car seats that have been in the sun and/or metal seat belt buckles.

In winters come burn dangers from exposed skin being too close to hot air vents, stoves and fires, which can directly burn skin or heat up wheelchair parts. "One day I was in my chair and had my back to the wood stove with my hands on my push rims and I asked my wife, 'What smells?'" Wolfe says. "She said, 'Oh my God, it's your elbows' — where I don't have sensation. They got so hot they were actually smoking, and I ended up with severe blisters."

Heated car seats also pose potential burn danger because they can malfunction and inflict severe burns. This happened to Arwen Bird, 48, a T8 para for 30 years, who purchased a new car with heated seats. "I was driving home from the coast and switched on the seat heater for the first time," she says. During the drive home she started to feel nauseous but chalked it up to fatigue. The fatigue lingered the next day and she thought it must be an SCI thing. "That afternoon I did a transfer and saw two wet spots on my seat cushion. I went to the bathroom and could feel that I had wounds on my skin that were the size of silver dollars!" Her dad rigged a thermometer held under two water jugs to simulate sitting on the car seat, and it heated up to 180 degrees!

Her burns were so severe that a burn specialist had to remove the damaged tissue and surgically close the wounds. She was extremely fortunate that she only had to spend a few weeks in bed. "These days I never turn the car seat heater on," says Bird, "and even then, I will take my hands and feel the seat to make sure I know what my butt is getting exposed to and be sure I'm not getting burned."



has two products that help him stay warm while training in Boston's brutal cold winters. "I use a wireless muscle stimulator called PowerDot ($199) that I put on the back of my calves, which causes muscle contractions and promotes more blood flow. It seems to help keep my lower legs warm when I'm training on a cold day," he says. "The other thing that really helps keep my legs warm in cold climates are thigh-high compression stockings."

Evans gears up with electric heated gloves from Fly Racing and a heated jacket made by Gobi Heat. He carries reusable cold packs that can be microwaved and will remain at room temperature until you press on a metal tab inside the pack, causing them to heat up and stay warm for several hours.

Finding gloves to keep your hands warm — and most importantly, dry — while pushing a wheelchair is critical. In my 38 years of trying every option available, I've found that winter gardening gloves by companies like Atlas offer the best blend of warmth, water protection, traction for pushing, and price, at around $8-$12 a pair.

RESOURCES

- **Craig Hospital Nurse Advice Line**, 800/247-0257.
- **Wintertime SCI Skin Protection**, newmobility.com/wintertime-sci-skin-protection
- **Hydration With a Spinal Cord Injury**, craighospital.org/resources/h2o-to-go-hydration
- **Escaping the Hot Seat**, newmobility.com/escaping-the-hot-seat
- **Hotel Hot Water and Rental Car Burn Dangers**, newmobility.com/hotel-hot-water-and-rental-car-burn-dangers

PRODUCTS

- **AlphaCool**, mycoolingstore.com/alphacool-original-cooling-ice-vest.html
- **Vanvene Cooling Neck Wrap**, amazon.com/VANVENE-Cooling-inflated-Soaking-Activities/dp/B089B1D1ZB
- **Mission Cooling Towel**, homedepot.com/p/Mission-Hydro-Active-12-in-x-33-in-Unisex-Blue-Microfiber-Large-Cooling-Towel-107100/312468491
- **Liberty21 Corn-Filled "Corn Cuddler" Heating Pad**, amazon.com/Heating-Removable-Washable-Natural-Shoulders/dp/B07G4L2LSR/
- **Fly Racing Heated Gloves**, speedaddicts.com/motorcycle/fly-racing-ignitor-heated-black-gloves
- **Glacial Comfort Gel Ice Pack**, amazon.com/Glacial-Comfort-Pack-Back-Pain/dp/B0BDQPPNSQ
- **Gobi Heat Heated Outerwear**, gobiheat.com
- **Swiss Tech Straw Lifeguard Hat**, walmart.com/ip/Swiss-Tech-Men-s-Straw-Lifeguard-Hat/1206710542?athbdg=L1600
- **Stetson Wool Hat**, huckberry.com/store/stetson/category/p/67477-the-rawlins-cowboy-hat-exclusive
- **Therabody PowerDot muscle stimulator**, therabody.com/us/en-us/powerdot-muscle-stimulation-devices/
- **Savior Heat Heated Gloves**, saviorglove.com

CASTER WHEELS AND FORKS

CASTERS ARE AN OFTEN-OVERLOOKED COMPONENT OF YOUR WHEELCHAIR'S PERFORMANCE. MAYBE THAT'S BECAUSE IT'S SO HARD TO FIGURE OUT WHAT'S AVAILABLE. BY SETH MCBRIDE

We can't show dozens of options for caster wheels and forks that you can easily put on your manual wheelchair because there is only one well-known third-party caster company: Frog Legs. Otherwise, there are a variety of caster wheels and caster forks available from wheelchair manufacturers — think of these as original equipment manufacturer parts for cars. They're made to go on a specific chair brand, sometimes a specific chair model. Many of them are very similar, but you have to know details like caster barrel type, fork length and caster barrel-to-floor height to know whether forks from another manufacturer will work on your chair.

So, think of this Gear Guide as less of a catalog and more of an explainer of what to look for if you want to replace, swap or upgrade your current caster forks and/or wheels. For links on where to buy and find more information, visit newmobility.com/gear-guide-caster-wheels-and-forks. We'll take all the help we can get — so let us know if you see anything we missed or find a better price by emailing smcbride@unitedspinal.org.

REPLACE

This is the simplest option of the three. If you like your current caster fork and wheel setup, finding replacements is straightforward. Going through the durable medical equipment provider where you got your wheelchair is the most obvious solution. The company has service technicians to make sure you're getting the right equipment and can bill insurance.

But maybe you don't want to deal with the hassle of appointments, billing and potentially multi-month wait for a simple parts replacement. Wheelchair manufacturers typically don't sell directly to consumers, so the quickest, easiest option is to check the major online DME websites like DME Hub, Spinlife, Living Spinal, Rolling in Paradise or others. Caster wheels are easy to find. Use a tape measure to check your caster diameter and width. Plug those into Google and you should have multiple options to choose from. They're all very similar, so don't be afraid to go with the lowest price.

Replacement forks can be harder to find, depending on the brand of your chair. But even if your preferred online DME store doesn't have your particular forks listed on their website, it's worth calling or emailing. If they sell your brand of wheelchair, they can likely get replacement forks for it. As long as you know your wheelchair brand and model and the size of your casters, they should be able to find you what you need. Pro tip: We've had great experience with the customer service at DME Hub.

SWAP

There are a few reasons you might want to change your caster wheel size or fork style, such as smoother rolling over rough terrain or easier cleaning of hair away from your bearings. But switching sizes and styles does complicate things a bit. Here are some different options and what you need to know about them.

CASTER WHEELS

Caster wheels for ultralight, manual wheelchairs are typically available in diameters from 3 inches to 6 inches. The bigger the wheel, the better the roll-over capabilities on cracks, gravel or dreaded pine cones. Sports wheelchairs use small, Roller-blade-style casters because they're fast on smooth surfaces and stable at high speeds. People who spend a lot of time outdoors or off pavement often want a larger-diameter caster so bumps and debris don't pitch them out of their chairs.

The problem with big casters is that they can flutter at high speeds, and they have a wider swing radius. If you have a narrow chair, be careful about switching to larger-diameter casters as they could hit your feet when they swing in. You may also need new forks if you increase your caster diameter, depending on the length of your current forks.

Changing your caster height can also change your front-end height. That might be a good thing, but it does offer its own set of complications. For a detailed breakdown of seating position considerations, check out "Modifying for All-Purpose Wheeling." For those who don't want to change their caster diameter, a wheel at least 1.4 inches wide will typically roll over rough ground better than a narrow wheel of the same diameter. You may need new forks to go with those casters though, depending on your current chair setup.

FINDING THE RIGHT MOBILITY PRODUCTS IS HARD. OUR GEAR GUIDES ARE HERE TO HELP: NEWMOBILITY.COM/GEAR-GUIDES

FORKS

Standard manual wheelchair forks have two arms, and the caster goes between them with a bolt and spacers. They are available in a variety of lengths and widths. Changing your fork length can also change your front seat height, increasing dump and changing your backrest angle. Even a 0.5-inch change in front seat height can noticeably affect your chair's feel, balance and pushing characteristics.

Some manufacturers offer single-sided forks, which feature one arm, usually with an integrated bolt. A screw and cap secure the caster wheel on the other side. Single-sided forks look slick, they collect less hair (there's only one side for it to get caught in), and they make it easier to pull your caster off for cleaning. Usually, you only have to remove a single Allen screw — no mucking around with spacers and multiple wrenches. The downside to single-sided forks is that you can bend them more easily than standard forks if you happen to slam into a sidewalk crack or otherwise put a lot of force onto them. It's not common, but it does happen. Frog Legs single-sided forks fit chairs that have the caster barrel bearings in the frame. TiLite single-sided forks have the bearing in the fork.

UPGRADE

If you are looking to upgrade your stock caster forks, all the same considerations apply as with swapping out your caster wheels or forks. You or your DME supplier need to know your caster barrel type and the distance from your caster barrel to the floor. Here are a few upgraded caster fork options to consider.

FROG LEGS

Shock Absorbing Forks

These are the classic suspension caster forks. They have a rubber damper that is designed to reduce jostling over rough ground, bumps and cracks. These forks are made out of aluminum and can be ordered with wheel diameters of 3 inches to 6 inches. They will only fit in caster barrels with integrated bearing.

BEST FOR: Wheelchair users who regularly roll over rough ground or who have issues with spasms or nerve pain that is worsened by vibrations.

PRICING/AVAILABILITY: Frog Legs Shock Absorbing Forks retail for $299 but can be found $279 at Living Spinal.

Phase II Forks

Frog Legs Phase II Forks are an updated version of their classic suspension forks. Phase II Forks feature lighter-weight composite forks and a wedge damper. Frog Legs says the new damper rides like a solid fork on smooth surfaces yet absorbs bumps when needed. Phase II Forks are available with caster wheel diameters of 3 inches to 6 inches.

BEST FOR: Wheelchair users who regularly roll over rough ground or who have issues with spasms or nerve pain that is worsened by vibrations.

PRICING/AVAILABILITY: Frog Legs Phase II Forks retail for $499, but can be found for as low as $279 from Living Spinal.

BOX WHEELCHAIRS

Off-Road Recoils

The Off-Road Recoil caster combines a suspension caster fork with a 3-inch diameter by 3-inch wide caster wheel. The super wide caster wheel rolls easily over rough terrain and provides better float on soft surfaces. The caster wheel surface is tapered so when you're rolling on smooth ground only a small portion of the caster touches, decreasing rolling resistance. These caster forks are used by many of Box Wheelchair's WCMX riders, including Aaron Fotheringham, so you know they're meant to take some abuse. They are only available for wheelchairs with caster barrels that have in-frame bearings. There is no adjustment on fork length or wheel placement, so if your caster barrel-to-floor height is shorter or taller than 6.5 inches, they will change your front seat height.

BEST FOR: Wheelchair users who regularly roll over soft ground or who have issues with spasms or nerve pain that is worsened by vibrations. WCMX riders.

PRICING/AVAILABILITY: Off-Road Recoils retail for $1,095 but can be found as low as $799 from Living Spinal.

TILITE

Glide Suspension Forks

Glide Suspension Forks are made specifically for TiLite chairs. They are similar to other suspension forks — smoothing out vibrations and easing passage over cracks and bumps — while offering a compact shape. They come in three different damper densities to fine tune the suspension, and three different wheel positions to accommodate varying diameter casters and caster barrel heights.

BEST FOR: TiLite users who regularly roll over rough ground or who have issues with spasms or nerve pain that is worsened by vibrations.

PRICING/AVAILABILITY: Glide Suspension Forks are available for $201.75 from DME Hub.

OWN IT

By Regan Linton

> “I was reminded that there are folks with disabilities in every part of the world, and one of our greatest travel assets is connecting with them.”

TRAVEL BEYOND YOUR COMFORT ZONE

I love when summer approaches. Warm weather revs up my energy for adventure and travel. Growing up, I was fortunate to travel a lot. Nothing fancy or exotic, just places different from what I knew. My parents adhered to a “swing by” philosophy when determining our family travel, taking any opportunity to see a new place, even if it meant going out of the way. Like, if we were visiting my grandparents in Philadelphia, we’d “swing by” Niagara Falls, because it’s “in the area” — the “area” being the entire northeast region of the country. Despite at times begrudging the long car rides, my siblings and I grew up with the itch to see the world.

Sometimes getting out of your comfort zone means traversing a sandy beach in your wheelchair.

Then in college came my spinal cord injury. Suddenly some of the far-flung places I’d always dreamed of visiting — China, Africa, New Zealand, India — felt nearly impossible to reach. Previously, I thought I could just figure it out … work to raise the money, then hop on a plane with a moderately sized bag and go with the wind.

But post-injury, it felt like there were so many logistics. I couldn’t just wing it without risking major snafus like not having an accessible place to sleep or workable transportation. Everything required more planning and investigation to make sure that what was advertised as “accessible” actually was — and typically required more money. Then you pile on the extra luggage, long plane rides without stretching or bathroom access, lack of accessibility at the destination, oftentimes needing a companion, and all the other unpredictable elements of spinal cord injury — urinary tract infections, upset stomachs, broken equipment, skin issues — and it almost didn’t feel worth the hassle.

On top of it all, I’ve always had a bit of snobbish idea of *how to travel*: I wanted to get away from the touristy spots, off the beaten path. To me, this meant venturing into wildly inaccessible places. I was crushed to think that my only remaining options would be cruises or Las Vegas.

I was compelled to rethink what I truly valued in travel:

- Exposure to something unfamiliar.
- Immersion in the sights, sounds, smells and sensory input of a different culture or community.
- Getting to do something I’d never get to do at home.
- Feeling a sense of accomplishment.

I realized that distance or exoticism weren’t necessarily the most important factors. Yes, the definition of “travel” is to go from one place to another, typically over a great distance. But as any of us who has ever used a mobility aid can attest, the impact of distance can be relative. I mean, pushing around the hills of downtown San Francisco can leave me with a sense of accomplishment equivalent to someone else's running a marathon. And distance doesn't necessarily guarantee an expansive experience; sometimes going to another section of the same city can provide insights akin to traveling halfway across the world.

Getting Back Out There

I started, slow and small. A road trip back to college in California. A work retreat to Boston. Simply driving by myself somewhere that I'd never been within a couple hours of home. I started to develop a sixth sense for accessibility in new places and honed my processes for finding hotels, loading onto planes, packing judiciously and venturing into unfamiliar territory. I learned to ask for help when I needed it.

I also started to discover unique programs like Mobility International USA, which provided my first opportunity to travel internationally to Japan as part of an exchange program for young adults with disabilities. I felt totally supported and was surrounded by an international community of people, with and without disabilities. I was reminded that there are folks with disabilities in every part of the world, and one of our greatest travel assets is connecting with them.

As my entire attitude around travel shifted, I saw through the veneer of others' travel experiences. Friends of mine would flash impressive selfies from far-off places where they climbed a famous mountain, visited a famous site or posed in a famous bar. But they often didn't really get to know the essence of a place or its people. They played it safe, doing the same thing halfway around the world as they'd do at home. Aside from selfies, the most meaningful parts of their experience would boil down to a person they met, getting out of their everyday comfort zone, and feeling a sense of accomplishment — all things you don't have to travel to Timbuktu to find.

Near or far, the wonders of the world are not as out-of-reach as we may think.

I still love to travel, and I've done it a LOT in the last 21 years. Work and pleasure opportunities have taken me to Japan, Dubai, Italy, Switzerland, Mexico and more. When I go far away, the very act of doing so feels 10 times more special because I know what a big accomplishment it is. And getting outside the U.S., especially as a person with a disability, gives you perspective about accessibility, opportunity and human rights.

Domestic travel has been just as eye-opening. I've lost count of the times I've driven cross-country by myself in my accessible van. Traveling alone, I'm more apt to connect with people I don't know, and I've discovered fascinating places and people all over the U.S.

I still love cool, off-the-beaten-path spots. Taking the time to research has led me to memorable places, like the kitschy accessible African safari hotel I stayed at outside of Dachau, Germany. And as I've strengthened my travel wheels, I've felt more comfortable to go with the wind and have some pretty wild experiences. But I also don't turn up my nose at cruises or Vegas, both of which I really enjoy for different reasons, including eclectic humanity and broad accessibility. Now I prioritize fully accessible accommodations, so that I can spend my energy on exploring a place and not wasting it on maneuvering in a bathroom.

I still have some big goals on my travel list, but others have fallen off — not because they aren't possible, but because my priorities have changed. I've also added some spots that are just a 30- to 45-minute journey away.

If we're open to it, we can get outside our comfort zone the second we leave our pad, by chatting with our cabbie, getting to know the random guy at the coffee shop, or turning left instead of our usual right. Sure, it's still nice to have the Instagram selfie of the hammock in a rainforest. But you can dig deep and cultivate a new story regardless of how far you get.

PRODUCTS

By Michael Franz

BATTLE OF THE GRIPPING GLOVES

Since UK-based Active Hands launched its General Purpose Gripping Aid in 2007, anyone with limited hand function seeking a good workout has not needed to look any further. Active Hands' sleek, sturdy design coupled with its simple functionality made its selection a no-brainer. But a new contender has entered the market: the Grip Glove USA. With new features differentiating it from the rest, does it have what it takes to knock out the champ? We put both to the test and have the results below.

The Champ: Active Hands General Purpose Gripping Aid

The Active Hands General Purpose Gripping Aid has enjoyed a long reign as the top gripping aid. It got there by mimicking the design of the generic suede gripping aids so many of us received in therapy, but wisely adding several features that improved the performance and functionality for users. The Active Hands gripping aid is made of neoprene and has a strap around the wrist and another that wraps around the hand, both of which are secured using strong Velcro to ensure a firm grip on the object being held. For quads, and others with limited hand dexterity, the Active Hands gripping aids have rings at the ends of the straps, allowing the user to to pull the strap tight with a finger or even their teeth, like I do. I have used the Active Hands gripping aids for many years and have found them to be easy to use, versatile, and durable. I have used them for everything from lifting weights and using cardio machines, to holding utensils while cooking. The only problem I have while using the Active Hands gripping aids is the amount of stress put on my wrists when lifting weights. As a C5-6 quad, I have decent wrist extension strength but no ability to flex my wrist with my palm facing upwards. When using the Active Hands gripping aids, the weight of dumbbells or a cable machine will pull my wrist down causing stress on the joint and limiting how much I can lift.

The Active Hands General Purpose Gripping Aid starts at $94.95 per glove and can be purchased individually or in pairs. They are available in small, standard, and large in several colors. For more information, please visit activehands.com.

The Challenger: Grip Glove USA

The Grip Glove USA is the newest contender trying to take Active Hands' title. The Grip Glove USA looks like a bulked up take on the Active Hands aid, with several additional features that set it apart from previous also-rans. The Grip Glove USA features a removable aluminum bar that runs across the top of the wrist and forearm, a strap that wraps around the wrist, and a second strap that wraps around the forearm for additional support. The Grip Glove USA also has six D-rings for attachment of cables and pulleys, as well as a wraparound grip for the hand like the Active Hands gripping aid.

The best new benefit of the Grip Glove USA is the support provided by the aluminum bar. As previously mentioned, I have limited strength in my wrists that affects my ability to lift as much as I would like. The aluminum bar provides excellent support for my wrists and allows me to lift more weight with more control. It is especially beneficial when doing exercises like curls, chest presses, and internal and external rotations.

The six D-rings are another good addition that provides options for attaching cables and resistance tubes. For some exercises, I found it easier and more effective to attach whatever I was using directly to the D-ring instead of using a handle attached to a machine. The aluminum bar also enhances the utility of the D-rings. I have used wrist straps with D-rings to attach cables, but it always feels like there is not enough support and too much stress on my arm. The bar eliminates the stress and makes using the D-rings a good experience.

The only major problem I encountered with the Grip Glove USA could be unique to me, but is worth mentioning, nonetheless. When using the Grip Glove USA, it tended to make my forearm flip over. I do not have the ability to rotate my forearm from having my palm facing up to facing down. When doing exercises like rowing that required me to pull with my palm facing down, the gloves would twist my forearm and I could not counteract it. This may not be a problem for everyone, but it prevented me from doing some exercises.

The Grip Glove USA can be purchased individually or in pairs and is available in small or large sizes for $99.50 per glove. For more information, visit gripgloveusa.com.

The Verdict

In a close battle, the Active Hands gripping aids remain undefeated. The Active Hands gripping aids are still the best option for most use cases — they work the best for gripping handles on cardio machines and sports equipment, and work very well when using a handle attached to a cable machine or resistance tubes. If you prefer to not grip a handle, or if a lack of wrist strength hinders your workouts, the Grip Glove USA gives much-needed support to the wrists and may improve your workouts. If cost is not an issue, I would recommend buying both to have the option to use either as needed.

Hospital and Organizational Members

ARIZONA

Barrow Neurological Institute at Saint Joseph's Hospital and Medical Center, Phoenix, AZ; 602/406-3747

Encompass Health Rehab Hospital of East Valley, Mesa, AZ; 480/567-0350

Encompass Health Valley of The Sun Rehabilitation Hospital, Glendale, AZ; 623/878-8800

Honor Health Rehabilitation Hospital, Scottsdale, AZ; 480/800-3900

CALIFORNIA

Dignity Health - Northridge Hospital Medical Center, Center for Rehabilitation, Northridge, CA; 818/885-8500

Rady Children's Hospital San Diego - Division of Pediatric Rehabilitation Medicine, San Diego, CA; 858/576-1700

Sharp Rehabilitation Center, San Diego, CA; 858/939-6709

Sutter Rehabilitation Institute, Roseville, CA; 916/878-2588

COLORADO

Colorado Acute Specialty Hospital, Denver, CO; 303/264-6900

Craig Hospital, Englewood, CO; 303/789-8800

Post-Acute Medical Specialty of Denver, Denver, CO; 303/264-6800

CONNECTICUT

Gaylord Specialty Healthcare, Wallingford, CT; 203/284-2800

Hospital for Special Care, New Britain, CT; 860/827-2761

Hartford Healthcare Rehabilitation Network, Newington, CT; 860/972-0990

Mount Sinai Rehabilitation Hospital - a Trinity Health of New England, Hartford, CT; 860/714-3500

DISTRICT OF COLUMBIA

Medstar National Rehabilitation Hospital - SCI Program, Washington, DC; 202/877-1000

FLORIDA

Brooks Rehabilitation Hospital, Jacksonville, FL; 904/345-7600

Encompass Health Rehabilitation Hospital of Sunrise, Sunrise, FL; 954/749 0300

Pinecrest Rehabilitation Hospital at Delray Medical Center, Delray Beach, FL; 561/498-4440

GEORGIA

Atrium Health Navicent Rehabilitation Hospital, Macon, GA; 478/201-6500

Emory University Hospital Center for Rehabilitation Medicine, Atlanta, GA; 404/712-7593

Rehabilitation Hospital Navicent Health, Macon, GA; 478/201-6500

Shepherd Center - Southeastern Regional SCI Model System, Atlanta, GA; 404/350-7645

HAWAII

Rehabilitation Hospital of the Pacific, Honolulu, HI; 808/531-3511

ILLINOIS

Shirley Ryan Ability Lab, Chicago, IL; 312/230-1000

The Spinal Cord Injury Program of Marianjoy Rehabilitation Hospital, part of Northwestern Medicine, Springfield, IL; 217/788-3302

INDIANA

Rehabilitation Hospital of Indiana, Indianapolis, IN; 317/329-2000

IOWA

Childserve, Johnston, IA; 515/727-8750

KANSAS

Mid America Rehabilitation Hospital, Overland Park, KS; 913/491-2400

KENTUCKY

Cardinal Hill Rehabilitation Hospital, Lexington, KY; 859/254-5701

Frazier Rehabilitation Institute, Louisville, KY; 502/582-7490

Gateway Rehabilitation Hospital Florence, KY; 859/426-2400

LOUISIANA

The Gilda Trautman Newman Rehabilitation Center, New Orleans, LA; 504/899-9511

Touro Rehabilitation Center- Spinal Cord Injury Rehabilitation, New Orleans, LA; 504/897-8560

MASSACHUSETTS

Spaulding New England Regional Spinal Cord Injury Center, Charlestown, MA; 617/952-5000

MARYLAND

Adventist Rehabilitation Hospital of Maryland, Rockville, MD; 240/864-6132

International Center for Spinal Cord Injury at Kennedy Krieger Institute, Baltimore, MD; 888/554-2080

Medstar Good Samaritan Hospital Spinal Cord Rehabilitation Program, Baltimore, MD; 443/444-8000

University of Maryland Rehabilitation and Orthopaedic Institute, Baltimore, MD; 410/448-2500

MICHIGAN

Mary Freebed Rehabilitation Hospital, Grand Rapids, MI; 800/528-8989

DMC Rehabilitation Institute of Michigan, Detroit, MI; 313/745-1055

Special Tree Rehabilitation System, Romulus, MI; 800/648-6885

MINNESOTA

Essentia Health Miller-Dwan Rehabilitation Services, Duluth, MN; 218/727-8762

MISSOURI

Ability KC, Kansas City, MO; 816/751-7812

SSM Select Rehabilitation Hospital, Bridgeton, MO; 314/768-5200

NORTH CAROLINA

Cone Health Inpatient Rehabilitation Center, Greensboro, NC; 336/832-8153

UNC Hospitals Rehabilitation Therapies, Chapel Hill, NC; 919/966-4131

Vidant Medical Center, Greenville, NC; 252/975-4100

Wake Forest University Baptist Inpatient Rehabilitation Program, Winston-Salem, NC; 336/716-2011

WakeMed Rehab Hospital, Raleigh, NC; 919/350-8861

NEBRASKA

Madonna Rehabilitation Hospital SCI Rehabilitation Program, Lincoln, NE; 402/489-7102

QLI - Spinal Cord Injury Program, Omaha, NE; 402/573-3700

NEW JERSEY

HMH JFK Johnson Rehabilitation Institute, Edison, NJ; 732/321-7070

Kessler Institute for Rehabilitation, West Orange, NJ; 973/252-6367

NEVADA

Renown Rehabilitation Hospital Reno, NV; 775/982-5000

NEW YORK

Garnet Health Medical Center, Middletown, NY; 845/333-1000

Helen Hayes Hospital, West Haverstraw, NY; 845/786-4000

Mount Sinai Medical Center, New York, NY; 212/241-6500

Rusk Rehabilitation at NYU Langone Medical Center, New York, NY; 212/263-6012

St. Charles Hospital Rehabilitation Center, Port Jefferson, NY; 631/474-6011

St. Mary's Hospital for Children, Bayside, NY; 718/281-8987

Strong Memorial Hospital of the University of Rochester, Rochester, NY; 585/275-2100

Sunnyview Rehabilitation Hospital, Schenectady, NY; 518/382-4560

The Burke Rehabilitation Hospital - Spinal Cord Injury Program, White Plains, NY; 914/597-2500

OHIO

Metrohealth Rehabilitation Institute of Ohio, Cleveland, OH; 216/778-3483

Ohio Health Outpatient Neurological Rehabilitation, Columbus, OH; 614/484-9600

Summa Rehabilitation Hospital, Akron, OH; 330/572-7300

OKLAHOMA

Integris Jim Thorpe Rehabilitation Network, Oklahoma City, OK; 405/951-2277

Valir Rehabilitation Hospital, Oklahoma City, OK; 405/609-3600

OREGON

Legacy Rehabilitation Institute of Oregon, Portland, OR; 503/413-7151

PENNSYLVANIA

Allied Services Integrated Health System Spinal Cord Injury Program, Scranton, PA; 570/348-1360

Encompass Health Rehabilitation Hospital of Altoona, Altoona, PA; 814/944-3535

Magee Rehabilitation Hospital - Jefferson Health The Regional Spinal Cord Injury Center of the Delaware Valley, Philadelphia, PA; 215/587-3000

Moss Rehabilitation Hospital, Elkins Park, PA; 215/663-6000

Reading Hospital Rehabilitation at Wyomissing, Wyomissing, PA; 484/628-8000

Spinal Cord Program at The Children's Institute, Pittsburgh, PA; 412/420-2400

UPMC Rehabilitation Institute at Mercy, Pittsburgh, PA; 800/533-8762

UPMC - Williamsport Joint Commission Certified SCI Inpatient Rehab, Williamsport, PA; 570/321-1000

SOUTH CAROLINA

Roper Rehabilitation Hospital, Charleston, SC 843/724-2800

TENNESSEE

Patricia Neal Rehabilitation Center, Knoxville, TN; 865/541-3600

Regional One Health Rehabilitation Hospital, Memphis, TN; 901/545-7100

Vanderbilt Stallworth Rehabilitation Hospital, Nashville, TN; 615/963-4051

TEXAS

Texas Rehabilitation Hospital of Fort Worth, Fort Worth, TX; 817/820-3400

TIRR Memorial Hermann Hospital, Houston, TX; 713/799-5000

TIRR Memorial Hermann Hospital - Outpatient, Houston, TX; 800/447-3422

TIRR Memorial Hermann Hospital The Woodlands, The Woodlands, TX; 713/897-2300

Trustpoint Rehabilitation Hospital of Lubbock, Lubbock, TX; 806/749-2222

UTAH

Neuro Specialty Rehabilitation Unit at McKay-Dee Hospital, Ogden, UT; 801/387-2800

Neuro Specialty Rehabilitation Unit at Utah Valley Hospital, Provo, UT; 801/357-7850

Neuro Specialty Rehabilitation Unit at Intermountain Medical, Salt Lake City, UT; 801/507-1261

Neuro Specialty Rehabilitation Unit at St. George, Saint George, UT; 435/251-6250

University of Utah Craig H Neilsen Rehabilitation Hospital, Salt Lake City, UT; 801/646-8000

VIRGINIA

Sentara Norfolk General Hospital, Norfolk, VA; 757/388-3000

Sheltering Arms Institute, Richmond, VA; 804/764-1000

UVA - Encompass Rehabilitation Hospital, Charlottesville, VA; 434/924-0211

WASHINGTON

University of Washington Harborview Medical Center: Northwest Regional Spinal Cord Injury System, Seattle, WA; 206/221-7390

WISCONSIN

The Spinal Cord Injury Center at Froedtert and The Medical College of Wisconsin, Milwaukee, WI; 414/805-3000

UW Health Rehabilitation Hospital, Madison, WI; 608/592-8100

Organizational Members

Florida Spinal Cord Injury Resource Center, Tampa, FL; 813/844-4711

High Rollers Adaptive Sports Foundation, Las Vegas, NV; 702/372-9622

Miami Physical Therapy Assoc., Inc.
Miami, FL; 305/444-0074

NextStep - Orlando
Sanford, FL; 407/571-9974

Project Walk Boston
Stratham, NH; 603/583-5119

Project Walk New Jersey
Mt. Laurel, NJ; (856/439-6772

Push to Walk
Oakland, NJ; 201/644-7567

TRYAbility Neurorecovery Center
Downers Grove, IL, (331) 775-2813

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VACATIONS

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LAST WORD

MEMEWATCH

Meme by @adam__lucio

SEE IT FIRST ON NEWMOBILITY.COM

Lignorims Pushrims Reviewed (Early July)
Austrian company Lignorims offers a few models of pushrims made from wood. They're a striking design that the company says are more comfortable and functional in inclement weather and the heat than metal or vinyl rims. Now that they're available in the U.S., Seth McBride gave them a multi-season test to see how they perform.

Best Of: Accessible Train Trip (Late July)
Planes have become the standard long-distance travel option for most Americans, but there are a lot of benefits to train journeys, including easy boarding, equipment safety and access to bathrooms while traveling. Craig Kennedy, who has done accessibility consulting for Amtrak, reveals his favorite overnight train trip for wheelchair users: a 20-hour ramble from Chicago to New York known as The Lakeshore Limited.

Interval Training for Wheelchair Users (Mid August)
Personal trainer and C7 quad Ben Clark helps other wheelchair users maximize their fitness through his Adapt to Perform online training service and Youtube channel. He reveals the health benefits of one of his favorites workouts for wheelchair users — interval training — and shows you how to get started with an interactive video workout.

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