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NEW MOBILITY



THE MEMBERSHIP PUBLICATION
OF UNITED SPINAL ASSOCIATION

Consumer Guide: Products that Fit Your Life



**Alana Nichols:
Balancing Sport,
Motherhood,
Advocacy & Media**

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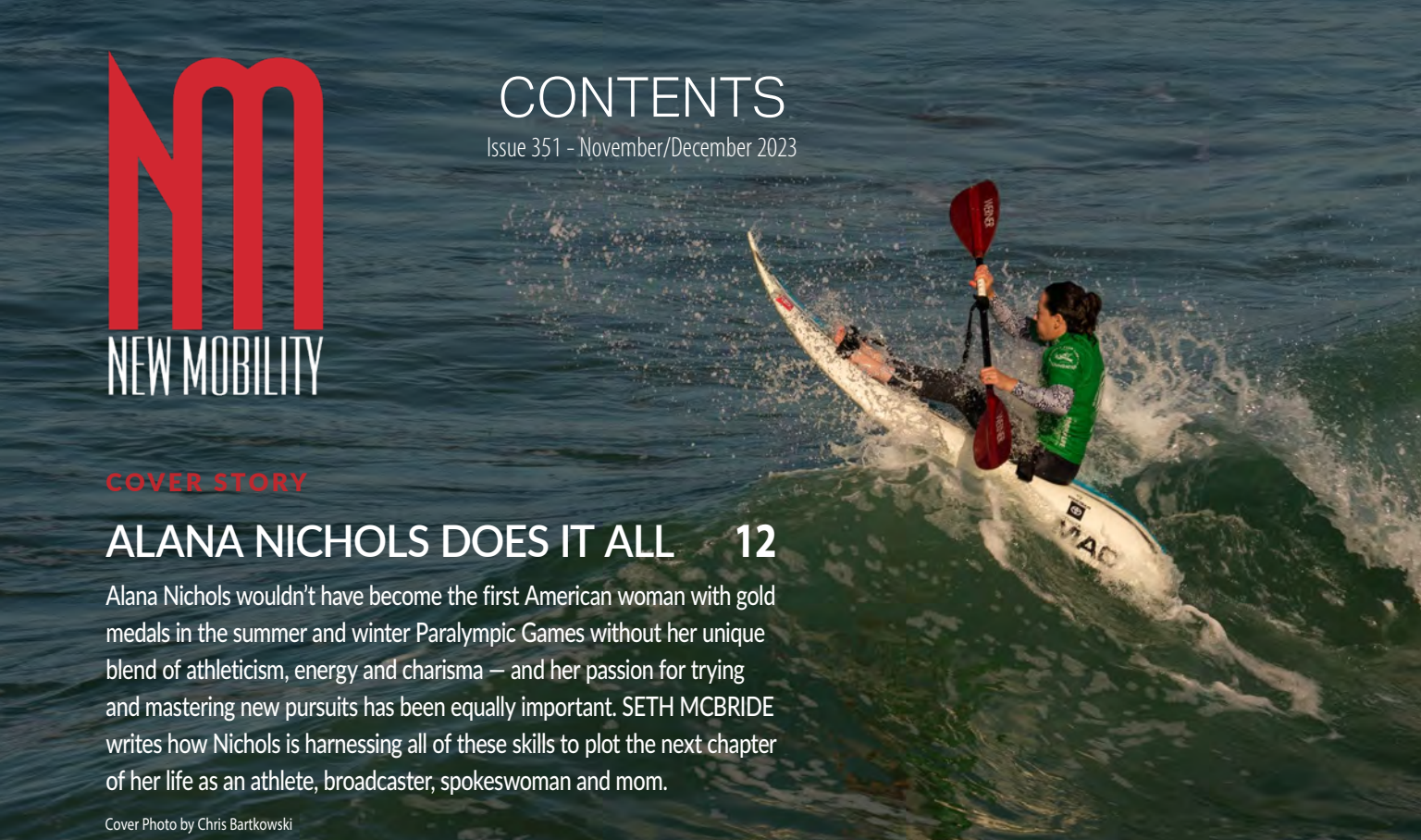
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COVER STORY

ALANA NICHOLS DOES IT ALL 12

Alana Nichols wouldn't have become the first American woman with gold medals in the summer and winter Paralympic Games without her unique blend of athleticism, energy and charisma — and her passion for trying and mastering new pursuits has been equally important. SETH MCBRIDE writes how Nichols is harnessing all of these skills to plot the next chapter of her life as an athlete, broadcaster, spokeswoman and mom.

Cover Photo by Chris Bartkowski



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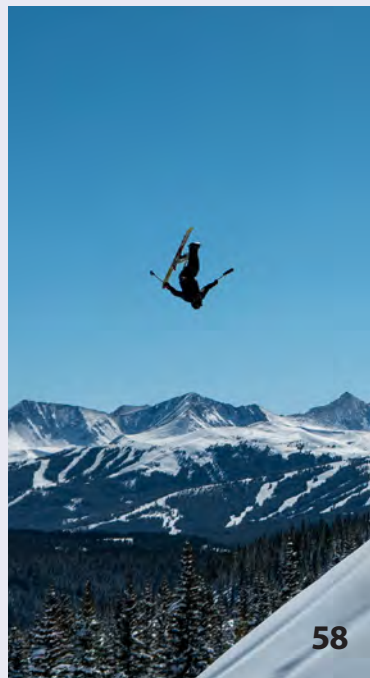
58 MEDIA *Full Circle* began as a documentary about up-and-coming sit-skier Trevor Kennison but became something much larger when filmmakers learned how he was connected to longtime NM editor Barry Corbet. SETH MCBRIDE tells the story.



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BULLY PULPIT

By Ian Ruder



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MONKEY MADNESS

A friend recently asked me what my secret SCI obsession was. Initially confused, I tamped down the instinct to ask what the hell she was talking about, forced a pensive face and blurted out, “Monkeys.”

Before she could verbalize the confusion on her face, I tried to explain.

I told her my simian obsession dated back to the early days of my initial rehab stint. In those dark times, someone threw out the idea of a canine companion in hopes of brightening my day. My lack of enthusiasm must have been obvious, because the conversation quickly segued to less traditional companion animals and, eventually, to monkeys.

I was sold.

Let me preface this by saying, yes, I know monkeys and gorillas are not the same, but ...

I instantly pictured myself riding a giant silverback caregiver. Who needs pivot transfers or sliding boards when you have a soft, cuddly 400-pound ball of muscles to swing you around? I could cling to his back or he could effortlessly swoop me around. I might not even need a wheelchair!

The nurses and therapists got a good laugh out of my dream, and it took my mind off the less cheery reality of inpatient rehab. Maybe that would have been the end of my monkey obsession, if not for the unit psychologist.

She remembered reading about a place that actually trained (much smaller) capuchin monkeys to help quadriplegics and provide emotional support. She couldn’t remember where she’d read about it, but she swore there was a movie about the service and promised to help track it down.

It wasn’t my silverback, but the idea of a cute, tiny monkey helping me existed right at the perfect intersection of interesting, ridiculous and hilarious so as to make it unforgettable. Without the

instant gratification of today’s internet (it was 1998), my imagination ran wild anticipating what the helper monkey setup would actually look like.

I didn’t have to wait long, as somebody figured out the name of the movie and tracked down an old VHS copy. I can still remember someone rolling one of the old TV/video carts into my room and showing me the movie box: *Monkey Shines*. The cover featured a psychotic-looking stuffed monkey holding a bloody straight razor with the caption “An Experiment in Fear.”

As I watched the quadriplegic protagonist try to save all of his friends from the homicidal wrath of the possessed primate, I couldn’t stop thinking about how genuinely excited the psychologist was upon hearing I was going to watch the movie. I wondered if she had any idea the film wasn’t a documentary about a service monkey organization, but rather a psychological horror film about an ill-adjusted quad and the scientifically-altered monkey that serves as a physical manifestation of his rage. As ridiculous as it was to be watching this in SCI rehab as a newly-injured 18-year-old, the fact she had all but endorsed it blew my mind.

Any serious flirtation with the idea of getting a helper monkey ended there for me, but my obsession with the concept only grew. My parents and I occasionally joked about my caregiver ape, and I made a point of recommending *Monkey Shines* to any quad friends who hadn’t seen it. Fifteen years later, I even wrote a story about a Massachusetts nonprofit that actually provided quadriplegics with trained monkeys.

By the time I finished relaying all of this to my friend, she had totally checked out. “That’s funny,” she said, “but I was just trying to find out if there is a wheelchair user you secretly follow.”

Oh. “Not really.”



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SHARE

“We will keep advocating until we achieve air travel reform.”

SEPTEMBER-OCTOBER 2023 ISSUE

Taking on the Unfriendly Skies: Are Airlines Hearing Wheelchair Users' Protests?

Done Flying: The last time I flew, they “lost” my wheelchair, my wheelchair was too wide to fit down the center aisle, and even though I had called them numerous times before my flight to make sure they would be able to accommodate me, when I showed up, the staff on the airplane said they never knew of any [device] to help me. Never again.

Samantha Theobald

Newmobility.com

Flying in Your Wheelchair? Not for me:

I want to fly as “normally” as possible. I spend most of my waking moments trying to get out of my wheelchair. The last thing I want to do, is stay in it while flying. No thanks.

Dennis

Newmobility.com

#RightsOnFlights: We will keep advocating until we achieve air travel reform to protect the rights and safety of disabled people.

@maayanziv_

Instagram

Great Idea: Love the idea of staying in your chair on the plane without transferring.

@iam_bwebbl

Instagram

Air Travel Tips for Wheelchair Users

Five More Tips: Thanks for the reporting on this. My wife’s power chair was damaged multiple times with \$20,000 in cumulative damage that airlines had to pay out. It finally abated (mostly) when I started asking the airline personnel at the gates if I could speak with the person or ramp manager that will be loading the chair. I then explain to them each time, in person: 1. How the motor disengages. 2. It CANNOT be loaded sideways. 3. How to lower the back of the chair to fit in the hold of the plane. 4. How much they’ve paid out already. 5. How fragile the hand controller is and to protect it. Now, it all goes out the window [if] they transfer straight to another plane during the trip; a large sign on it helps sometimes.

B. Young

Newmobility.com

Please Remain Seated: Career Day

Ouch: Woah. Too close to home to laugh. Well done.

@Okanlami

Instagram

Educate the Educators: The teacher needs diversity training!

Wendy Townsend Vaillancourt

Facebook



WEB-FIRST CONTENT

If You Want To Get Back on the Water as a Wheelchair User, this Adaptive Sailing Center in Maryland Is Worth the Trip

CRAB Fest: Thanks for the coverage of a great organization. Friends say sailing saved my life after my childhood polio came roaring back in the form of post-polio syndrome.

Barry W. Considine

Newmobility.com

fuelService App Helps Disabled Drivers Find Refueling Assistance

Helpful: It’s great! I just started using it here in B.C., Canada. Sure saves a lot of hassle phoning around hoping a station has someone available. They do it all for you — all you do is show up, text them the spot you’re in, and they come gas you up! It’s fantastic ... finally a hassle-free way to gas up. Now if the app could only drop the price a buck a liter, we’d be laughing!

Carol

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By Shannon Kelly

Meet Louis Linebarger: Director of Tech Access

For the disability community, accessible technology is not just a luxury, it's a necessity. United Spinal Association's new Director of Tech Access, Louis Linebarger, says he first realized the power of technology when observing his deaf relatives as a child. "I was always amazed by the technology that one of my deaf relatives used in her house to be more independent, such as the lights flickering when the doorbell rang or the phone rang," says Linebarger, who was born with spina bifida.

Over the years he has used a variety of technology to impact his independence, including AFOs to support his ability to walk, a handcycle, which allows him to join social activities and exercise, and a mobility scooter that facilitated his college journey and allows him to navigate large venues effortlessly. "I've witnessed firsthand the transformational power of assistive technology. It's not just about convenience, it's about independence and participation in all aspects of life, from education to employment, healthcare and community engagement," he says.

Prior to joining the United Spinal team, Linebarger began his career in the corporate world at Wells Fargo and later transitioned into the tech industry at WalkMe, a provider of virtual training. Now, as a part of the United Spinal family, his vision for the Tech Access Initiative is clear. "We aim to make accessible technology truly inclusive, ensuring that individuals with spinal cord injuries or mobility disabilities have access to the tools and knowledge they need to thrive," he says. "This involves raising awareness about existing assistive technology and advocating for policies that address gaps in accessibility."

Linebarger was excited to spotlight the Tech Access Initiative at the SWTCon conference in October. This event offered an opportunity to showcase assistive technology and included a grant-facilitated session for training for new wheelchair users on assistive technology.

He is eager to connect with members about accessible technology at United Spinal's bi-monthly TechTalks. Learn more at unitedspinal.org/events/techtalks.



Linebarger



Sandlin

Pickleball for All

If you're in the Dallas-Fort Worth area and are looking to try something new, join United Spinal's North Texas chapter for their Para Pickleball Program. The program is open to all individuals living with a disability. People can play from a sports wheelchair provided by the group, and the program welcomes standing players such as amputees or those with limited mobility.

"Pickleball truly is a sport anyone can play," says Taylor Nichols, founder of the program and board member of the North Texas chapter. "It's a community-oriented sport and it bridges the gap within diverse communities and allows people from all different backgrounds to enjoy playing together. It is beneficial for mental and physical health to get out there, be active and burn calories while bonding over friendly fun."

The group meets from 6-8 p.m. the first and third Wednesdays of the month at the Grand Prairie Chicken N Pickle, and on second and fourth Wednesdays at the Chicken N Pickle - Grapevine.



Meet New Member Sharon Sandlin

Multiple Sclerosis, Age 58 from Broussard, Louisiana
Hobby: Freshwater Fish Keeping

Why did you join United Spinal?

Now that I'm using a wheelchair exclusively, the difficulties of being disabled have become real. I faced many challenges and didn't know where to turn for help. I went online and found United Spinal Association. I signed up because of the wealth of information and support they provide.

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

My long-handled grabber. The grabber saves me from falling out of the chair and landing on the floor. It's also a life saver for things that are up high.

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

I propose a comprehensive approach centered on education and empathy-building. My vision is to create a society where people truly understand the wheelchair user's perspective by promoting inclusivity and compassion.



Photo Contest Advances Representation

We live in a world of visual storytelling and yet, wheelchair users are often confronted by canned stock images and nondisabled actors attempting to tell their stories. United Spinal Association wants to move beyond depictions of disability that are certainly not for us, by us. The organization held a photo contest to expand its library of images that authentically portray the disability experience.

Our community delivered over 200 diverse images capturing slices of life in a number of categories: lifestyle, family and friends, fitness, outdoor recreation, transportation and more. A sincere thank you to everyone who participated, kudos to all who voted and a hearty congratulations to the winner, Austin Meredith, whose image is above.

SWTCon Unites the Disability Community

United Spinal Association hosted its first-ever StrongWheeled Together Conference in October, bringing together members, chapter leaders, clinicians and corporate partners for a three-day event in Las Vegas that inspired connection, learning and action.

Through breakout sessions, attendees explored the role of technology in enabling independent living and a better quality of life for wheelchair users. Another priority was facilitating dialogue with clinicians about a better care experience for the disability community based on health equity principles.

The event showcased the collective brilliance of the disability community, concluding with the StrongWheeled Together awards ceremony which recognized wheelchair users who are trailblazers in their fields. Here are the winners:

ENTREPRENEURSHIP AND INNOVATION: RYAN GEBAUER

— Ryan is the owner of Ryan Realty Group, a real estate sales instructor and a dedicated volunteer and accessible housing advocate in his community.

PERFORMING ARTS: KING

KHAZM — When he's not on the road touring or fulfilling other commitments to hip hop and the disability community, King Khazm is the executive director of 206 Universal, a commissioner on the Seattle Disability Commission and a board member of the Here and Now Project.

SPORTS AND RECREATION:

ARTHUR RENOWITZKY — Arthur is the executive director and a co-founder of the Life Goes On Foundation and plays guard for the Golden State Road Warriors, who won the national championship in the National Wheelchair Basketball Association this past year.

VISUAL ARTS: XI NAN — Xi has exhibited her performance art and sculpture around the world, including at the Venice Biennial. She also participates in numerous nonprofit and philanthropic initiatives to lift up other artists with disabilities.

WRITING: ANJA HERRMAN — Anja has been published by the Reeve Foundation, *Teen Vogue* and the *Huffington Post*, and was part of the inaugural class of EmpowHer Camp, prompting her to write a groundbreaking paper on school districts and students with disabilities during school shootings.

YOUTH LEADERSHIP: GIANA BISNETT — Giana is a young disability advocate who successfully persuaded her school district to purchase Evac-Chairs for its students with disabilities. She is now working to replicate her work and spread her message about disability rights and emergency preparedness around the nation.

Learn more about United Spinal's StrongWheeled Together campaign at unitedspinal.org/strong-wheeled-together.





OWN IT

By Regan Linton

FIGHTING FOR THE EQUIPMENT WE NEED

There once was a time when I looked forward to getting a new wheelchair. It was thrilling to retire my used metal friend that had been scratched, spilled-on, dented and tweaked in its dutiful job of getting me around for at least five years, per insurance rules. I looked forward to finding a shimmering new metal friend with a smooth coat of paint, unbent frames, fresh springy foam, tight hinges, unstripped screws, gunkless casters and axles free of rust — a chair that actually fit my body after several years of the unavoidable shifting of flesh and bones.

As wheelers, we know getting a new chair isn't all about aesthetics. When you use a chair 24/7/365, rain or shine, for all activities, it is crucial to update it for health, productivity and to prevent pain and injury. We want to feel in flow with our chairs, and not be constantly fighting them. But what used to be a fresh beginning has sadly become an unreasonable, disheartening slog.

Between the complex referrals needed just to start getting a chair, the absurd difficulty of scheduling all the needed players, and the unreasonably short appointments, you are exhausted before you even figure out what chair you want. Then, with scarce demo options and limited trial windows, you are on the clock to decide — only to at last make a decision and find out that insurance won't cover it, the supplier can't order it, or everything that works for you is considered "custom" and will cost

you thousands out of pocket. Then it's back to square one — and all this time languishing in equipment that is failing, painful or slowly distorting your body.

Look, if I ordered a bedazzled, gold mini-Porsche built with Magic Eye rims, a diamond seat belt, auto-fireworks, and an insulated Bloody Mary holder for my pet capuchin monkey, then fine, I understand an insurance company saying, "Um, maybe you can cover that."

But appropriate measurements? Lighter materials to prevent torn rotator cuffs? A contoured cushion to prevent deep pressure sores? These should not be "custom." Getting the equipment we need to maximize our health and productivity should be the standard; sadly it has become a privilege.

For transparency's sake, my private insurance recently offered \$1,500 of coverage for a new chair. Given the five years they expect me to use the chair, that works out to \$300 per year — about one-twentieth of what they make off my premiums in a year — for the primary thing I need in order to live. And the supplier could not tell me the full price negotiated with the manufacturer — so that I could pay the difference if I chose — only saying it was too expensive so they couldn't order the chair.

I consider myself an empowered person ... yet this makes me feel helpless. But that was my light bulb: If we accept their crumbs, then we have GIVEN them our power. And I can't accept that.

It's easy to forget about your power

"If I ordered a bedazzled, gold mini-Porsche built with Magic Eye rims, a diamond seat belt, auto-fireworks, and an insulated Bloody Mary holder for my pet capuchin monkey, then fine, I understand an insurance company saying, 'Um, maybe you can cover that.'"

when you're in the small, bunkerlike room of a wheelchair clinic, trying to make decisions before your time runs out. That's when it is crucial to take a breath and channel the intelligence, expertise and voice of our entire disability community. If we just sit back and let the nonwheelers call the shots, we have little right to complain.

The federal government, state governments, insurance companies, manufacturers and suppliers make the decisions over what equipment options we have coverage for. And let's be honest, we have plenty of evidence that our bodies aren't their top priority.

So What Do We Do?

First, don't feel bad if you're not an expert on Medicare and Medicaid policies or you don't know what Complex Rehab Technology or Durable Medical Equipment are. There are plenty of great organizations, like United Spinal Association and the National Coalition for Assistive and Rehab Technology, who can get you up to speed quickly. (See below.)

Second, remember that we know our bodies best, and it is our responsibility to

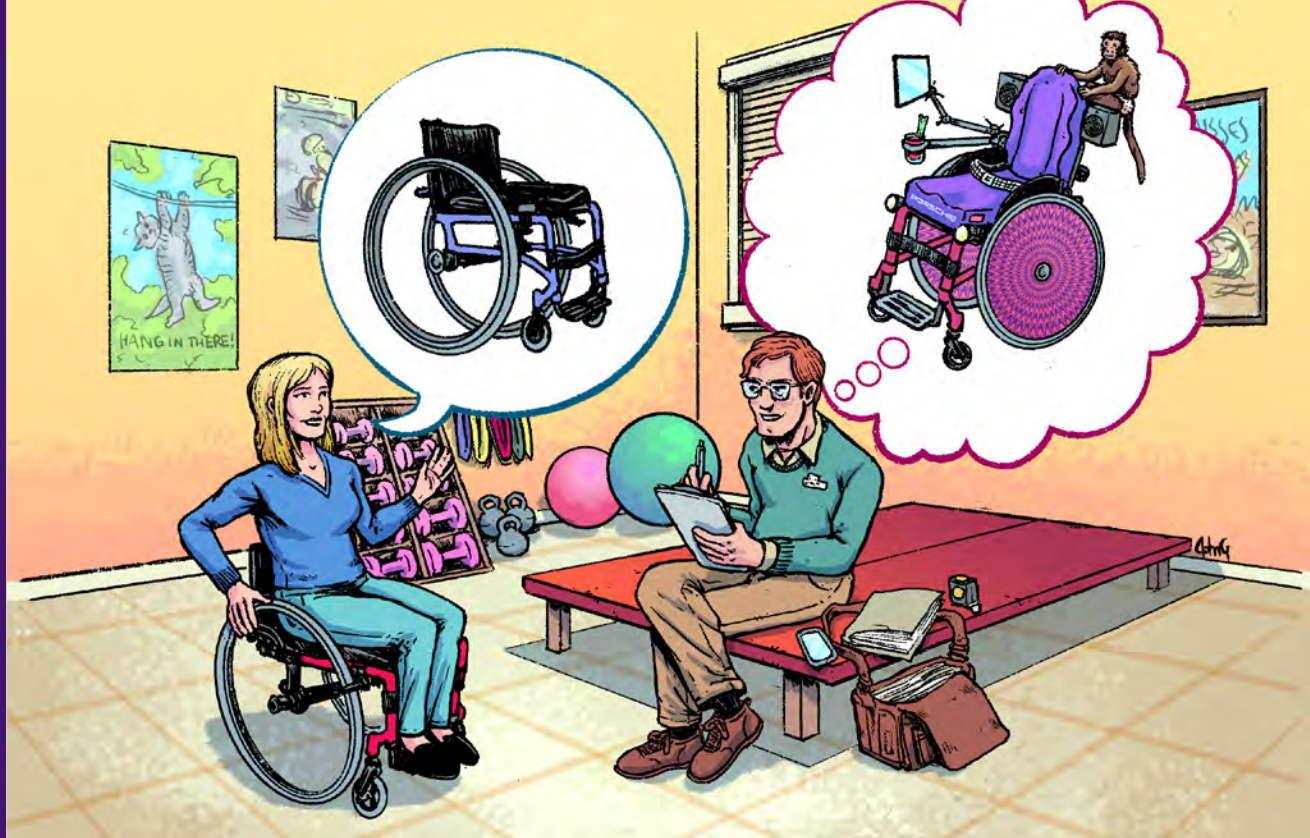


Illustration by John G

get to know our adaptive equipment intimately and to articulate our needs. The reality is, CRT isn't rocket science — it is built to be user-friendly. Watch and learn when a tech works on your chair, and try it yourself at home when you can.

Third, treat the process like a collaboration between you, the physical therapist and the supplier rep, because they are our advocates too. Write down issues and needs, and do not leave until they have been addressed. If, sadly, you have someone who isn't listening to you, respectfully say so, or request a different therapist. It's not about being pissy and entitled but, rather, self-aware and assertive. A good PT or supplier rep will welcome your insights, questions and engagement.

Fourth, remember that we've been disempowered from making decisions about our chairs and getting transparent info about equipment options. How many times have you been told by insurance or a supplier that "we're still working on it," with no specifics? Over time, many of us default to do-it-yourself service and directly pay for parts because of this opaqueness and inefficiency.

Who would have ever imagined

we'd need a LAW to say we have the right to fix our own chairs? But that's exactly what led state Rep. David Ortiz to create Colorado's "Right to Repair" law. Efforts like this are necessary because the system has developed in a way that prioritizes profit and mass production over common sense and personalization.

Finally, communicate. Ask questions, request details. Advocate. Educate. Connect. Learn from others who have been through the process. Make the dreaded call to the insurance company. Write a letter. Tell your family, friends and local newspaper. Go in person to meet with a member of Congress and tell them why this matters. We must take responsibility to act — for ourselves and each other.

I'll be honest, I resist being a squeaky wheel. It gets uncomfortable for many of us, especially in a world where we constantly have to advocate or fight for more than what's offered. It's exhausting. But aside from our own flesh and bones, our equipment might be the most important element in our lives. Squeaking is fighting for our livelihood, our humanity.

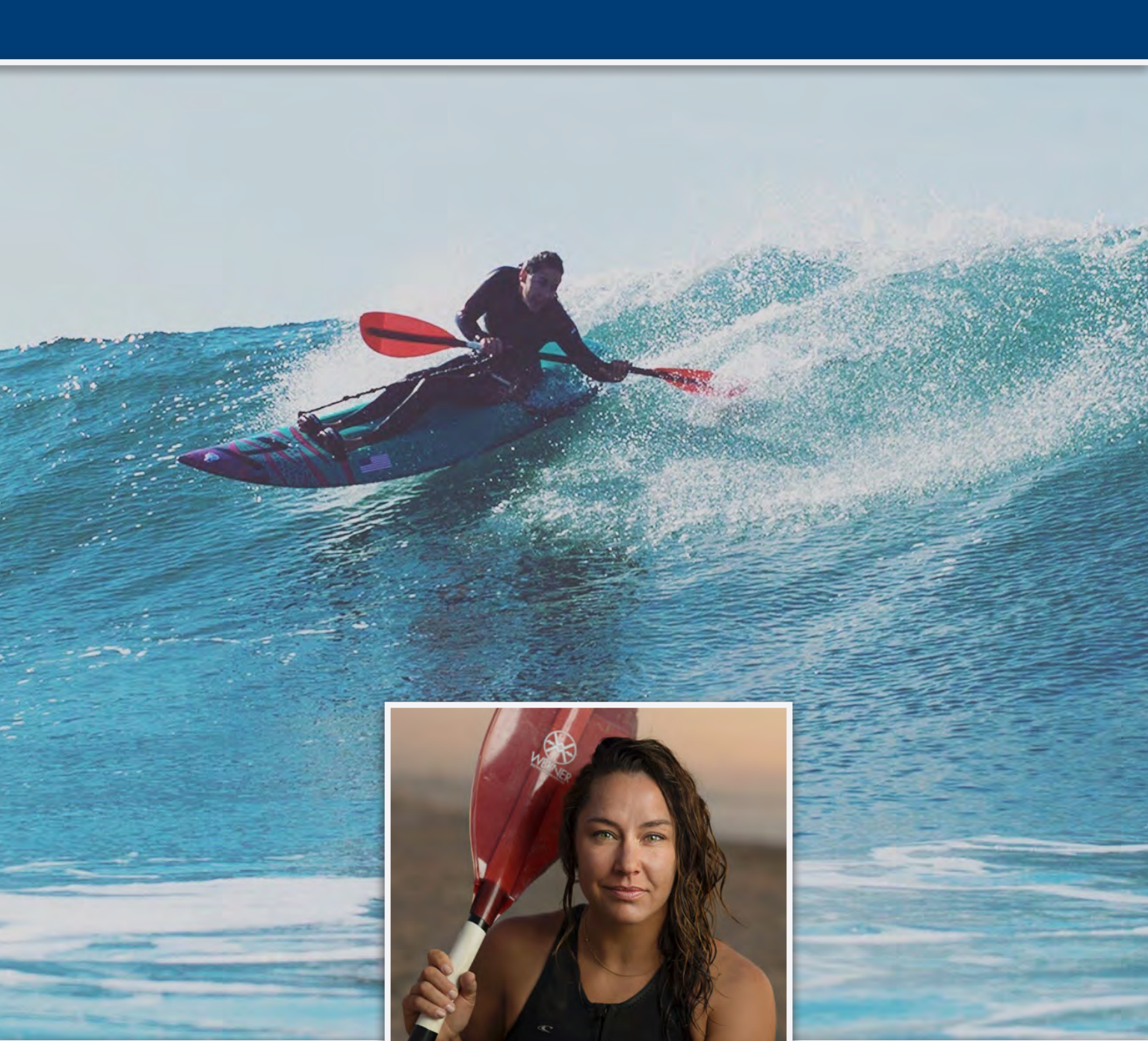
Many of us know that even when we're working with well-intentioned people from outside our community, there are gaps in awareness of how much our issues matter. Together, we must fill that gap. Unless we raise our voices collectively, the people pulling the purse strings will be off in the Caymans with their mini-Porsches and capuchins, and we'll be painfully lumbering through the streets like on a bombed-out Saving Private Ryan steel tank, with derailing casters, shaky backrests, fragmented cushions and asymmetrical frames.

We deserve better.

For now, I'm still waiting patiently for responses about options for my new chair. While I wait, I'm researching CRT efforts, connecting with fellow wheelers about their issues and composing letters to my congresspeople.

Squeak ... squeak ... SQUEAK.

Learn how to advocate for the CRT you need with the resources available at United Spinal and the National Coalition for Assistive and Rehab Technology: unitedspinal.org/wheelchair-resource and ncart.us



ALANA NICHOLS:

Juggling Adaptive Sports, Advocacy,
Motherhood and Media

BY SETH MCBRIDE

It's 2016 and Alana Nichols is bobbing in the swell off the coast of Oceanside, California. She sits atop her waveski — a seat attached to a surfboard that you power with a kayak-style paddle — waiting for her heat to start in the U.S. Open Adaptive Surfing Championship.

There are no women in her category this year, and her all-male competition includes arguably the best waveskier the U.S. has ever seen, Jeff Munson, who Nichols describes as being able “to read waves in binary code.”

The waves at Oceanside are big that day. Heats start with surfers watching the swells come in and making split-second calculations about which ones will turn into a wave they can ride. Nichols starts paddling into her first wave, anticipating a central break that she could surf to the right, her strong side.

She drops in, picking up speed to outrun the break, cutting at the bottom and back up again, carving the face of the wave, making a couple more moves and finally getting spit out in the perfect spot to paddle back into the lineup to search for her next wave. For the whole 20 minutes, Nichols says, “I was in a flow state unlike any other. Every moment, I was actively making the right decisions.”

She nails one of her best surfing sessions, and in doing so, outscores Munson and the rest of the men to win the national championship. “I beat all the boys. It was like a dream come true,” she says.

FINDING COMMUNITY

For anyone else, the day would have been the high point of their athletic career, but Nichols didn't even mention it in our first interview together. We talked about her Paralympic career, winning gold in both wheelchair basketball and alpine skiing. We talked about her sponsorships and advertising campaigns with major corporations like Toyota, Nike and Visa, and her work as a broadcaster for NBC's Tokyo Paralympic coverage. We talked about her husband — Roy Tuscany, who runs the adaptive mountain sports nonprofit High Fives Foundation — and about mom life. When the conversation turned to surfing, it was mostly centered on her young son, Gunnar.

It wasn't until I talked to Tuscany that I heard about the surfing national championship, but it's not because Nichols doesn't care about that day. You can still hear the joy and excitement in her voice when she talks about it. It's just that her resume, sporting and otherwise, is extraordinary — there's a lot to get into.

So, let's start by saying Nichols is like that kid in middle school who could

Prevo, a longtime friend and mentor of Nichols who competed with her on USA Wheelchair Basketball. “She just has this skill that you can't teach.”

For Nichols, though, sports have always been about more than just skill and athleticism. They've been the backbone of her identity for her whole life. Nichols grew up in a nontraditional household. Her father was killed by a



Patty Cisneros Prevo, left, and Nichols celebrate the NWBA national championship in 2011. “She just has this skill that you can't teach,” says Cisneros Prevo.

run faster and hit a baseball farther than everybody else, and do all the pullups in the presidential fitness test without even looking tired. In Nichols' case, instead of becoming an assistant manager at Quiznos, that kid went pro in basketball, ski racing, surfing, and ... sprint kayaking. “She is just so freakishly athletic,” says Patty Cisneros

drunken driver when she was a baby, and she was raised by her grandparents in Farmington, New Mexico. “I know there was a kind of trauma involved in that, but I didn't really acknowledge that until much later in life,” she says. “Sports came into my life to give me what I was missing at that time. Sports really were a safe place and a family of

Photo by Kellie Coughlin



Nichols still skis recreationally but gave up racing for fear that crashes and injuries would limit her long-term mobility.



Nichols with Jeff Munson after she won the U.S. Open Adaptive Surfing Championships in 2016.

people that made me feel welcome and gave me a sense of belonging.”

In high school, Nichols was a two-sport athlete planning to play collegiate softball. “It was my ticket out of my small town,” she says. Then in 2000, at the age of 17, she broke her back while skiing in Colorado. Living in a small town in New Mexico, it took Nichols two years to find adaptive sports, a time she calls the lowest in her life.

The first sport she found was wheelchair basketball, and she threw herself in immediately. Nichols had been going to college in New Mexico, but quickly transferred to the University

of Arizona so she could join their wheelchair basketball team. A year after she’d started playing, Nichols was already attending camps for the U.S. national team, and in 2004 she was selected as an alternate for the Athens Paralympic team.

It was in these early years that she first met Cisneros Prevo, who had been playing on the U.S. team since 1999. The two initially bonded over their shared love of jam bands, and in Cisneros Prevo, Nichols saw a role model. “[Cisneros Prevo was] actually doing the things that she loved, which included at the time, going to bars and flirting with guys. I needed to see that to believe that I could also be a whatever-you-want-to-call-normal 18-year-old girl in college. When I saw her be her best self, it was life-changing for me.”

STRIKING GOLD

Nichols made her Paralympic debut in 2008 and took home a gold medal alongside Cisneros Prevo and the rest of USA women’s wheelchair basketball. Within months of returning from the Paralympics, she moved to Colorado so she could start training in Alpine skiing. Two years later, she competed at the Vancouver Winter Paralympics, winning golds in the downhill and giant slalom, a silver in the super-G and a bronze in the combined. She was the most decorated



Nichols had a nasty crash in the downhill sit-ski event at the Sochi Paralympics, but recovered to win a silver medal in the Super G.

athlete at the 2010 Paralympics and became the first American woman to sit atop the podium in both the Summer and Winter games.

Her sudden, overwhelming success brought attention and opportunity. Nike Inc. reached out with a contract offer. “It was a no-brainer,” she says. Then, at a U.S. Ski Team fundraiser after the 2010 Paralympics, Nichols met a representative from Visa Inc., the credit card giant, and they brought her on as a sponsored athlete. In the lead-up to Vancouver, Nichols had to throw hometown fundraisers to be able to afford training and travel to get to the games. Now, major corporations were asking her to be the face of their brands.

When I ask how she was able to draw the kind of A-list companies that, to that point, had rarely touched Paralympic athletes in their advertising and sponsorship deals, Nichols focuses on external factors. She credits the medals she won, and the fact that she competed in both winter and summer sports, for making her an easier sell for sponsors. Companies could consistently work with a single athlete like her, instead of having to wait for the once-every-four-year exposure window of a typical Olympic/Paralympic cycle.

But if you talk to anyone who’s close with Nichols, external factors are only part of the story. “Once you meet Alana, you’re just drawn to her,” says Cisneros Prevo. “I don’t know anyone who hasn’t been drawn to Alana and the energy she carries around for herself but also for other people.”

Russ Koble, who has worked with

Nichols since 2017 as the senior manager for sports sponsorships at Toyota Motor Corporation, says Nichols makes the sponsor/athlete relationship easy for them. “She’s available. She’s a ball of energy. She is very authentic and genuine in who she is as a person, and she has passion that comes through in everything that she does,” he says.

THE POLYMATH

In 2012, Nichols again competed in wheelchair basketball at the London Paralympics, where the USA women’s team took home a disappointing fourth place following a heartbreaking, controversial finish in the semifinal game.

After London, Nichols returned to skiing. During training for the 2014 Sochi Paralympics, she had a nasty crash on the slopes of Mt. Hood that left one arm in a sling for months. She recovered in time for Sochi, competed and took another hard fall in the high-speed super-G event. She was able to continue and won a silver medal in the downhill, but the crashes made her reassess her commitment to ski racing. “It just started



Appearing on Conan O'Brien in 2014, Nichols pranked the host by switching her “training footage” for something much more ... ridiculous. Watch the video at bit.ly/3LWpeNN

to get really wearing — the crashes, the injuries and the surgeries,” she says. “It felt like, naturally, now it’s time to turn the page. What’s next?”

It didn’t take long for Nichols to find next. She traveled to Hawaii after the Sochi Games and went surfing for the first time with a local nonprofit called AccesSurf. Like with wheelchair basketball, she was hooked immediately and went all in on surfing. “I was like, great, now I gotta move

to California,” she says. But as a brand ambassador for big-name companies, much of the value of her sponsorships was tied to the media frenzy that surrounds the Olympic/Paralympic games, and adaptive surfing wasn’t a Paralympic sport. So, she also had to figure out how to stay a Paralympic athlete.

At the same time Nichols started surfing, she had also met a sprint kayaking coach. Sprint kayaking, or paracanoe,

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Alana's GEAR PICKS

SUNGLASSES: SMITH BOBCAT (\$219)

Nichols is sponsored by Smith Optics and one of her favorite models is the Bobcat — made for mountain biking and snow sports — because they're light and stay on your face no matter how fast you're going. Plus, they've got style for everyday wear. Huge lenses give you goggle-like protection, and Smith's Chromapop coating "just makes everything look fun," she says.



EVERYDAY WHEELCHAIR: HANDS ON CONCEPTS RIGID SERIES (\$5,500-\$6,500, DEPENDING ON OPTIONS)

This small, San Diego-based manufacturer makes custom titanium wheelchairs. Measuring, building and fitting is all done in collaboration with the chair builders. Everything is fixed, so you need to be sure you get your geometry right. But the lack of adjustability makes for a frame that's superlight and durable. Nichols has had her latest frame for more than four years and says the only maintenance she's had to do was removing hair from casters and replacing caster wheels and bearings.



TIRES: SCHWALBE RIGHTRUN (\$22.50)

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POWER ASSIST: FIREFLY 2.5 ELECTRIC SCOOTER ATTACHMENT (\$2,649)

The Firefly is an attachable, trike-style power assist. Nichols got one recently and has been loving it. Situations that were a pain before in her manual chair — like navigating an outdoor food festival with her son on her lap and a drink in hand — are much more enjoyable with one-handed power and a big wheel up front to smooth out those dreaded extension cord covers.



SKI: NISSIN MONOSKI

This monoski from Japanese manufacturer Nissin works for everyone from a world-class racer to a weekend warrior. Nichols likes it because it's strong, responsive and offers a ton of adjustability, which is helpful whether you're trying to optimize your performance or you're a newbie still figuring out what positioning works best for you. Nichols often swaps out her skis, but one of her favorites is Head's Joy, a women-specific all-mountain ski that's extremely lightweight and nimble to turn.

SURFBOARD: MACSKI WAVESKI

Nichols rides a board custom-made by world-champion waveskier Ian Macleod. Fun sidenote: Waveskiing was started by nondisabled surfers who needed a way to keep their limbs out of the water while paddling into the shark-infested waters of South Africa. Nichols says her boards have progressively gotten more aggressive over the years, less stable but more agile. She named her current board the "party board" on account of its neon color scheme and pink flamingos decorating the base.



happens to be a Paralympic event. Problem solved. Nichols threw herself into two brand-new sports at the same time. “I might have a splash of ADHD, like lack of focus,” she says. “But I also love a good challenge. ... I wouldn’t say I mastered basketball. I wouldn’t say that I mastered skiing. I certainly wouldn’t say that I mastered sprint kayaking. But it was all about the chase of that [mastery]. I really wanted to get there.”

Trying new sports has always felt natural for Nichols — she describes it as being open to the flow of what life is throwing at her. “Her big thing is, just try,” says Tuscany. “That’s always been one of the coolest things that I’ve seen her do is whether it’s a dinner or a speaking engagement or whatever it is, it’s always just try. I think when you use that mentality, it opens up doors.”

Nichols says that the constant exposure to new challenges does make navigating them easier. “You get better at learning because you know you’re supposed to suck at something first,” she says. “Sucking at something is the first step to sort of being good at something.”

“Sucking at something is the first step to sort of being good at something.”

Unlike the rest of us, though, Nichols goes from sucking, to sort of good, to really good, to better than almost anyone else in the world in the blink of an eye. The second time Nichols went surfing, she won her division at Duke’s OceanFest, in Waikiki, Hawaii, one of the biggest contests on the adaptive surfing calendar, and a year later finished seventh in an otherwise all-male field at the International Surfing Association World Para Surfing Championship. Meanwhile, less than two years after picking up the sport, she qualified in sprint kayaking for her fifth Paralympics. The 2016 Rio Games would be her last as an athlete, but if anything, her life seemed to speed up from there.

ADVOCATE, MOM AND TV COMMENTATOR

Nichols now lives in Reno, Nevada, near where the High Fives Foundation is

based, and streams in for an interview from her family home in New Mexico. Toward the end of our chat, Gunnar, now 3 1/2, runs into the room in Batman pajamas and proceeds to wipe Cheetos dust on the sleeve of Nichols’ cream-colored sweater. “Gunnar!” she says. “Are you eating Cheetos? It’s only 10:00 in the morning.” She wipes herself off, and after a brief discussion of the awesomeness of Batman, manages to shoo him out of the room. She handles it like someone who has plenty of experience with their child interrupting various work obligations.

Shortly after Gunnar was born, in 2019, Nichols was elected president of the Women’s Sports Foundation, a nonprofit founded in 1974 by tennis icon Billy Jean King to provide more opportunities for women and girls in sports and in life. Nichols had been on the WSF board of directors for six years, and her post as president put her



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Nichols has passed on her love of surfing to her son, Gunnar. Today, much of her work is to spread awareness of the power of adaptive sports.



in the rare position to lead discussions about equity and advancement from the perspective of a disabled female athlete who was also a new mom.

Nichols and Tuscany are both active parents with busy lives who travel a lot. Nichols has toted Gunnar cross-country countless times to foundation galas, advocacy events, surfing competitions, media obligations and just about everything else you can think of. It's not easy, but she has a lot of experience to fall back on. "All those hard days, the never-ending amounts of stress I put my body under, kind of prepared me to be a mom," she says.

One trip she didn't take Gunnar on was to Tokyo and her sixth Paralympic Games, this time as a broadcaster for NBC. "I'm kind of cliché and a bit basic, because I'm an athlete who retired, tried her hand at and is still dabbling in broadcasting," says Nichols. This might actually be true if Nichols was some nondisabled former football star. But television opportunities for female athletes have only started to open up in the past few years and are still nowhere

near as common as they are for male athletes. Nichols, a disabled woman, appearing on live national broadcasts as a studio presence and sideline reporter for wheelchair basketball and rugby was groundbreaking for authentic disability representation.

As Nichols pursues her career and her mission to raise the profile of adaptive sports, she hopes society can start to move past the typical "overcoming disability" trope that anchors much of the storytelling in mainstream media. Nichols says it was only recently that she started to unpack the ableism that her own thoughts about wheelchair sports were rooted in. "It was very much, 'Don't feel bad for me. I'm playing wheelchair basketball — I'm doing all these cool things,'" she says.

It took years for Nichols to start moving past the mindset where physical accomplishment is the only path toward "normal." As her perspective has broadened, Nichols has gotten more sophisticated in crafting her own narrative, whether in interviews for major publications like *The New*

York Times or the *Today Show* website, or when giving a studio monologue on NBC. She tries to steer away from the superathlete narrative, instead highlighting both the challenges and the joys of her life as a disabled woman outside of sports. "I think that wheelchair sports and adaptive athletics are a great starting point for conversations around disability, but it's one small aspect of the lived experience of so many individuals with disabilities," she says. "For people with disabilities who are not elite athletes, I can see it being really frustrating that [sport is often] the only representation."

SHARING THE STROKE

One of Nichols' best days since Gunnar was born came when he was about 3 years old. The family was vacationing on the west coast of Maui. Nichols and Tuscany were going to get in a quick surfing session while Gunnar played with a good family friend on the beach. But when they paddled out, Gunnar started screaming and crying. "He didn't care that I was out there. He didn't care that his dad was out there. He wanted to surf, and we left him on the beach," she says.

Nichols and Tuscany kept paddling, knowing Gunnar would get over it soon enough. Meanwhile Gunnar was negotiating with the family friend, himself an experienced surfer, to take him out in the water. "The next thing you know, Roy and I are sitting in the lineup and here comes Gunnar paddling up with our friend," she says. The friend got Gunnar on a few waves and soon the blonde toddler was grinning and laughing. "He just had such a good time," she says. "Something about the fact that he decided on his own what he wanted to do and figured out a way to make it happen, ... it made my whole life."

For Nichols, seeing how catching a wave — or skiing a new run, or balling on the court with your friends — can light up a person's life has given her purpose as she continues to flow into new phases of her own life. These days, much of her work outside of being a mom revolves around growing the adaptive sports scene. Nichols is on the athletes' commission for the 2028 Los Angeles Games, where she hopes Paralympic sport can make the jump to prime time,



like it did in Britain when London hosted the 2012 Games.

She's also on the board of the International Surfing Association, where's she's active in starting a professional adaptive tour and making surfing a Paralympic event. She still competes when her busy schedule allows. Every year there are new events and riders, a growing community to share the stoke with. "It's so cool to watch [a sport] that's growing up right before your eyes, kind of like a toddler," she says.

"For people with disabilities who are not elite athletes, I can see it being really frustrating that sport is often the only representation. It's one small aspect of the lived experience of so many individuals with disabilities," says Nichols, pictured with her husband, Roy, and son, Gunnar.

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FITNESS & SPORTS

Wheely-X: Peloton for Wheelchair Users?

BY MIKE FRANZ

I think that most wheelchair users would agree with me that doing at-home cardio workouts can get a little boring. No matter how I try to change it up, every workout ends up feeling the same. My favorite way to get exercise is to push outside, but the Michigan weather does not cooperate as often as I would like. Recently I had the opportunity to try the Wheely-X, a new fitness option from South Korea-based Kangsters that aims to do for wheelchair users what Peloton did for bicycle riders.

With an elegant design and the option of Bluetooth sensors that track your every push and allow you to use your wheelchair like a controller for proprietary training software and videogames, the Wheely-X has the potential to be much more than a wheelchair treadmill. But \$2,095 — the cost of the base unit — is a lot to pay for potential. I tested the Wheely-X out to see if it is worth it.

Kangsters currently offers three models, the Wheely-X Train, Wheely-X Data and Wheely-X Play, that share the same footprint but differ in terms of connectivity and interactivity. For \$500 more, the Data adds a Bluetooth sensor that allows you to track your pushing in a free app. The Wheely-X Play lets users play three video games designed for the system but is currently only available for facilities. I tested the Wheely-X Data.

The Wheely-X comes in a single large box and weighs just over 60 pounds. As a C6 quad, the size and weight kept me from unpacking and assembling it myself, but a lower quad or para should be able to handle the assembly process, assuming they can get the box where they want it and transfer to the floor. The ramps and rollers fit together cleanly and feel sturdy once assembled. The whole process took my aide about 20 minutes.

Once the hardware is assembled, you can download the Wheely-X app, available for both iOS and Android devices, and connect the battery powered sensors via Bluetooth. [Editor's Note: The early version tested relied on two small Bluetooth transmitters. Kangsters has replaced those with the Wheely Hub, a Bluetooth box that they

promise is more stable and reliable.] The Wheely-X has a small footprint, about 15 square feet, and is easy to fold up and store, making it an appealing option for people with limited space.

Using the Wheely-X is a straightforward process. The ramps that are attached to the base have a manageable slope, making it easy to roll up backwards and into place on the rollers.



PLAY VIDEO GAMES USING YOUR WHEELCHAIR AS A CONTROLLER

The app that comes with the Wheely-X's Bluetooth connected versions makes it easy and fun to track your pushing progress, but the system's three proprietary games allow for a deeper interactive experience. Unfortunately, for now, the games are only available on the Play model for facilities. Mike Franz did not have access to the games for his review, but I got to watch three different users try each of the three games — Ant Journey, Wheelchair Racing and Balance Racing.

Each game allows a Wheely-X user to control their character by pushing their chair. As simple as that may sound, watching the enthusiastic reactions of the users as they saw their onscreen avatars responding to how they pushed their chairs made me think the developers may be on to something if they can expand on and improve the current offerings.

In Ant Journey, you move an ant across a series of tiles, searching for hidden tiles that break and allow you down to the next level. In Wheelchair Racing, you line up on a track in a racing chair alongside other racers and sprint to the finish, and Balance Racing tests your pushing form as you try to keep a bike upright on a course.

It's easy to envision and a fun, quality workout racing your friend or strangers, but for now, multiplayer requires the Wheely-X devices to be connected over local Wi-Fi. That means you'd need multiple units in the same place, which is unlikely outside a rehab or gym setting. The developers say a gaming package will be available for all owners by July 2024. Additionally, they are working on expanding connectivity options and hope to someday be able to allow users to connect remotely.

—IAN RUDER

Once on the rollers, the Wheely-X has safety locks that attach to the wheelchair much like tiedowns you would find in a vehicle. The hooks on the tiedowns were not big enough to latch onto the thicker parts of my wheelchair frame as instructed, but they were able to hook on to the part of the frame where the casters are attached. Tightening the locks requires you to pull on the attached rope, which could be tricky for users with limited hand function but should be doable. After the safety locks are in place, just unlock the brakes and start pushing.

I was skeptical about how it would feel to push my wheelchair on the Wheely-X, but it feels smooth and surprisingly resistance-free. As a quad who uses power assist wheels, I didn't experience any unnecessary stress on my arms and shoulders while pushing. As a word of caution: It is important to wear the same gloves that you would wear when pushing your wheelchair for a workout. I wore a pair of gloves that were shorter than the ones I use

to push outside and ended up with a nasty blister on my wrist.

The best feature of the Wheely-X that I tested is the app that pairs with the sensors and tracks workout data. The app keeps track of elapsed time, speed, distance traveled, RPMs, and calories burned. It also allows you to track each wheel individually so you can see how efficiently you are pushing. For users in rehab or those who want to refine their pushing, the feedback could be a boon.

The app stores the data from each workout so that progress can be tracked over time, and it also has several programs that can be used for different workouts. You can set interval training programs based on time or distance, plus there are sprint training, endurance training modes, and a free training mode to push at your own pace. The app also has a course training mode that takes you through a workout led by a trainer.

Unfortunately, the demo unit I received had a problem with one of the sensors that prevented me from

trying the course training mode. There are many videos provided on the app that can take you through a variety of workouts as well. As of the time I am writing this, the text on the app is partially in English and partially in Korean, though the app is intuitive to use, and the language was not an issue for me.

The workouts I did during my time with the Wheely-X were very effective from a cardio point of view. Most of the time when I work out, it is difficult to elevate my heart rate much higher than 100 bpm. With the Wheely-X I could get my heart rate up to 115 to 120 bpm at times. Doing cardio as a quad can be really challenging, but the Wheely-X is among the best cardio machines I have used.

The Wheely-X is a solid option for all manual wheelchair users from beginners looking to build strength to athletes training to improve their speed and stamina. The Wheely-X would also be great for those who live in areas where the weather and terrain

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“Doing cardio as a quad can be really challenging, but the Wheely-X is among the best cardio machines I have used.”

—Mike Franz

are not conducive to pushing a wheelchair outside year-round.

The cardio benefits of the Wheely-X are enough to consider purchasing one, but with the bare bones Train model listing at \$2,095, the price is very high. If Kangsters can expand the games and interactive options (see sidebar on page TK), it would be more in line with something like Peloton, and the cost might be more justifiable. Right now, it is a quality piece of workout equipment with more features than are typically available, but it doesn't yet offer the same experience as mainstream interactive fitness machines.

For more information, please visit wheely-x.com.



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United Spinal CEO Vincenzo Piscopo flew off a stage after he couldn't get his wireless SmartDrive controller to respond. He has ordered a wired controller.



MOBILITY & SEATING

Controller Recall Puts SmartDrive Safety in the Spotlight

BY SETH MCBRIDE

It was like a scene out of a movie. Vincenzo Piscopo, the CEO of United Spinal Association, was about to give a speech on the final day of the organization's annual Roll on Capitol Hill. He rolled up a ramp to the stage with the help of a Permobil SmartDrive MX2+ power-assist device. But when he tried to slow the SmartDrive after ascending the ramp, it wouldn't decelerate. It pushed him across the stage as he repeatedly tried to stop it, and eventually forced him off the stage. He crashed into a 10-foot-high curtain before falling 3 feet to the ground and pulling the curtain down on top of him. "It just happened so quickly," Piscopo says.

People screamed and rushed the stage. Fortunately, Piscopo was OK — the drape helped arrest his fall and stopped him from hitting his head. He injured his wrist but otherwise escaped serious injury. After dusting himself off, he was able to get back to his speech, making a joke about starting with a bang. For those of us in attendance, it was good to see he was OK, but it was clear the mishap could have been much worse.

I flashed back to a moment when I was testing an earlier-generation SmartDrive. I was pushing along a city sidewalk and couldn't get the unit to stop. It pushed me into a stop sign, up onto my front casters, where the unit then rotated on my axle and jammed underneath my chair. I was stuck until I transferred to the ground and wrestled the SmartDrive back into place. As with Piscopo, my incident could have been worse. I was lucky the stop sign was there, otherwise I would've been pushed off the curb onto a busy city street.

Incidents like these bring up many questions. Was there something wrong with Piscopo's specific unit? How often does something like this happen? Is a Bluetooth connection really a good idea for a power assist device? And why is there no easily accessible kill switch on the SmartDrive?

THE RECALL

To answer my first question about any problems with Piscopo's specific unit, I talked with Richard Foshee and Au-

dra Watt, who both work in marketing at Permobil. The short answer is yes: Piscopo's SmartDrive, or more specifically the smartwatch that he was using to control the unit, had a known software malfunction that could cause the unit to not respond to his attempts in stopping it. Since early 2022, Permobil has received 34 other complaints from users who had the same failure-to-disengage issue with watches sold with SmartDrive units from May 2019 to Feb. 10, 2023. (The watches may be branded as the Mobvoi TicWatch E2, the PushTracker E2 or the PushTracker E3.) "Anytime that we hear of a product complaint, we are required and obligated to respond very quickly, and not only document the issues but do a full investigation," says Foshee.

A recall of SmartDrive's wireless controller raises questions about operating a mobility device via Bluetooth. The default configuration now uses a wired controller.

According to Watt, in "most instances, the failure could not be duplicated during the complaint investigations and [the] root cause was not found. In early 2023, through unrelated design and development activities, Permobil identified a software issue with the [SmartDrive] MX2+ application operating on Android Wear OS [smartwatch operating system] that was [the] cause of the previous customer complaints."

They completed an investigation of that root cause in early April 2023, and on May 10 Permobil issued what they call a "voluntary field correction" — the FDA calls it a product recall — on

affected units, numbering 6,196 sold worldwide. According to the recall, when "multiple processes are running on the watch's Central Processing Unit, ... the application may fail unexpectedly. If this happens, the motor on the power assist device continues to run and the user may not be able to stop the device using tap gestures."

This is likely what happened to Piscopo. The fix for his specific issue is easy: a software update. The problem was, Piscopo didn't receive notice of the recall until July 12, three weeks after his incident. "A bit too late," he says.

Foshee with Permobil says that users could have had delays getting their notices because of the steps involved: Permobil had to inform dealers, then dealers had to look through their records and forward the notice to customers who purchased the product. Foshee says anyone who has questions or concerns about whether they are affected, or who needs assistance correcting their unit, can either contact their provider directly, call Permobil's customer experience team at 800/736-0925, or visit Permobil's support page.

THE PROBLEM

To find out about my second question — how often other users have control issues — I turned to Erin Gildner, the director of chapter relations for United Spinal. It's Gildner's job to coordinate with United Spinal's 47 member-chapters across the county. She knows a lot of wheelchair users. Gildner was in the audience when Piscopo flew off the stage, and as it turns out, had her own incident with a SmartDrive when she first bought one. "I was on a trip with my family, excited to be using the SmartDrive because I was going to be doing a lot of pushing and I didn't want to wear myself out just getting around," she says. "But it wouldn't always respond to me, and at one point it kept pushing me toward a mom and toddler while I tried to stop it. Fortunately, I didn't run into them but that's only because someone grabbed the toddler and pulled her out of the way."

The incident left her shaken, and the SmartDrive has been sitting in



Bob Ness, a C6 quad, stops his SmartDrive well in advance of any intersections in case the device doesn't immediately respond to his gestures, and he always turns it off before crossing streets or navigating crowded areas.

her garage ever since. “I don’t feel comfortable using it,” she says. “If you talk to other wheelchair users who have a SmartDrive, almost everyone has a story about an incident with it.”

Gildner had the original PushTracker, different from the E2 model Piscopo was using that was subject to the recall. I was using the same, older-style device during my stop sign incident. A Facebook post in an SCI group with over 10,000 members yielded dozens of responses from users who had issues with the SmartDrive not responding to physical cues or starting without warning. Respondents experienced a variety of connection issues, including with the older-style wrist device and the Apple Watch, which can also control a SmartDrive.

I asked the Permobil reps whether they knew of any issues with controllers other than the TicWatch E2/PushTracker E2. Watt says that the newer PushTracker E3 operated on the same Wear OS system as the E2 model and is also subject to the recall. Additionally, Permobil did identify issues with the first PushTracker, which was the original Bluetooth controller developed by Max Mobility, noting “limitations with its hardware and Bluetooth connectivity that could cause a lost connection, but the

SmartDrive was designed to shut off if this happened.”

Mine certainly didn’t shut off when it pushed me into a stop sign, but I also didn’t file a complaint with Max Mobility, which owned SmartDrive at the time. It was hard to tell whether it was user error, or the device had actually malfunctioned, or if I just needed more experience operating the unit in tight quarters.

Still, even if a controller doesn’t have a specific fault like the one leading to the recall, it’s worth asking whether a Blue-



Bob Vogel says it's important to master the device in a safe environment — like when you learn to drive a car.

tooth-reliant wearable device can maintain a sufficiently stable connection for controlling your power of movement. Many SmartDrive users I spoke with have moved away from a wristwatch being their only connection, and some that do use only a Bluetooth controller will make sure to turn the unit off around busy streets or other locations where an unresponsive or hyperresponsive unit could cause serious damage.

THE LEARNING CURVE

Bob Vogel, a paraplegic and longtime user of the SmartDrive, loves his power assist unit. “It has saved my shoulders and I’m grateful for it,” he says. But it’s something he’s had to fine-tune to be able to use safely. “I’ve found in the early days that it would just take off when I was in the middle of telling an animated story,” he says. “Thank goodness I wasn’t on a street corner or a stage or anything like that.”

Vogel says he’s found that the watch will often have issues, mainly failing to engage the unit, when he’s in a busy public place like an event center, where there are a lot of people and a lot of Bluetooth devices being used. But he says that most of his early incidents with the SmartDrive were due to operator error. “There absolutely is a learning curve,”

he says. For manual wheelchair users who aren’t used to operating a powered device, it is imperative to learn how to use it and iron out any potential issues in a safe environment first. “It’s a bit like learning how to drive a car,” he says. He recommends lowering the SmartDrive speed when first learning to use it, and he keeps the sensitivity settings of his unit set low, so that it takes more forceful movements to engage the motor.

But even with proper training, having the control unit attached to your wrist can cause problems. Piscopo has owned his SmartDrive for a few years and uses it regularly while traveling. He normally turns the unit off with his watch whenever he stops somewhere, but it’s easy to forget. Not

long before Piscopo was pushed offstage at ROCH, he was giving another talk when the unit pushed him into a table, knocking off some drinking glasses. He says that nearly every time he uses his SmartDrive, it has issues of starting when he doesn't want it to. "I talk with my hands," he says. "It's really hard to stop being Italian."

A BETTER WAY FORWARD?

My third question — why the SmartDrive doesn't have an easily accessible kill switch — turns out to be moot. It does now. In the past few years, Permobil has released a few different wired-controller options.

There is the SpeedControl Dial, basically a small wheel that mounts on your wheelchair frame at about cushion-level. You rotate it forward to start the SmartDrive, keep rolling it to go faster, and then roll it in reverse to slow and stop the unit. One Facebook responder said she had issues all the time with controlling her SmartDrive by the TicWatch and Apple Watch. She switched to the SpeedControl Dial, which she calls her "only reliable means of using it."

The speed dial isn't for everyone though. Bob Ness, a C6 quadriplegic who lives in Chicago and produced the video embedded in this article, says he was offered the SpeedControl Dial by his durable medical equipment supplier. "Because of where it mounts, I couldn't put it on," he says. "It blocked the part of my frame that I use to transfer."

Other wired options include SwitchControl, which offers two programmable buttons. It attaches to your chair's frame and is much smaller than the SpeedControl Dial. In the most common setting, you press the button once to turn the unit on; press and hold to bring the SmartDrive up to the maximum speed you've set; and press again to disengage the motor. As one Facebook responder put it: "Get the physical switch as a backup. Even if you're using the watch, the physical button will override and stop. You'll have to relink [the watch], but that's what I do."

Permobil also has a Buddy Button, similar to the SwitchControl but with



WATCH THE VIDEO

About 3 minutes. Key moments:

00:30 Apple Watch compatibility

00:58 Operation (hand gestures)

02:15 Approaching intersections

newmobility.com/controller-recall-puts-smartdrive-safety-in-the-spotlight

a larger button that is easier to operate with limited hand function.

As of last year, Permobil made the SpeedControl Dial and SwitchControl buttons the no-charge options for controlling the SmartDrive. Now you must pay for the watch separately, or use an Apple or Samsung watch if you have one. You can also upgrade to a SpeedControl button with a mono jack, that you can use with other adaptive switches. The wired controllers come with zip ties or Velcro straps for anyone who wants to be able to take the wires off their chair during travel.

After her incident with the toddler, Gildner bought a SMOOV one power-assist device similar to the SmartDrive, with a wired, wheel-style controller. "I love the predictability and safety that comes with having a speed dial," she says. The SMOOV one will also automatically shut off the motor if you brake using your handrims, which Gildner says comes in handy when she doesn't have time to reach the dial. Now that a speed dial is available with the SmartDrive, Gildner says she'd consider switching back. "[The SmartDrive] is more agile, lighter and easier to use when attached to your chair [and] not powered on," she says. "If the speed dial solves the problem of unpredictability, that would be a game-changer."

Piscopo agrees. He's getting a SpeedControl Dial and doesn't plan on using his SmartDrive until he has the wired controller installed. He saw firsthand how dangerous a lack of control can be, and he isn't eager to test his luck again.

This story generated a tremendous response online. See the next page for a selection of reader comments.



Erin Gildner switched to the SMOOV one power-assist device but would consider switching back to a SmartDrive with a wired SpeedControl Dial.

SmartDrive: Reader Insights and Tips

STILL TRYING TO MAKE IT WORK FOR THE FREEDOM IT PROVIDES

I used to love the freedom it gave me to use my chair for cardio exercise and getting around a university campus for my job. But I've had enough problems with it that I use it less and less.

The TicWatch has been awful for the two years I have had my SmartDrive. It malfunctions constantly, takes at least 5-10 seconds to respond to ANY screen



Photo by Ace Jones-Taylor

command, and at this point I have to do factory resets at least once a month. The only things I can download are the SmartDrive app and the PushTracker app. Even then, there have been at least two times where I was depending on it to work and it was unresponsive, stranding me in a place I was only willing to go in the first place with the help of my SmartDrive.

I've also had the unit flip upside down under my chair, which was terrifying. Also, the tech who set it up for me originally didn't secure the axle brace for my folding frame chair, and it used to bump completely off my chair on a regular basis. I was always checking to make sure it was still attached and not

just sitting in the middle of the road half a mile behind me. And once I'd retrieved it, it was super hard to reattach it myself without standing up from my chair and bending over to reattach it. I'm lucky to be an ambulatory wheelchair user who currently has the strength and balance to do that, instead of needing to transfer to another chair or sit on the ground to reattach it. But I also hate dealing with the ableism of strangers who witness me standing up and accuse me of faking my disability just because I can take a few steps. I will deal with ableism to retrieve an expensive piece of equipment that fell off in the middle of the road. But not everyone has the option to reattach it without help. Either way, frustrating and so embarrassing.

I also find that the wired switch alternatives are hard to figure out. I had to have a tech spend two hours on customer support reworking the settings, and even though I took a lot of notes, I get nervous I might mess it up. I find you have to press the buttons pretty hard to get them to work. I wish I could afford the new dial — it seems the safest option. [Editor: The SpeedControl Dial sells for \$206 at online retailers.]

The worst experience I had with my SmartDrive was when the button zipped to the frame of my folding chair got turned around and, unbeknownst to me, was being constantly pressed down by the pressure of the frame. I was out for a walk with my partner, intending to use the TicWatch to control it, but I attached the wired option as a backup. Thank God my partner was there, because the SmartDrive started picking up speed and crashed me into a stranger's yard, flipping the chair completely.

I was miraculously unhurt, but as someone with FD/MAS and a fragile skeleton, I am under no illusions about how much the SmartDrive could hurt me. Just this weekend I wanted to take it to the Austin Pride March, but even after spending several hours wrestling with a factory reset and the upgrade to the TicWatch, I couldn't get it to work and ended up leaving it home even

though I really could've used it to navigate a massive hill.

While writing this, I was just interrupted by a phone call from Permobil, trying to make sure I'm aware of all this. They offered to do customer service with me on the watch, and I am willing to try, but at this point I just don't know how I can trust the TicWatch, or even the Apple Watch. Unless I find a way to save up for the expensive dial, I don't know if this device is worth the risk. Which is a shame, because it was a wonderful, liberating thing to know I could go miles on my own, if I had to.

— LINDSEY CARMICHAEL

MISS THE ORIGINAL

The original SmartDrive (MX1) was great — it had a battery under the seat, which was not ideal, but it was wired, did not require a watch, and it started and stopped when I braked with the handrims, which was super user-friendly. The MX2 is unpredictable, dangerous and difficult to use. It is also inconvenient to have to charge both the watch and the SmartDrive.

— I. HANSON

I CHOSE POWER-ASSIST WHEELS

I tried a SmartDrive once (on its slowest setting, and in a hallway thankfully) and also couldn't get it to stop. Meanwhile, E-Fix/E-Motion wheels have served me just as well over the years at saving my shoulders and being relatively easily removed. Never an issue with those.

— MARK

ACCIDENT BARELY AVERTED

I also almost had an accident at a red light. I was waiting for the green light, and suddenly the smart drive started. I was able to turn immediately to the right then stop the unit with double tap. This kind of device should not be authorized to be without [a wired connection].

— GABRIEL GOLDBERG

APPLE WATCH FIXED ISSUES

I've had a number of experiences where it's tried to start itself as I've been at my desk, obviously misinterpreting wrist

movements for a “double tap to go.” That was with using the old, Max Mobility supplied PushTracker (yes, mine is that old — still going strong, though!).

Since moving to the Apple Watch to control it, I now just have a specific “face” for the SmartDrive — so if I’m on a different face without a complication for the SmartDrive’s control, it can’t false start. I’ve never had the issue where it hasn’t stopped when I’ve asked it to, though. That’s a little scary to read about.

— ELIZABETH FERRIS

UPGRADE YOUR WATCH, BE CAREFUL WITH YOUR HANDS, AND HAVE A BACKUP PLAN

I have been using the SmartDrive for some years now, and I find it excellent because of the power it has to push you up steep ramps. Also as a paraplegic person, I can fit it on the wheelchair while [in my chair] without help. I had some connection problems in the past, and I decided to upgrade to the Tic-Watch Pro 3, and since then I’ve had no problems. However, I have trained myself so that in case of emergency I access the SmartDrive on/off button to switch it off. It’s very important, though, to remember not to move our hands while talking at a level that will start the SmartDrive! A few times I forgot and moved my hand rapidly while talking and switched it on, but I switched it off before causing problems.

— DIMITRIS LAMBRIANIDES

SMOOV WAS RIGHT FOR ME

I tested both the Smoov and SmartDrive in rehab and decided to go with the Smoov. I’ve used it now for over a year without incident. It’s been a game-changer for me — I have a neuromuscular disease and cannot wheel up inclines or long distances — and the device is easy to use, and I feel safe with the custom settings (the app allowed me to customize top speed, acceleration, torque, etc.).

— TONI J

IS BLUETOOTH THE CULPRIT?

I both love and loathe my SmartDrive. Such potential, but so many problems with operating via both PushTracker and Apple Watch. This includes diffi-

SPEEDCONTROL DIAL WORKS

IT WOULD BE DIFFICULT for me to count the number of times the SmartDrive didn’t stop and I ran into walls, tables and people. And then there are the times when the drive flipped on the axle and jammed underneath my seat. Until the recall, I thought it was operator error on my part. It’s scary when this happens, especially when the drive flips, as it is nearly impossible for me to move out of my chair and put the drive in the correct position on the axle. I now use the Speed Control Drive which is a much better way to control the device.

— CLAUDIA GAROFALO

I HAD THE WATCH FOR YEARS and hated it! It wouldn’t engage when I needed it and can’t recall how many times I hit walls trying to stop. The control dial is the way to go for reliable power and speed control. I love it.

— ELIZABETH

I’M USING THE WIRED SpeedControl dial. It works really well for me — I need it to go over rough pastureland, and it does this well [especially with a Free-wheel attachment in the front].

I put the SpeedDial knob on the lower bar (BELOW where I transfer and grab), so it doesn’t get in the way. Yes, this knob does require one to let go of a hand rim and quickly reach down to adjust speed, or press to shut off, but it’s easy and just a habit thing, like learning a car hand control. And one learns quickly how to intuitively adjust the speed and slowness depending on topography and where one is. It becomes second nature after a while.

The downside of the SpeedDial knob is the wire and extra “stuff” on my chair that I’d rather not have. But I decided against the watch control since I move my hands way too much with what I do.

culties starting in crowded places; signal dropping out and then difficult to restart (worst when crossing busy road); and difficulties stopping, so that I’ve had to push people out of the way and have driven into things a few times before I can get it to stop. The problems have



Claudia Garofalo

I also hate wearing watches. Or anything impeding my wrists and arms. I also didn’t trust Bluetooth, as I’ve had other devices get confused if other Bluetooth devices are nearby. I didn’t trust its reliability. And now that I’ve read about this concern I DEFINITELY don’t want it. Too bad, because less wires is always nice.

— TUFFY

GOT THE SMARTDRIVE with my new chair 14 months ago. Initially I was using the Tic watch that came with the unit, but I wasn’t at all happy with it. I felt like I had no control to start or stop the SmartDrive when I wanted to. I quit using the SmartDrive while I searched for a better solution. I got and installed the SpeedControl Dial and love it. I feel much safer now. I always transfer to the left side, so mounting the SpeedControl Dial on the right side of my frame works and isn’t in the way.

— JEFFREY DILLON

gotten worse over time, and I wonder whether that’s because there’s so much more Bluetooth equipment around. I often don’t use it when it would otherwise be helpful because it demands constant vigilance.

— LIZ SMITH



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BACK IN THE SADDLE:
With the Vicair AllRounder,
the author was able to
use an old golf cart to get
around his farm.



MOBILITY & SEATING

Testing the Vicair AllRounder 02 Cushion

BY TIM GILMER

In my 58 years as a paraplegic, I have owned a boatload of cushions, but none have been as eccentric, unique and surprising as the one I am now trialing — the Vicair AllRounder O2.

Headquartered in the Netherlands, Vicair makes several wheelchair cushions. All have in common a unique system of small air-filled packets called “smart cells” that fill five connected sections of the cushion. Each section is formed to protect a particular area — one for the coccyx, one for each ischial area, and one for each trochanter — five sections filled with a total of about 435 air-filled, pyramidlike packets. You can hold a few in the palm of your hand. You can set one on a table and move it by blowing. The four tips on each smart cell feel pointy in your hand, so my first impression was that they would not be comfortable to sit on, but the tips fold over with just a minimal amount of force and there is no discomfort. When you cram more than 400 of these into five strategically placed compartments and sit on it, they conform with one another to create a seating surface that is relatively lightweight, supportive and yet not solid, with just enough space between packets to allow for movement. You can add or remove smart cells to adjust for the feel and protection you want.

The surface of the cushion is a meshlike material that allows air and liquid through, and is machine washable. The AllRounder is aimed at active wheelchair users who want to get out of their chairs and sit on non-cushioned or minimally cushioned surfaces, especially for sports and recreational activities such as sailing, handcycling, kayaking, mountain biking, etc., but the cushion works for anything that requires sitting on a relatively hard surface.

Now here’s the best part: The five-part cushion zips into a durable, surrounding fabric cover with adjustable straps that fit around your waist and thighs, so you strap the cushion on your butt. It’s almost like wearing custom shorts that are open on top and have padding that covers only your

weight-bearing skin surfaces. Wherever you go, your cushion goes with you, like your own personal bucket seat, minus arms and back.

The AllRounder is not meant to replace your regular wheelchair cushion, so it is recommended that you transfer into it and then strap it on. At 78, I can no longer do pivot transfers safely by lifting and swinging my butt over the target surface and then letting myself down. I now use a two-piece sliding board called the Buckingham Glideboard, which is what I used when trialing the AllRounder.

THE TRIAL

I wanted to drive an old adaptive golf cart I still have from my golfing days, but there is no padding left in the seat. Rather than go to the expense and trouble of removing it and having it repadded and covered, I ordered the AllRounder from Vicair in the Netherlands, which ended up costing about the same — \$282 — shipped to my door. Hooking up was easy with adjustable waist strap and thigh straps, which have loops for easy tightening. I was able to slide into the golf cart and land easily on my AllRounder. My initial fear of not being able to slide into the seat without pushing the cushion off on the ground was unfounded.

I was off to the races, my course a three-acre piece of farmland with rows of hops towering 15-20 feet overhead, kind of like driving down lanes flanked by skinny trees. The ground was grassy and rough with divots and small hills, so I went slow. To my surprise, the ride was comfortable despite being uneven. As I toiled around inside and outside the hops field, my confidence grew. I felt safe and stable strapped into my cushion and secured to the driver’s seat with a seat belt. My butt was protected. I was able to make small adjustments to sit straighter by using the fold-down arms of the golf cart seat.

I stayed in the cart for about an hour-and-a-half as I inspected a crop in the field, something I’ve not been able to do for the last seven years — a

period with multiple pressure sores and infections. It felt like I reclaimed an important part of my independence. I may tinker around with removing a few smart cells to get deeper immersion, but the AllRounder works fine as is.

To my surprise, when my field inspection was done, I was able to transfer back into my chair using the slide board with the AllRounder still strapped on. It was easier than I had anticipated. I landed on my chair cushion, a JAY Union, so I was considerably taller than normal, which made the chair a bit tippy. I had to be careful when wheeling. Before going up a ramp into my house, I unstrapped and my wife was able to pull the AllRounder out from beneath me. Now I know I can remove my regular chair cushion and slide safely onto the sling of my chair with the AllRounder strapped on.

For me, this was a proof-of-concept trial. I can envision any number of possibilities for wearing my AllRounder in everyday situations, such as getting into a nonpadded shower chair, an airplane seat, a car, if needed, or possibly an accessible exam table.

SAFETY AND PURCHASING INFO

Vicair cushions are available in 45 nations and can be provided to vets through the Department of Veterans Affairs. A para-vet, T12-L1, whom I have known for more than 30 years, has used Vicair cushions and likes the stability they offer when being active. The Vicair website has posted 10 “clinical cases” of their cushions that claim to provide specific benefits. However, very few involve wheelchair users with spinal cord injuries, and the descriptions of the cases do not read like scientific case studies. It is advisable, especially for regular sport or competitive uses, to pressure-test any cushion and routinely do skin checks. For more information or to purchase, visit vicair.com. Permobil also sells a selection of Vicair cushions, but does not currently list the AllRounder O2 on its website.



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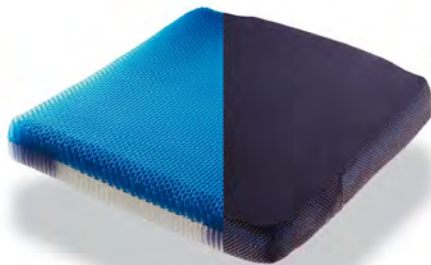




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TOOLS & TECH

A New Hands-Free Option to Control
Your Wheelchair: munevo DRIVE

BY IAN RUDER

Ten years ago, I wrote an article for *NEW MOBILITY* about Google's supposedly revolutionary Glass headset and what it might offer for wheelchair users. I had a lot of fun testing out the futuristic-looking device, but wasn't sure what its future looked like. I closed the article with a quote from a Google staffer who promised, "We're going to learn about things that Glass can help people do that we have no idea about now."

In case you've forgotten or never heard about Glass, it was a lightweight headset attached to a glasses frame, with a built-in visual display that let you make calls, take pictures and videos, and access social media hands-free, using voice, head tilt or other controls. Two years after my article, Google stopped making Glass for the public.

I forgot about my headset — packed away in its felt pouch in the back of my closet — until last year. A representative for a German company had sent a message through the *NM* website touting "a new technology combining smart glasses to help electric wheelchair drivers control their wheelchair (hands-free) through a minimalist head control device via Bluetooth." When I saw the pictures on their site, the device looked just like a Glass, and more importantly, it seemed to allow users to control their power chairs by simply tilting their heads.

The company, munevo, had been operating in Europe for three years and was preparing to bring their product, munevo DRIVE, to the U.S. Having heard numerous friends rant about their frustrations with current hands-free control options for power chairs, I was excited to hear about a new way to safely drive for those who can't use arms or hands.

The headset has been exhibited at Abilities Expos around the U.S., and munevo offered one to *NEW MOBILITY* so I could try it and get feedback from other testers.

PROMISING POTENTIAL

Using the glasses is about as close to plug-and-play as you will find when it comes to hands-free setups, but you will need an assistive technology professional to connect the adapter to your chair and configure the setup and speed adjustments. DRIVE is currently compatible with most newer Permobil, Sunrise Medical, Invacare and Q-Logic chairs, but check before purchasing.



With a lightweight, easy to wear frame, DRIVE provides a comfortable alternative to more cumbersome hands-free options.

As an avid gamer, I found the head-tilt control system easy to learn and felt comfortable driving at slow speeds within minutes. Each user calibrates how much head tilt is needed to drive, a nice feature that should provide users with all ranges of head movement ample control. I set mine to respond to more pronounced movements while my co-tester configured it for smaller gestures. "Driving with the device took a little bit of getting used to, though tilting your head in the direction you want to travel was intuitive, and with practice a driver can navigate quite nimbly," she said.

We both found the headset comfortable, even for longer periods of time. It's surprisingly stable, even with the tilting. The visual menu, used to change settings, has a clean interface and is easy to use once you get used to looking up and to the right for the prism that provides the visual display. The menu also has audio prompts that

make it easier to use while driving. This is helpful when you want to make sure you've toggled out of drive mode or switched between forward and reverse.

My co-tester thought DRIVE provided more freedom and control than her experiences with head arrays or sip-and-puff, but worried about battery life and connectivity. "I like to go out and stay out, and I wasn't able to go full days without needing a charge," she said. While plugging the glasses into a USB port isn't a huge inconvenience, what with more chairs providing them these days, she said that it does reduce your independence.

In light of recent revelations about Bluetooth connectivity problems with the Permobil SmartDrive, it's worth mentioning that neither of us had any issues with our chairs disobeying our commands or flying out of control. I reached out to munevo to see if they have an override solution similar to the SmartDrive SpeedControl dial. Independence isn't possible without safety. Chief technology officer and munevo co-founder Aashish Trivedi responded: "The Bluetooth connection between the smartglass and our adapter is secure and encrypted, and our product also has been tested according to the medical device standards to ensure that the Bluetooth connection is reliable without interruptions."

The munevo DRIVE is an exciting addition to available hands-free control options. "Having an innovative new choice to the standard alternative drive options where a joystick cannot be used is great," my co-tester said. "It's cool how they've leveraged existing gyroscopic capabilities in Google glasses to build a product for wheelchair users that has the potential to make controlling other electronic devices like your cellphone as easy as tilting your head."

She was referring to munevo PHONE, an app that allows users to control their phones via the same headset interface. The app is free with your DRIVE. Other add-ons that allow users to control a variety of home and adaptive appliances are available for purchase.

For pricing or to book a demo, visit munevo.com/en.



Adaptive gaming controllers



Key turner



Nail clipper holder



Portable toilet chair

TOOLS & TECH

Makers Making Change: Do-It-Yourself Assistive Technology

BY CHERYL ANGELELLI

Ever searched for a piece of assistive technology to solve an everyday problem only to find it doesn't exist, or the price tag was outrageous? Perhaps you've even purchased a piece of assistive technology in the past and thought, "why didn't I think of that?" or "I could have made this so much better." Now you can.

Makers Making Change, a Canadian nonprofit, connects people with disabilities to volunteer makers, who collaborate to build low-cost alternatives to commercially available assistive technology.

According to the World Health Organization, 2.5 billion people globally need one or more assistive products to help them with activities of daily living, and that number is expected to grow to over 3.5 billion by 2050. Unfortunately, assistive devices often aren't included in health care plans, leading to high out-of-pocket costs that are prohibitive for many people who need them.

MMC is bridging that gap with do-it-yourself assistive technology. Their growing online library currently has over 200 assistive devices ranging in price from \$2 to \$250. It includes items from low-tech, 3D-printed bottle openers, nail clipper holders and cupholders to higher-end customizable joysticks for gaming, and LipSync wireless, mouth-operated mouse controllers. You simply submit a request, and a volunteer maker near you will make it. You only pay for the cost of materials. Many of the devices have a 3D-printing component, which keeps costs low and makes it easier for people to build at home.

By working with volunteer makers, requesters have the ability to customize their devices to address specific needs. If the device library doesn't have the device you're looking for, you can submit your idea and work with a maker to turn it into an actual device. The turnaround time depends on the complexity of the design: Something that can be done with a 3D printer can be accomplished in days, while other items may take longer.

"Some of these are very simple, very

cheap-to-make devices, but they make a world of difference for people," says Suzanne Winterflood, MMC's central region coordinator. "Some of the ideas for the devices come from end users, our own engineers, therapists or design competitions we partner with. It's very collaborative."

Every device design contributed by MMC's team of engineers or their volunteer makers is open source, meaning anyone around the world can download the files and instructions for free to build their own devices. Open source also lets MMC collaborate with similar DIY assistive-technology organizations and makers globally, so they can build upon each other's work and contribute back to the community.

GIVING PURPOSE AND HOPE

As a quadriplegic, Garry Bartsch says 3D printing has given him a forum in which to create. "I really like it because I can't do things with my hands," says Bartsch, of Alberta, Canada. "I can type, and I can operate a computer, but I can't really make anything. But with the 3D printer, I can just design things [using computer-assisted design] and then the printer makes stuff."

After printing inventions for himself and friends for years, Bartsch put his skills to use for MMC. He has printed several low-tech assistive technology kits, each with seven items to assist with daily living, such as a tube opener, pen holder, and key turner.

MMC has over 50 chapters throughout Canada and the U.S. Noam Platt is the coordinator of MMC's Louisiana chapter and founder of MakeGood Assistive Design. Platt, an architect, was looking for a way to use his design skills for something where he could see the impact it made. "I feel like every time I deliver one of these [assistive] devices, I get a hopeful feeling that the world has been changed a little bit for the better for the next generation," Platt says.

Platt partnered with Quanteria

Williams-Porche, a physical therapist who had requested a portable adapted toilet chair for her 6-year-old son, Alexander, with spastic quadriplegic cerebral palsy. Among her requests was that the chair be safe for Alexander, with his poor motor control, to sit independently and not tip. She also wanted something that would not take up a lot of room in her small home.

After meeting Williams-Porche and Alexander, Platt quickly went to work designing and making the chair. The main body of the chair is made of birch plywood and the other components are different types of standard or high-end 3D-printed plastics.

Williams-Porche loves the final product (see photo at left). It takes only minutes to put together, it's lightweight and packs flat, which makes traveling easier. Platt has taken the chair on board a plane and says it fits easily in the overhead compartment.

Williams-Porche priced similar commercially available toilet chairs that ranged anywhere from \$600-\$1,500, but those were bulky and did not address Alexander's specific needs. The cost of materials to build the custom toilet chair that Platt designed was only a couple hundred dollars. "Just knowing my son will not be in diapers forever, that he'll be able to use this chair — it just opens up a new world and new possibilities for us," Williams-Porche says.

GET INVOLVED

MMC welcomes makers of all abilities and skill levels, whether you're just starting your maker journey or you're a skilled engineer wanting to donate your time. Many of the devices involve 3D printing, electronics, soldering, mechanics, design, and computer-assisted design.

There are several ways to get involved. Volunteers can fulfill a design request, tackle a design challenge, or start a chapter to bring DIY AT into their community. Learn more at makersmakingchange.com.



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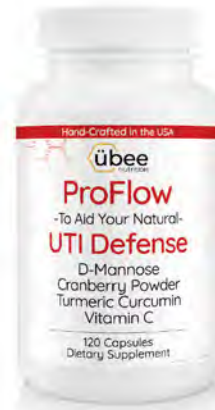
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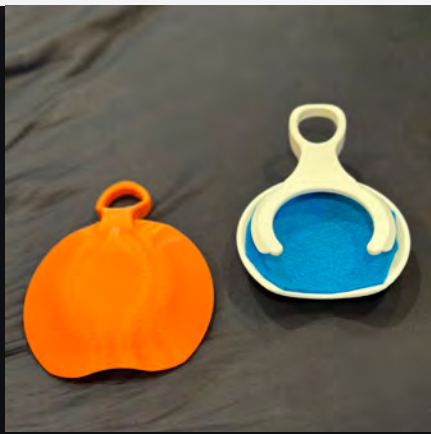
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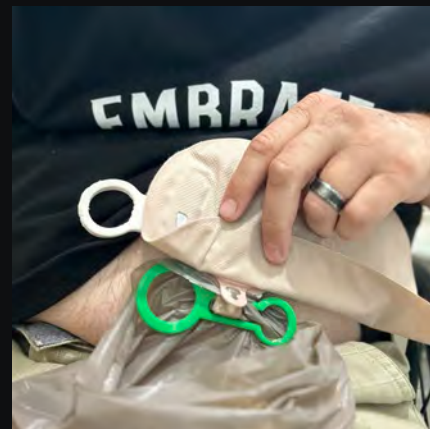
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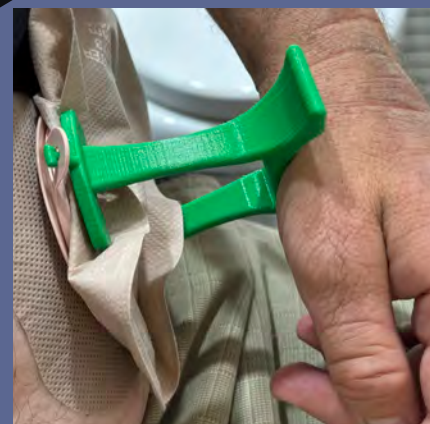
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HEALTH & HYGIENE

Making Sensible Ostomy Solutions

BY IAN RUDER

On top of all the new emotions and routines that come with the surgery, getting a colostomy leaves you with a whole new set of decisions to make about products. One of the keys to successfully managing your colostomy is finding the right products that work with your skin, your stoma and your lifestyle. With a good system in place, a colostomy can save you time and improve your overall health, while a problematic setup can lead to spiraling problems.

Mark Fuglevand became intimately aware of this when he got a colostomy. Now he is using his own experience and experiences shared with him by community members to design products that empower colostomy users. “My goal is to create simple solutions that can make living with and managing a colostomy easier,” says Fuglevand, a C6 quad and the founder of adaptive solutions purveyor Abilitease (abilitease.com).

While there are probably more ostomy-related products and options available now than ever before, Fuglevand noticed that very few of them incorporate quad-friendly design or were developed with the insights that only an active wheelchair user can provide. With two young sons, a wife, and a company to grow, Fuglevand doesn't have time to be fumbling with ostomy wafers and pouches. To that end, he's developing three 3D-printed colostomy-related tools that he hopes will help others and get more users to think about how to improve the process.

PRODUCT NO. 1 – STOMASECURE

The most refined of Fuglevand's devices addresses two common ostomy needs: sound and protection. With a colostomy, the stoma can be loud and embarrassing, and the skin around the opening can easily become irritated. Most wafer and pouch systems offer little protection from abrasion or unexpected gas noises.

“Some people with ostomies have a difficult time with the skin around their stoma, and the area can become raw and sensitive to touch. Clothing, seatbelts and even binders used in wheelchair sports not only rub against the stoma, but prevent output from flowing into the pouch,” he says. “There are numerous products available to protect a stoma, but

they aren't cheap.” Those products address the problem, but not key concerns like cost and ease of use. “You either have to apply Velcro on the top of your ostomy pouch every time you change it or wear an institutional-looking belt around your stomach with a cover,” he says. “They simply don't make sense.”

Fuglevand's solution is a removable plastic cover with a loop handle, that slides behind the floating flange on a Hollister wafer and covers the stoma, creating a little protective dome. The cover has a curved opening on one end to allow output to flow. The cover is open on both sides so you can turn it while it's on the flange to match up with the orientation of the pouch. He is currently lining the inside of the cover with felt or neoprene to help mute the noise coming from the stoma, but hopes to find a more effective damper.

Fuglevand notes that you still have to monitor the volume of output and gas but believes his solution improves ease of use and comfort. “It's nice and easy. You literally can just slide it on or off whenever you want to use it — no straps, no extra crap,” he says. Once on, “You forget that you are wearing it because there's not a tight strap holding it in place.”

PRODUCT NO. 2 – POUCHCOLLECT

For all the benefits of the colostomy, there's no getting around the fact that emptying or changing ostomy pouches can be a stinky, unpleasant experience. Regardless of whether you're using a one-piece drainable or two-piece closed-end pouch system, quad hands and limited dexterity only complicate the matter. “Every time I remove a full pouch, and I have to hold it up with my teeth instead of my hands during the change, there's the smell of poop going into my face,” says Fuglevand.

To address that situation and help minimize some of the potential for making a mess, Fuglevand is working on a removable kidney-shaped tray that attaches to a Hollister wafer the same way as the StomaSecure. The tray is designed to sit comfortably on the stomach and catch any potential loose stool when removing and emptying a pouch before it oozes onto the dressing or your clothes. The device can also secure a disposal bag, making it easier to keep it

in the right place while you detach and dispose of your ostomy pouch. “My tenodesis works really well, but detaching a full pouch and emptying it into a toilet or placing it in a disposable bag without making a mess can be difficult,” he says.

PRODUCT NO. 3 – POUCHASSIST

Fuglevand's final design focuses on making it easier to attach and remove pouches on a two-piece closed-end system. This includes being able to “burp” gas that accumulates in the ostomy pouch. Many pouches on the market have filters that allow some gas to pass through, but it's often necessary to slightly separate the pouch from the wafer and allow gas to exit. How easy this is depends on your wafer, system setup and dexterity.

For people who can't easily apply or separate the pouch from the wafer, Fuglevand has tested a plastic applicator that attaches to the side belt tabs of the Hollister two-piece, closed-end pouch. With semicircle tracks that fit snugly around the pouch flange, the applicator will help the pouch line up with the flange on the wafer to secure the pouch. “This device also allows you to turn the pouch to the desired position and separate a portion of the pouch to burp it when necessary,” says Fuglevand.

LOOKING FORWARD

All of the products Fuglevand is working on are designed to work with the Hollister products he relies on. He chose to use Hollister because he was already familiar with their catheters and he found that one of their wafers worked well with his stoma. “I love the flexibility and how quick I can pop a pouch on and off on my Hollister stuff — it's very easy. And I've gotten so comfortable with it,” he says.

He's open to working with other product lines to devise bespoke solutions. He wants to empower users to be more independent, and hopes to inspire industry leaders like Hollister and Coloplast to integrate more user input in their designs. He's already focusing on what's next, including products that could make flying with an ostomy easier. “It's simple, really,” he says. “I think about what I've learned, what I need and what works, and then I go to work.”



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HEALTH & HYGIENE

ShowerGlyde Shower Chair Reviewed

BY BOB VOGEL

Until recently, shower chairs seemed to come in two categories: the ones under the complex rehab umbrella that retail in the \$2,000-\$3,000 range; and the others available at online and big-box stores, which in my experience lack durability and don't feel very stable. These latter shower chairs are the ones that hotels tend to offer when all the accessible rooms are booked.

But earlier this year, SolutionBased, formerly known as ShowerBuddy, released a new line of sliding transfer shower seats

that promised a quality chair at a more affordable price. The product line is called ShowerGlyde, and recently I had the opportunity to try one out and see which of the two categories it falls in, or whether it transcends them both.

As the name suggests, ShowerGlyde transfer chairs enable you to glide over the lip of a bathtub or shower on two "glide rails." ShowerGlyde chairs are offered in three models:

SG1: Designed for bathrooms with plenty of space, the seat glides a full

seat-width beyond the outside lip of the bathtub.

SG2: Designed to fit bathrooms with a toilet next to the tub or shower, it enables a single transfer for toileting and then an easy glide into the tub or shower.

SG3: Designed for tightly spaced bathrooms, the chair extends about 8 inches beyond the lip of the tub and can swivel 90 degrees. Caveat: I found that transferring was easier without the 90-degree swivel. SolutionBased plans to offer a 45-degree swivel, which would

make transfers even easier. It should be available by Jan. 1, 2024.

All three models have backrests, seat belts, grab bars, standard commode openings for easy washing, smaller opening inserts and solid seat inserts. They are all height-adjustable and able to clear a tub lip of up to 19.5 inches, have a weight capacity of 330 pounds and come with a lifetime warranty on the frame. Frames are made from heavy-duty machine-welded aluminum with plastic and stainless-steel components that won't rust. Optional padded seat-rests and flip-up adjustable armrests should be available by January. The retail price for each model is \$529.66.

THE TEST

For a thorough test of the SG3, I enlisted the help of Matt Fritsch, who is in his 20th year as a T6 paraplegic. At 6 feet, 2 inches tall and 185 pounds, Fritsch uses a low-cost shower bench. Over the years he has had two of them fail from everyday use. Fritsch's tub is 15 inches high — right in the middle of average tub heights, which range between 14 inches and 16 inches.

The total weight of the SG3 is only 24.7 pounds, and I was able to unbox and assemble it myself. After viewing the online tutorial and printed directions, assembly was easy and took less than 15 minutes. A cool assembly feature is that every bolt uses the same-sized Allen key, which is included and snaps into the underside of the seat.

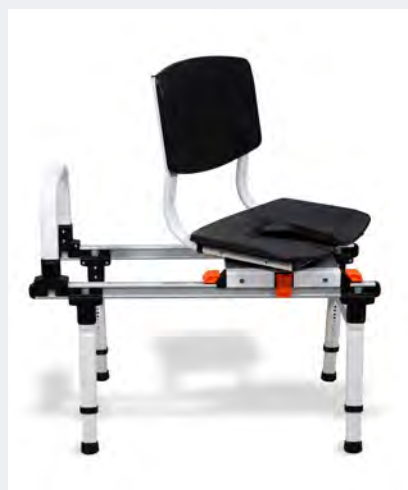
The ShowerGlyde frame has a solid look and feel. I did notice that without any weight on it there is about ¼ inch of play in the seat, though it's not noticeable when transferring and/or sitting in the seat.

Adjusting the ShowerGlyde legs to fit the varying angles of Fritsch's tub was also easy, thanks to one of Solution-Based's many astute attentions to detail: ½-inch increment adjustments. The industry standard for leg/height adjustments on a shower bench is 1-inch increments, but having twice as many options ensured a perfect, secure fit.

The ShowerGlyde seat locks into place at each end of the tracks, which creates a firm, sturdy platform for transferring. The seat is released for sliding

into tub or shower by pushing one of the orange buttons on each side. The front of both Fritsch's wheelchair and my own was 19 inches, which made for smooth, level transfers from our cushions.

I wheeled up and gave the ShowerGlyde a try. I found the transfer easy. The seat and frame felt solid. Once on the seat I picked up one leg, then the other — with the seat still in the locked position — and moved them into the tub. Although I didn't use the seat belt, I can see it will be helpful for those who need extra support or are still learning SCI skills. Once my legs were in the tub, I placed one hand on the grab bar, pushed the release button and easily



The ShowerGlyde's swivel feature may help some users with transfers.

glided into "shower position" as the seat clicked into place.

Having used solid shower benches before, I find that ShowerGlyde's roller tracks make moving from the outside of the tub or shower safer and easier. I didn't have to push up to lift my butt to avoid skin shear as I crossed the bench. Shearing forces can lead to deep-tissue pressure sores. Plus, lifting my butt to move would put additional strain on my aging shoulders.

When Fritsch tried the ShowerGlyde, he said it felt stable. He also liked the solid feel of the back and the ease of gliding from the edge of the tub into shower position. "I can see that without a solid shower bench it's going to be easier to clean the tub," he said. He also observed that he could cut two slits

in his shower curtain to go in between the seat rails, which should prevent the wet floors he gets when water flows over his shower bench. Fritsch noted that the ShowerGlyde's feet are made of tough plastic. "This is a big deal for me because my last bath bench had rubber feet over thin tubular aluminum, and over time the aluminum wore through the rubber and punched a hole in the bottom of the tub," he says.

When I tried the ShowerGlyde at home, I added the optional leg extensions to accommodate my very tall 21-inch bathtub, but the seat was too high for me to perform transfers without straining my shoulders. This is because the top of the ShowerGlyde SG3 seat is 6 inches higher than the top of the tub rail, hence a transfer to a 27-inch height.

When deciding if the ShowerGlyde is right for you, it is important to measure your tub-rail height and add 6 inches — or 4.4 inches for the SG1 or SG2 — and decide if that transfer-height works for you. For instance, a wheelchair's seat-to-floor height is often 18 inches to 19 inches, so with a tub height of 14 inches to 16 inches, the transfer to the ShowerGlyde should be as easy as chair to commode, or chair to bed and back. If your bathtub is higher than 16 inches or chair height is lower than 18 inches, I suggest trying a transfer to a demo prior to purchase. The same goes for ordering the SG2: If the lip of your toilet is higher than 16 inches and/or your chair is lower than 18 inches, I suggest trying to transfer on a demo to see if it is right for you.

THE VERDICT

I think the ShowerGlyde is a good value for the money. It is easy to set up, extremely adjustable, looks good, and feels durable and sturdy. If my bathtub was average height, or if I had a shower with a lip that prevented a roll-in chair, I would get one.

Based on what I've seen, the ShowerGlyde will benefit anybody searching for a superior shower/bathtub transfer bench at a good price. Seeing the way it's built, with details like extra adjustability, clean welds, and strong plastic feet, it looks like it will hold up over the long haul. The lifetime guarantee on the frame is also a plus.



AUTOMOTIVE

Inside Winnebago's Accessible Camper Van

BY SYLVIA LONGMIRE

Traveling across the U.S. in a recreational vehicle is a staple of American culture, and it's also a dream for many wheelchair users. Recently, Winnebago introduced two accessibility-enhanced RVs designed to make it easier for those with mobility disabilities to get out on the road. I had the opportunity to explore the inside of the smaller model, the 19-foot-9-inch Winnebago Roam, and while it's not suited for all wheelchair users, many with mobility limitations could benefit from its features.

Getting into the Roam is a breeze

a small refrigerator, several drawers and cubbies for storage, and a 12-gallon sink, all easily reachable from my power wheelchair. The microwave is installed high above the counter, however, and out of my reach. I would need a companion to operate it. Moving around the cabin is tight — it is a camper van, after all — but I was able to manage in my Whill, a smaller power chair. Most manual wheelchair users should be able to navigate the cabin, but those with larger, more-complex power chairs might find the interior aisles too small to be functional.

nette is a storage compartment with a strap that you can reach from a seated position. Many of the controls, including temperature, lights, sofa bed and water heater, are located on a panel to the left of the television, and are within easy reach.

At the rear is a custom-sized sofa that converts to a flat bed, with push-button controls located at the back of the vehicle and on the control panel. The bed measures 5 feet 10 inches from one side of the RV to the other, has a memory foam topper and is quite comfortable. There is a grab bar to help with transfers, and it's slotted to accommodate a cupholder.



The Roam has a dedicated tie-down area (left), and front seats rotate 180 degrees to make transfers easier. Right: A raised toilet inside the shower compartment could make for a tricky transfer.



with the BraunAbility Under Vehicle Lift, which can be controlled with a pendant or optional remote control. Once inside the Roam, you can transfer to the driver's or passenger seats, or stay in your chair using the Q'STRAIN'T tie-down system.

Moving from front to back, the first space to consider is the driver's compartment. The Roam is built on a Dodge Ram chassis and designed to ride like a minivan. The two captain's chairs rotate 180° to enable transfers between the front and main compartments. The chairs are several inches higher than a standard wheelchair, so you would need some combination of arm strength, sliding-board skills, or enough leg function to stand up and pivot for self-transfer. Hand controls can be installed on the driver's side.

Further back, the galley area includes

Right next to the galley is the toilet and shower compartment. There is a 3.5-inch step up to the toilet, which has a removable waste tank that detaches like a cassette. The toilet offers two grab bars and rotates 90° for easier showering while seated. The shower compartment has a handheld showerhead with hot and cold water, and a magnetic enclosure to prevent spillage. The bathroom may be the most challenging feature of the Roam because it requires that extra step up to the toilet. A strong manual wheelchair user might be able to make the lateral transfer, but it would be tricky.

Across from the bathroom area is the dinette. It features a table that folds and locks into place, has an extender and is high enough for a wheelchair user to easily roll underneath. There's also a 24-inch pivoting television with USB ports and streaming capability. Above the di-

While Winnebago describes the bed as accommodating two people, they would have to be two average-to-smaller-sized people.

The Winnebago Roam isn't a good fit for everyone. One chair user with a companion is probably the maximum you could comfortably fit — it would likely be too small for family travel. And some of its accessible features do require a bit of mobility. Still, for those with the right amount of function, the Roam could be a great option for road trips or longer camping vacations. Having amenities like a toilet and kitchenette could also make day trips or long days of running errands easier and more comfortable.

The Roam has a starting price of \$179,684. For more information, visit winnebago.com.

More photos on next page.



Left: The interior of the Room has a functional layout, but you may need assistance reaching some of the high cabinets. Above: The control panel is easily accessible from a wheelchair.



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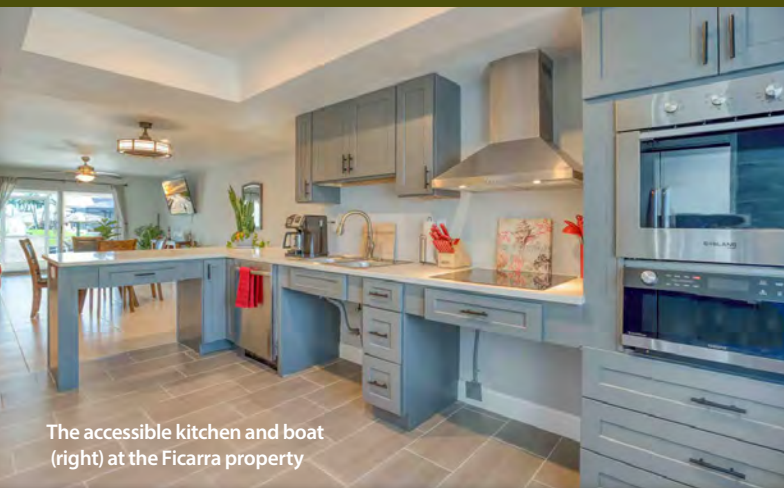
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The step-free entrance to the McCaffrey property



The accessible kitchen and boat (right) at the Ficarra property



SERVICES

Profit by Renting Your Accessible Properties

BY SHANNON KELLY

Demand is high and inventory low for accessible short-term rental properties. Wheelchair users across the U.S. have taken matters into their own hands by renting their own accessible properties. Here they get candid about what it takes to manage a rental, how to market it to the disability community and how much you can make if it's done right.

Lorraine Woodward founded Becoming rentABLE in 2021 after years of struggling to find accessible short-term rental properties for herself and her two sons, as all three have muscular dystrophy and use wheelchairs.

She started by buying and renovating a home in Carolina Beach, North Carolina, three hours away from her home in Raleigh. She made the house wheelchair accessible for her family's needs by including an elevator, zero-threshold floors, wide doors, a Hoyer lift, a hospital bed, a wet room, shower chairs and more.

When she began renting it out to others, the response was overwhelming. "We've had over 400 renters rent that space, and their stories were all the same about how hard it was to find a place. But what surprised me were the families that traveled 2 ½ days to get to us from Canada, or a family that was from Texas that said it took them 28 years to find an accessible property," says Woodward.

With the help of a group of volunteers, she began vetting other properties for accessibility and created a database which became Becoming rentABLE. The site now lists over 1,200 accessible properties across the U.S., but there's a long way to go. "There are 1.3 million short-term rentals in the United States right now. And of those properties, less than 0.01% or 1,300 are actually accessible," she says.

PROFITABLE PROPERTIES

Woodward isn't the only wheelchair user trying to improve this statistic. We talked to individuals with properties in Alaska, Florida and California who are trying to expand the market while reaping personal benefits as well.

Andrew Kurka has been a Paralympic alpine skier for 12 years and owns 5 acres of property in Alaska, where he built two wheelchair-accessible cabins.

Jeff McCaffrey, a T9 paraplegic, and his wife Natalie, moved into their gorgeous home in Fallbrook, California, in April of 2022. The property had a guest house, so they put some work into making it accessible and started renting it out shortly afterward.

Originally from the Northeast, Matt Ficarra, a C6-7 quadriplegic, moved to Florida during the pandemic to take advantage of the ability to work remotely. He bought a duplex and made both sides accessible, so he can live in one and rent



the other. The property sits right on the water, with a ramp leading to his fully accessible boat.

It's no surprise that one of the benefits of hosting short-term rentals is the financial gain. All of these owner/renters say they enjoy the extra income their accessible properties provide. Kurka's two cabins have allowed him to travel and earn income remotely — he was in Chile at the time of this interview. With two cabins, he makes around \$50,000 profit a year and is hoping to double that once he adds new cabins.

In Florida, it has been a challenge for Ficarra to market the property while he works full time as a life insurance broker. But even without his place being fully booked, Ficarra made \$14,000 renting for two months last winter.

Because their guest house is on their property, Jeff and Natalie McCaffrey use it to not only make money but to offset living costs. "For [investors] that buy the property individually, the financial situation obviously differs. But if you do have a situation where you can have a granny flat, where you're already paying the property taxes, the maintenance and upkeep, it's definitely financially beneficial," says Jeff.

The Woodward family often hosts guests for a month at a time at their home in Raleigh, charging \$750 a month for one bedroom and one bathroom with a separate refrigerator and shared kitchen. Their Carolina Beach house rents for \$215 a night. "It doesn't cover our mortgage, but it did take a nice slice out of it. I believe in multiple revenue streams. It really can impact your budget greatly," says Woodward.

Besides making money, the property owners enjoy providing meaningful experiences for others in the disability community. Kurka enjoys providing accessible Alaskan adventures. "I take guests with disabilities flying, fishing, hunting and doing outdoor things. That's a passion of mine and why I built this place," he says.

The McCaffery property is located near San Diego, where there is a lot to do but a lack of accessible lodging. "There is great recreation within our area, but there are not really any hotels that have adequate and ample accessibility. So we decided this is a great opportunity to provide that and make it available to others with disabilities so that they can enjoy all those things," says Jeff McCaffrey.

FINDING THE RIGHT AUDIENCE

Having an accessible property is one thing, but connecting with travelers who need it is another. Many hosts use the popular home-sharing app, Airbnb, to market their properties and find potential guests.

The company recently unveiled their Adapted category, specifically for homes that have been vetted for accessibility. "These properties have been reviewed and verified to ensure they

have step-free paths into the home and into at least one or more bedrooms and bathrooms,” says Cristina Calzadilla, global product communications lead for Airbnb. The Adapted category now features over 1,100 listings around the world, with Adapted hosts collectively earning over \$5.5 million.

Airbnb partnered with virtual-imaging company Matterport to provide Adapted listings with dimensionally accurate 3D scans of the house. These

models will help validate the property’s accessibility and provide images of access features. “The blueprint of the home is uploaded and tethered to the listing. A prospective guest can look at the home, look at the floor plan and feel really good that the building meets their needs,” says Calzadilla.

Airbnb’s Accessibility Review requires hosts to submit photos of their accessible features such as a step-free entrance, fixed grab bars or a bath or shower chair.

The photos are then reviewed and confirmed by Airbnb agents, allowing guests to book with peace of mind. Since Accessibility Review was launched in 2021, the number of listings with an accessibility feature on Airbnb has increased by over 450% to over 140,000 places to stay.

The McCaffrey’s guest house is listed in the Adapted category, and Natalie believes going through the Matterport process helped increase the number of bookings. “It makes it easier for people in wheelchairs to understand if it’s going to work for them. We definitely had a lot more inquiries about people interested in booking because of it,” she says.

No matter where the hosts are on their journey, they are continually learning how to better market their properties. Ficarra encourages hosts to harness the power of social media. “I’ll go on the Spinal Cord Injury Facebook group and post videos of people having fun — like on the boat, or in my garage, which is set up as a gaming room with a pool table and TVs. I’ve had other quads that have never played pool before and then they figured out that they can and then they love it,” he says.

Kurka’s Alaskan cabins are booked solid for two to three months at a time in the summer. Being near a ski resort ensures interest during the winter. Kurka stresses that finding a good manager has been key. “It can be difficult to manage the properties with a disability, especially with cleaning. So find a good manager and a good cleaner, someone who’s got your back and who you can trust,” he says.

Jeff McCaffery makes a point about communicating access details and answering questions with guests prior to their arrival. He enjoys offering advice on accessible excursions in the area. He advises prospective hosts to think about the way the space is furnished. “Consider table heights and bed frames that are conducive for someone in a wheelchair, configuring the couches and chairs in a manner where there’s actually [room] to get from the kitchen to the bedrooms,” he says.

Woodward advises people to start small: You don’t have to own a separate property to be successful. “That’s how Airbnb got started,” she says. “It wasn’t about renting the whole house. It was giv-

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Wheelchair-using property owners know the kind of features that make a rental work, such as a beach wheelchair in North Carolina, a sturdy ramp in Alaska and a roll-in shower in Florida.

ing people a place to sleep, a bathroom and possibly a microwave. It's a way to get into the industry, bring in revenue and possibly down the road, invest in something that's even greater."

She also says that having a room or a property for rent isn't always about destination. The other property she owns, her Little Yellow House in Conway, Arkansas, brings in \$110 a night. "Renting space out of your current home doesn't always have to be in the biggest city in your state."



ACCESSIBLE RENTAL RESOURCES

- **Airbnb**, airbnb.com/accessibility. Discover unique homes with verified accessibility features including step-free paths into the home, bedroom and bathroom.
- **VRBO**, help.vrbo.com. VRBO offers wheelchair-accessible rentals around the world.
- **Becoming rentABLE**, becomingrentable.com. Identifies and advocates for accessible short-term rental properties across the U.S.
- **accessibleGo**, accessiblego.com. The leading accessible-travel website in the U.S. for people with disabilities to book travel and be part of a community of like-minded travelers.
- **@access_the_best**, instagram.com/access_the_best. Lynsey Gesell, a quad, curates a great selection of accessible properties.

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Above: Trevor Kennison performs the first-ever sit-ski double backflip as he launches into Vail Pass. Below, left to right: Kennison soon after his injury; Kennison drops into Corbet's Couloir; Barry Corbet shoots one of his films about life after spinal cord injury.



MEDIA

Coming *Full Circle*

BY SETH MCBRIDE

In February 2019, Trevor Kennison did something that no sit-skier had done before. At a professional ski/snowboard contest in Jackson Hole, Wyoming, he launched himself off a snow cornice into Corbet's Couloir, one of the most difficult and legendary ski runs in North America. At the time, Kennison was a relatively little-known skier based out of Colorado. By the time he skied out the bottom of Corbet's, Kennison had put the action sports world on notice: He was ready to take sit-skiing to a level no one had ever seen.

The feat made a bigger impact on the skiing and snowboarding community than it did in the disability community. *Freeskier* magazine dubbed Kennison's accomplishment "the send heard 'round the world." Skiers who knew things knew about Corbet's, but they didn't know how Corbet's got its name; long-time NEW MOBILITY readers may know the name Barry Corbet, our editor from 1991 to 2000, but most of them probably don't know anything about the run that bears his name.

Those are the two worlds that the new documentary *Full Circle* seeks to piece together. It tracks Kennison's journey from wayward youth and nondisabled recreational snowboarder, through his 2014 accident at Vail Pass in Colorado and the "post-traumatic growth" following his T11-12 spinal cord injury. It weaves in Corbet's story, using Corbet's own words from his 1980 book, *Options*, as narration for the journey that both men take to find acceptance and ultimately thrive in their new, wheelchair-using lives.

TOO GOOD TO BE TRUE

Located at Jackson Hole Mountain Resort, Corbet's Couloir is a steep chute, hemmed in by vertical rock on three sides. Legend goes that Barry Corbet spied this frightening passage while working as a mountain guide in 1960, and said, "Someday somebody will ski that." Corbet's name got stuck on the couloir, which was first skied by a Jackson Hole ski patroller in 1967 and shortly thereafter by Corbet himself, and then

the connection was mostly lost to the passage of time.

When ski film director Josh Berman first signed on to do a project with Kennison, it was supposed to be a short film about Kennison returning to ski Vail Pass, where he'd broken his back. Then, Kennison dropped into Corbet's Couloir, and there was no way the movie couldn't feature that. In a chance encounter at a memorial service, Berman got talking to a friend's parents who had worked at Craig Hospital in Englewood, Colorado, and knew Corbet. His friend's mom commented on how cool it was that he was doing a project with

Full Circle will be screening at theaters across the country this winter. The filmmakers expect it to be streaming on major platforms in January 2024. Visit fullcirclefilm.co for showings and updates.



Kennison and Corbet's Couloir, what with Barry Corbet being a paraplegic. "It didn't make sense," says Berman. "I remember thinking to myself, 'Oh sure, sweet old lady, that's great, but Trevor's the paraplegic.' Whatever I said to her, she was like, 'You don't know, do you?'"

As the woman filled him in on the outlines of Corbet's story — an adventurer and mountaineer who was on the first American team to summit Mount Everest, then broke his back in a helicopter accident while making a ski movie, and would go on to become a disability sports, filmmaking and storytelling pioneer — Berman couldn't believe what he was hearing. "My mind was blown," he says. "The further down the rabbit hole we went, the more compelling and wild it became, not only Barry's story, but also his connections to Trevor. It became a much bigger project and a much more universal story."

THE JOURNEY

The resulting film is a fascinating watch for skiers, and for people who don't care a lick about skiing. Kennison is a likeable hero, quick to laugh and find joy as he progresses in his skiing, and also unafraid to share his struggles — whether with drugs and depression before his accident or with the unglamorous realities of pissing himself in a sit ski and worrying about how he'll be able to have children post-accident.

Kennison's path as a skier provides a unique perspective, in part, because Kennison wasn't that good before he got hurt. "There are lots of stories of very talented people out in the world who get injured and then work really hard to regain some degree of performance similar to their pre-injury level. But Trevor was just a recreational, Joe Schmo snowboarder," says Berman. "His story is so awesome to me because he's performing at a higher level as an adaptive athlete than he ever was as [a nondisabled] athlete."

Corbet's own journey and wisdom provide the depth that should make *Full Circle* enjoyable for anyone interested in the full spectrum of the disability experience. Corbet's life, both pre- and post-disability, is fit for a movie. For wheelchair users who don't know of him or how he helped change the way our community sees and talks about disability, *Full Circle* serves as a good primer and motivation to look up some of his writing.

The way the filmmakers structured the movie, it sounds as if Corbet is often speaking directly to Kennison, though really, he is talking to all of us who've had a traumatic injury:

"I don't want to tell you that life will become easier, or the choices simpler, or that spinal cord injury is in any way beneficial to one's mental and physical health, because those things aren't true.

"I do want to tell you that this monumental inconvenience can be lived through, lived with, loved with, laughed with, surmounted, shared, transcended, and that you have not been deprived of choice. You do have a lot of options. You can be OK if you choose to be OK. The future, however unfathomable, is yours."

Hospital and Organizational Members

ARKANSAS

Arkansas Children's AcuteCare Rehabilitation Program, Little Rock, AR; 501/725-6428

Baptist Health Rehabilitation Institute Little Rock, AR; 501/202-7000

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

CALIFORNIA

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

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

PAM Health Specialty Hospital of Denver, Denver, CO; 303/264-6900

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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

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

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

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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

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

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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

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

The Ohio State Wexner Medical Center, Columbus, OH; 614/293-8000

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

OKLAHOMA

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

OREGON

Legacy Good Samaritan Hospital 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

Encompass Health Rehabilitation Hospital of Harmarville, Pittsburgh, PA; 412/828-1300

Good Shepherd Rehabilitation Hospital, Allentown, PA; 610/776-3100

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

Jefferson Moss-Magee Rehabilitation Hospital - Center City, 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

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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

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

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

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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ROLLING INTO PARENTHOOD

Being a parent with a mobility disability brings on a whole new set of challenges! All parents with disabilities and their partners currently raising children are welcome. This group is a safe place to share valuable information, advice, support and resources with your peers.

The group's facilitators are Matt Castelluccio, a dad with a spinal cord injury of twin 10-year-old boys; Lesly St. Louis, a dad with spina bifida of a 5-month-old daughter; and Erin Gilder, a mom with a spinal cord injury of two teenage boys aged 16 and 18.



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www.unitedspinal.org/pathways-to-employment/



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MEMEWATCH

“For your next task, you must put the fitted sheet on the bed alone from your wheelchair...”

Me:



Meme by @adam_lucio

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A Weekend in Fargo

Sylvia Longmire wanted to travel to all 50 states before her 50th birthday, and she accomplished her goal with a trip to North Dakota this fall. She takes us along as she rides public transit around Fargo to see if, as the local tourism bureau assured her, she really did “save the best for last.”

Gear Guide: Wheelchair Cushions

There are a ton of wheelchair cushions on the market. In this Gear Guide, we help you make sense of your options and what will work best for you, whether you're looking for superior stability, extra skin protection or a budget model that will keep your backside happy.

Inside the Life of a Wheelchair User Working at the White House

Fresh off a year as a White House fellow, Elizabeth Ragan shares the highs and lows of her experience and writes about why it is important that people with disabilities apply for prestigious opportunities that are not focused on disability and are open to nondisabled candidates.

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