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The wrong wheelchair can transform a fun day at the gym into a painful slog. The right wheelchair can be the difference between bronze and gold. BOB VOGEL suits up and hits the courts to find out what chairs athletes are using, why they chose their wheels and what they do to maximize their performance. PAULA LARSON reports on the world of power soccer and how it has grown into a high-level international sport.

Cover and Contents Photos by Loren Worthington

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16 SUNDANCE EXTRAVAGANZA
Disability was front and center like never before at this year’s Sundance Film Festival. DAVID RADCLIFF took on the snowy sidewalks of Park City for the behind-the-scenes scoop.

34 CAMELS, MUMMIES AND MORE IN MOROCCO
Whether you dream of riding through the desert atop a camel or camping in an accessible oasis in the sand, CORY LEE WOODARD has you covered.
CHAMPION SLEEPER

At some point in the last 10 years, I started sleeping like a baby — not the angelic cherubs that gave rise to the saying “slept like a baby,” but the needy insomniacs that wake up every two hours.

The nights of putting my head on the pillow and falling into a deep, refreshing sleep gave way to a frustrating blend of lying in bed, watching mindless videos and occasionally drifting off.

I replaced any hopes of attaining the fabled eight hours of sleep with metaphorically crossing my quad fingers and praying for a solitary stretch of four straight hours without waking up.

I knew my new normal couldn’t be healthy, but my struggles slowly infected my perception of what constituted a good night’s sleep. I disregarded the fact I’d often catch myself drifting off after lunch, and I adjusted to constantly feeling achy and exhausted. I learned to be careful with a glass of red wine and to embrace coffee after 39 years of avoidance.

Between struggling to focus and immediately forgetting passages I’d just read, the evidence was right in front of my tired face: I had a problem.

I got a referral to a sleep doctor who affirmed what I knew: Sleep apnea is very common — even more so among quadriplegics — and highly treatable with a CPAP or BiPAP machine. Despite countless people telling me how the breathing masks have grown less cumbersome and Lecher-ish, I’ve fervently resisted the notion of even considering one. No more.

When I went to the hospital for my overnight sleep study, I was actually excited for any mask — no matter how hideous — and the relief it might provide. Eight restless hours of constant interruptions later, I rolled out with more questions than answers.

The sleep technician swore I slept for two hours. I swore I didn’t. She said everyone says that. She told me to expect the results in one to two weeks.

Two weeks later, a nurse called me back during the evening rush hour commute.

“To put your results in perspective, one to four sleep incidents per hour is considered normal, four to 15 is a mild problem, 15-30 is moderate and anything over 30 is severe,” she said, and then paused. “You had 102 incidents per hour.”

Um ... I didn’t know what to say.

“We’d like to get you back in for another sleep study as soon as possible,” she continued. “This is serious.”

Over 22 years of living with SCI, I’ve received enough test results over the phone to earn my merit badge in “Deciphering Nurses’ Intentions.” In the world of disability, where chances are there is always something “wrong” with you from a medical perspective, knowing when to head to the ER and when to pour yourself a stiff whiskey and call it a night is an essential skill.

“Knowing when to head to the ER and when to pour yourself a stiff whiskey and call it a night is an essential skill.”

I sensed this nurse was genuinely worried about my wellbeing. That worried me.

I did the basic math in my head: 102 incidents per hour means I stopped breathing for 10 seconds or longer, almost two times every minute.

I expected the results to be bad, depressing even, but the idea of spending pressing even, but the idea of spending more than a third of my time not breathing caught me off guard. Still unsure how to respond, I did my best to turn my frown upside down.

“Is that at least a record?” I asked.
In Park City’s heyday, miners from around the country flocked to the snowy Utah town, dreaming of silver and riches. These days, the miners have been replaced by filmmakers and Hollywood hoi-polloi who make an annual pilgrimage for the Sundance Film Festival. This glitzy scene isn’t the typical place you’d find a New Mobility reporter, but thanks to the tenacity of David Radcliff, we were there this February when disability took center stage. This is Radcliff’s first time writing for NM, but he brings a long résumé that includes work for TV, Netflix, magazines and more. He braved Park City’s hills with his wheelchair to capture the vibe and see what attendees had to say about the eventual Audience Award-winner Crip Camp. “It was quite the adventure,” he says. “I think Crip Camp’s win speaks to the value of having disabled people telling their stories.”

When I started thinking about assigning this month’s feature on power soccer, a picture of Paula Larson geared up for sled hockey popped into my head. The fact that she is a San Francisco Giants fan (my team) might also have reinforced her status as my go-to sportswoman. Aside from seeing a power soccer demo at an adaptive sports day years ago, Larson had little knowledge of the burgeoning sport. Talking with people from various power soccer backgrounds gave her a deeper appreciation of the game’s nuances and impact. “The real story to me was how this game changed people’s lives,” she says.

As I write this, Cory Lee Woodard is gallivanting around Antarctica, knocking another item off his bucket list and scoping out the seventh continent’s accessibility so others don’t have to worry. In this issue, Woodard takes us to Morocco and on the camel ride of his dreams (also on the bucket list). As he is a previous New Mobility Person of the Year and a longtime contributor, it’s always a pleasure to have Woodard’s work in the magazine. The thing I don’t think most readers or followers of his website know is how relentlessly hard he works. Antarctica and Morocco may sound glamorous, but the logistics behind these trips, writing about them and maintaining his growing online empire are not. Still, you’ll never see those obstacles diminish his enthusiasm for traveling and helping others.

Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org
Accessibility Makes Sense
When I read something that’s so mind-blowingly amazing but so obvious after the fact, my mental eyes cross (“2019 New Mobility Person of the Year: Karen Braitmayer,” January 2020). Of course, if you don’t live your life in a chair or use assistive devices, you’re not going to think of certain necessities. I’m a family physician with experience in geriatrics. The percentage of those over 85 is growing quickly. We’re going to need accessible residences and public spaces. I loved this article and am inspired by Karen Braitmayer’s creations — beautiful, relaxed, streamlined spaces that everyone can enjoy. I want to go to Seattle!

Joisse Gefiltafish
Newmobility.com

Amazing
What an amazing article and person! Thank you for this information on Karen Braitmayer. It was a pleasure to read about her life and her contributions!

Susan Scofield
Newmobility.com

Communication is Critical
I have cared for a number of complex care quadriplegic clients as an RN. I agree that good communication from both client and caregiver is foundational to a great working relationship. What really stood out to me, though, was the client who noticed things about me, and remembered to follow up with questions in regards to previous conversations we had had. She had a lot to keep track of personally, yet she managed to show her interest in me as a person, and it really made an impact. I loved working for her.

Liisa Holm
Minneapolis, Minnesota

Keys to Home Care
I found this article very helpful for sharing various perspectives on caregiving relationships (“What Caregivers Care About,” January 2020). In any successful relationship, it’s important that all voices be heard. Accepting — let alone welcoming — someone into one’s home is sometimes a daunting, necessity-driven choice. In our home, we rub up against the employer/employee relationship and the family-like nature of spending many hours together doing tasks that are essential for living. Finding compatibility and compromise are pretty key, just like in any lasting interaction. With all due respect, one of my personal coping mantras is: This is better than a nursing home.

Sheila-Rea York
Newmobility.com

Feel the Bern
So glad to see you highlight Bernie’s disability plan (“Sanders Unveils the Most Comprehensive Disability Plan to Date,” Blogs, Newmobility.com, Jan. 31) To win this election, it will take all of us. Bernie calls on us to fight for someone else as much as we would for ourselves. That is how we win!

Maria Rinaldi
Newmobility.com

Looking Forward
2020 has so much potential — I hope we all realize this and can do even the little things that will make life better for people with disabilities (“New Year, New Start, New Energy,” Reframed, January 2020). I’ve been in this game for 37 years and I’m still willing to “fight the good fight.” Thank you, Reveca Torres, for starting the new year on a positive note.

Chuck McAvoy
Newmobility.com

Tech Ascendancy
Your words are inspirational and your use of technology to level the playing field proves that the mind and soul are the most important elements of humanity (“Technology: Winning The Uphill Battle,” Todd Against The Machine, January 2020).

Kenny Man
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“...and her contributions!”

Joisse Gefiltafish
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Segway + Baby Yoda = S-Pod

Segway unveiled its latest self-balancing vehicle earlier this year, much to the consternation of the general public. Best described as a blend of Baby Yoda's crib, the airplane-like seats used by future people in Disney's Wall-E and a giant egg, the S-Pod is a two-wheeled transporter capable of traveling up to 24 mph. Like other Segway products, the S-Pod relies on gyroscopes to keep riders upright and maintain balance. Unlike other Segways that move in response to how the rider shifts, the device is driven by a small joystick. Segway did not announce the S-Pod’s price, but did say to look for it later this year or early in 2021. Perhaps designers can use that time to work out some of the kinks, as the S-Pod quickly earned headlines for more than its “unique” looks when a reporter crashed into a wall just moments after being reassured about the product’s safety.

Scope out the S-Pod at segway.com/segway-s-pod.

Disability Data for Days!

The University of New Hampshire-based Institute on Disability released the “2019 Annual Report on People with Disabilities in America” on Feb. 11. In addition to its traditional focus on indicators like population size, educational attainment, employment, earnings from work, poverty and health insurance, this year’s Annual Report tracks statistics related to institutionalization, mass transit, housing and the role of the environment in the enablement/disablement process. Here are a few stats to tide you over:

In 2018, there were 322.2 million people living in the United States, and 40.6 million of them were individuals with disabilities — that’s 12.6% of the population.

People with disabilities are more than twice as likely to live in poverty in the United States. In 2018, 26.1% of people with disabilities lived in poverty while 10.7% of people without disabilities lived in poverty.

On the bright side, the gap between disabled and nondisabled people who have attained high school degrees shrunk to the smallest margin — 9.0% — since the report’s inception in 2008.

To read the full report, visit: disabilitycompendium.org.
Parking Rage

A confrontation over an apparent disabled parking violation quickly escalated into a nightmare scenario for one California wheelchair user this January. Moments after Phillip Kensler confronted a woman who was illegally parked in a disabled spot, Target security camera footage shows him being accosted by a man, later identified as Jimmie Tiger, the boyfriend of the woman in the car. Tiger pushed Kensler away and then violently picked him up and flipped him from his wheelchair onto the floor. The shocking footage made national headlines and was reposted widely on social media.

“He says, ‘You need to apologize to my girlfriend,’ and I didn’t know what to say,” Kensler told KRON-4. “He just got behind me and started to push me out of the store. I grabbed onto my wheels real tight and he picked me up in my wheelchair and he dumped me out of my wheelchair.” Kensler said he had to have a titanium plate and screws implanted in his wrist. Tiger was charged with attempted kidnapping and assault.


Midnight Needs

Calling a caregiver in the middle of the night can be complicated for quads living in residential settings. United Spinal board member, Backbones founder and Reframed columnist Reveca Torres suggests the Honeywell Home Series 5 Wireless Portable Doorbell as a simple, cost-effective solution:

“I bought this and it works really well! It has different ringtones so your PA can choose which they prefer, and you can adjust the volume. It has lights that flash, too! I added some tape to the raised button to help me push it, especially at night when I’m half asleep. And I attached it to a lanyard so I wouldn’t lose it.”

The doorbell is available via Amazon for $34.99, amzn.to/2SGWWv9.

Living Gets Easier

Fresh off her run as Ani in the Citadel Theatre’s production of the Pulitzer Prize-winning play Cost of Living, NM media columnist Teal Sherer is already gearing up for a May 22-Jun. 14 performance in her hometown of Seattle (seattlepublictheater.org). The 2016 play examines “diverse perceptions of privilege and human connection through two pairs of mismatched individuals: a former trucker and his recently paralyzed ex-wife, and an arrogant young man with cerebral palsy and his new caregiver,” according to promotional materials.

Cost of Living won the 2018 Pulitzer Prize for Drama and is now popping up in quality productions all over North America. NM contributor Regan Linton is slated to perform as Ani in Round House Theatre’s Washington, D.C., run, opening April 1 (theatermania.com).
MEMBER BENEFITS
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Membership in United Spinal Association is free and open to all individuals who are living with SCI/D, their family members, friends, and healthcare providers. Visit unitedspinal.org or call 800/962-9629.

UNITED SPINAL SUPPORTER

First in an occasional series about allies of the disability rights movement

WILLIAM WACHTEL: ACCESS IS A CIVIL RIGHT

As the owner of BillyBey Ferry Co., William Wachtel helped oversee New York City’s longest-running ferry company and, in conjunction with NY Waterway, was responsible for 32 boats that carried more than 32,000 passengers every day.

Needless to say, he was a busy man.

But when he received a call from United Spinal Association CEO James Weisman — at the time a complete stranger — asking why disabled people had to pay for their attendants’ fares on the NY Waterway ferry when they didn’t have to on paratransit rides, Wachtel changed the policy immediately. Weisman made sure Wachtel knew the law didn’t necessarily require such a change, but Wachtel instantly recognized the injustice. "I have a passion for all people who are the subject of discrimination," says Wachtel, "whether it’s for race, creed or disability."

And, a year or so later in 2016, when United Spinal Association became aware that the Statue of Liberty Ferry was dangerously inaccessible, Weisman dispatched a staffer who uses a power chair to board the boat. "It was indeed dangerous," says Weisman. "Eventually Bill’s law firm took the case directly, for free." That case is still wending its way through the federal courts.

Why did Wachtel take the Ferry case? For the same reason he immediately changed the Waterways policy when the problem was brought to his attention. "Just the same simple fact that people should not be discriminated against," says Wachtel. "It’s that simple." And for him, it is.

Son of the Civil Rights Movement

Wachtel, who is the founder of the Wachtel Missry law firm, grew up with the civil rights movement — literally. His father, Harry Wachtel, was Martin Luther King Jr.’s lawyer and close friend, and the two families socialized together. To this day, Wachtel is close friends with Martin Luther King III, and they both serve on the board of the civil rights organization their fathers started, the Drum Major Institute.

United Spinal has over 70 years of experience educating and empowering individuals with SCI/D to achieve and maintain the highest levels of independence, health and personal fulfillment. We have 50+ local chapters and 190+ support groups nationwide, connecting our members to their peers and fostering an expansive grassroots network that enriches lives.
His family background explains his drive to fight racial discrimination. But often, people who readily see how one group is mistreated are not always able to understand another group's struggle. How did Wachtel come to realize disability rights are civil rights?

It all started about 10 years ago when Wachtel was president of the commercial vehicle company Karsan, which built a fantastically-accessible entry for New York City Mayor Mike Bloomberg’s ill-fated Taxi of Tomorrow contest. In fact, it would have been the first totally ADA-compliant automobile ever produced in the world. Unfortunately, the contest winner was the miserably-inaccessible NV200. But during the contest, Wachtel got to meet prominent disability rights advocates, including Sen. Tom Harkin, who was the original sponsor of the Americans with Disabilities Act.

Wachtel was impressed by Harkin’s passion and conviction about disability rights and reflected on how both the Civil Rights Act and the Americans with Disabilities Act were signed into law on the same Presidential desk. Wachtel shared his thoughts with Weisman, who replied that disability rights are an extension of civil rights. "People with disabilities are often treated as second class citizens," Weisman told him.

"I said, wow, Jim, you've got me," says Wachtel. "And from that day forward I always saw the rights of the disabled as [the same as] the rights of people who are discriminated against because of color." And today Wachtel is a rock-solid supporter and ally of disability rights and United Spinal Association.

On Martin Luther King, Jr. day in 2018, William Wachtel joined interfaith leaders to pray for national unity.
GEAR HACKS
By Seth McBride

Out here in the wettest Oregon winter I can remember, project Home Hack is moving along nicely. As I explained in a previous column (Hacking a Home, July 2019), my wife, Kelly, and I are building our own accessible home, and we’re trying to do it as inexpensively as possible. After months of hassling with dirt work, water connections and permit applications, we finally have something to show for all the money we’re spending: a weather-tight 30-by-50-foot pole barn with a concrete slab foundation. Here are a few things I’ve learned about hacking a home so far.

Getting Out of the Ground
A common aphorism about building is that getting out of the ground is the hardest part, and so far for us, that’s no joke. That’s because you have to have your building plans set, permits in hand, utility hook-ups figured out and site work completed before you can start building anything above ground.

Last column, we had our initial dirt work done, but found that didn’t leave us with a flat pad large enough for the building size we wanted. It took us from May — when we did initial dirt work — until November before we had materials delivered and were ready to start putting up the building. In the interim, we had more dirt work done, drilled a well after learning the costs and hassles of hooking up to city water, resized our building and therefore had to reconfigure our layout. Then we drew up our interior and under-slab plumbing plans, secured our order with the pole building supplier, fought with the county over where our driveway could enter from (we lost) and, finally, got our permits.

I’ve spent a lot of time at the property; it’s a mix of sloped grass, flat dirt and a gravel driveway. Depending on weather and how much I needed to move around, I either drive around in my car, park on the flat dirt and get in my wheelchair there, or I transfer on to my dad’s ATV, secure my legs with a bungee cord and use that as my mobility device.

Meeting with dirt workers, contractors or county employees, I often encounter either casual ageism or able-ism. Needing to make the most efficient use of my time at the property (we live an hour away), I often am doing some other task with my dad when workers show up. More than once, they’ve addressed my Dad instead of me. And even when I’ve taken the lead and explained what I need, they’ve still directed questions to my Dad. They look at him, he shrugs his shoulders and says, “I don’t know, ask him.” Eventually they get it, but I often feel like I have to be extra confident and direct in my interactions.

Come November, we’d been going for six months and only had a flat piece of dirt and much smaller bank accounts to show for it. Because winter was rapidly approaching and Kelly is the only member of our building crew who isn’t over 65 or disabled, we decided to spring for a contractor to put up the exterior shell. Facing tasks like climbing around on the roof and manhandling 6-by-6 posts into 4-foot-deep holes, I figured we didn’t need to further disable our crew right from the start. Once our contractor got there, it took only 5 weeks to behold our slab foundation and weather-tight building shell — complete with windows and doors. It was time to move inside.

Finding Help
After dealing with everyone from general contractors to HVAC specialists, water filtration companies and others, I’ve come up with a rule: Never hire someone who says, “There’s one way to proceed, and if you don’t do it that way, you’re making a mistake.” There are always multiple ways to get to a particular outcome, and which one is right for your project is dependent on any number of variables — from budget to environmental impact, to personal preference, among others. Absolutes are the terrain of salespeople and those unwilling to think outside their own lane.

Listen to what people have to say, but once you understand the pros and cons of specific approaches, be confident in your decision making. Everyone is going to tell you the way you “should” do something, but nobody knows your priorities and, particularly, your access needs better than you. Find someone who is willing to work with you, rather than take your money so they can do things the way they want.
Moving Inside

We settled on a simple interior layout: three beds, two baths, a small utility room, a pantry closet and a large open space where our kitchen and living room will go. The floors will stay concrete — we’ve had concrete floors before and loved them, and they’re great for rolling because there won’t be any transitions. The accessibility priorities with the layout were:

• To have a kitchen that provides me with access to everything I need at a low height, while giving enough space for both Kelly and me to move around. We decided on a long row of cabinets against the wall, separated by 5 feet of open space from a 10-foot-long peninsula. This layout gives us significant lower cabinet storage with only a few high wall cabinets. A separate pantry closet will provide even more storage space within my reach. The back of the peninsula will feature a bench seat, allowing us to push our dinner table as close to the peninsula as possible, giving me a lower surface area to prep food. That allows us to keep our kitchen counters at standard height, saving expense and hassle.

• Easy access to outside. We’re moving to the country to be outside as much as possible, and I wanted our house to facilitate that. To bring the outside in, we decided to add two glass garage doors to our main living space, giving views and light, and the ability to open up doors on nice days and roll outside with no threshold. Even without a powered opener, I can open and close the spring-loaded doors with minimal hassle. We also put a 12-foot roof extension with a concrete slab at the back of the house. I’ll have enough space to keep an off-road wheelchair and my Bowhead off-road bike under cover and easily accessible, giving me full access to the hills, grass and woods on our property.

• To minimize hallways. They’re wasted space and are annoying to navigate, especially if I’m lucky enough to get so old that I need a power chair.

So far, interior progress has consisted of staining roof trusses — we’re vaulting the ceiling in our main living area — and framing the interior walls. There’s no way for me to reach the trusses without renting a cherry picker, and wall framing would be inefficient at best with my function. Instead of hands-on building, I’ve had to embrace being the errand boy. Need some work lights and caulk? I’m on my way to the hardware store. Kelly needs some water up on the scaffolding? I’ll go refill the bottle. We need to figure out the lengths of lumber for our wall plates? I’m at the plans, making a list so my Dad can keep nailing. When I’m on site, for now at least, my priority is to keep everybody else operating smoothly and not having to stop for tedious, time-consuming tasks. It might not be glamorous, but I bet it’s more productive than wrapping my quad hands around a nail gun.

MARCH 2020

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motioncomposites.com
Since the age of 5, Tucker Cassidy, 44, has always been interested in politics. In 2016, when the privatization of Medicaid in his home state of Iowa left him without the daily care he needed, Cassidy, a C4-5 quadriplegic, rolled into the fray and became, in his words, “the tip of the spear.”

Cassidy says he became a political activist to try to reverse the three biggest problems with Medicaid privatization of personal assistance in Iowa — how difficult it is to get caregivers, how difficult it is to stay independent and how difficult it is to find care agencies that accept Medicaid.

“The reason why all these things are difficult is because people who make laws aren’t listening to people like me,” says Cassidy. “They have no clue what our problems really are. And, unless we tell them, nothing is ever going to change, and things possibly are even going to get worse.”

Things did get worse. When private for-profit companies gained control of Iowa’s Medicaid system, homecare reimbursement rates were in doubt, which caused care staffing shortages and, eventually, agencies to stop providing services to Cassidy and other Medicaid clients. He was dropped by his provider in 2016, just as he developed a skin breakdown.

“My agency dropped me three days before Christmas,” he says. “So I was stuck in this nursing home that’s an hour and a half away from my house while I was paying mortgage payments on a house I should be living in.”

Ultimately, he was forced to sell his house in Iowa City and move to Waterloo. “I had to allow friends to do my bowel regimen and give me showers. These are people who’d never seen me naked, and I’d never imagined in a million years they’d see me naked,” he says.

Fortunately, he found an agency in Waterloo that accepted Medicaid recipients — but by then, he had depleted his savings, cashed in his IRA and started a GoFundMe. He is thankful for the support he received from friends and family but doesn’t want anyone else to go through that.

“It makes me angry to think that there are literally thousands of people out there who are not well-equipped, don’t have a safety net, don’t have the liquid assets I had at the time and don’t have the experience to navigate the system,” he says.

He realized the power of his story when it was featured in a 2018 campaign ad for Iowa gubernatorial candidate Fred

**Since the age of 5, Tucker Cassidy, 44, has always been interested in politics. In 2016, when the privatization of Medicaid in his home state of Iowa left him without the daily care he needed, Cassidy, a C4-5 quadriplegic, rolled into the fray and became, in his words, “the tip of the spear.”**

**The Tip of the Spear**

Cassidy says he became a political activist to try to reverse the three biggest problems with Medicaid privatization of personal assistance in Iowa — how difficult it is to get caregivers, how difficult it is to stay independent and how difficult it is to find care agencies that accept Medicaid.

“The reason why all these things are difficult is because people who make laws aren’t listening to people like me,” says Cassidy. “They have no clue what our problems really are. And, unless we tell them, nothing is ever going to change, and things possibly are even going to get worse.”

Things did get worse. When private for-profit companies gained control of Iowa’s Medicaid system, homecare reimbursement rates were in doubt, which caused care staffing shortages and, eventually, agencies to stop providing services to Cassidy and other Medicaid clients. He was dropped by his provider in 2016, just as he developed a skin breakdown.

“My agency dropped me three days before Christmas,” he says. “So I was stuck in this nursing home that’s an hour and a half away from my house while I was paying mortgage payments on a house I should be living in.”

Ultimately, he was forced to sell his house in Iowa City and move to Waterloo. “I had to allow friends to do my bowel regimen and give me showers. These are people who’d never seen me naked, and I’d never imagined in a million years they’d see me naked,” he says.

Fortunately, he found an agency in Waterloo that accepted Medicaid recipients — but by then, he had depleted his savings, cashed in his IRA and started a GoFundMe. He is thankful for the support he received from friends and family but doesn’t want anyone else to go through that.

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He realized the power of his story when it was featured in a 2018 campaign ad for Iowa gubernatorial candidate Fred

**WORST ATTENDANT STORY:**

I had a guy who ran over his own foot with my chair. He got really angry about it and wouldn’t let it go. **With Cory Booker and Rosario Dawson.**

**CAN’T LIVE WITHOUT:** My Google Pixel XL 2 Phone. I can literally do almost everything hands-free and it saves so much time. **With Amy Klobuchar.**
Buttigieg called me in between campaign stops, and we ended up talking for a half-hour. I was so nervous, even though I’d talked to him face-to-face three times before that. He was very quiet. He wanted to just listen and hear my thoughts.

I told him that infrastructure needs to include people with disabilities. If you want us to lead independent lives, you need to provide accessible transportation and curb cuts. I don’t even have sidewalks on my street, and that’s a major barrier to going to the grocery store or renting a movie. I told him if he thinks about functional accessibility with universal design, then he could make mobility easier for everyone, not just people with disabilities. I’ve been telling this to all the candidates, but he got it right away: If you create an infrastructure that can support people with disabilities, parents with strollers and an increasingly aged population, everyone is happy. He said, ‘Yeah, that’s a good way to look at things.’ He and I also talked about the need and a few ideas for creating better access to long-term services and supports.

Hubbell. Hubbell lost his race, but Cassidy’s ad went viral. Cassidy joined Iowa’s Democratic Party and the Disability Caucus and became an early member of a disability-focused political action committee called Accessibility For All.

He’s also one of the organizers for United Spinal’s #UpgradeMedicaid awareness campaign. Last spring, he helped organize Meet With Your Legislator Day, which saw the highest turnout of wheelchair users anyone in the Iowa state capital had seen. Attendees got a chance to talk to their representatives and tell their story. “I realized storytelling is really the way to get people to understand what’s happening,” he says, “so we have to get more people to tell their story.”

There’s never been a better time to tell those stories. As the host of the nation’s first primary, Iowa plays a critical role in the early stages of the presidential race. Most candidates vying to run for president make their first campaign stop in Iowa, which has given Cassidy the opportunity to bend the ear of some pretty big names.

SOCIAL MEDIA WIN
Connecting with a Candidate

An unexpected Facebook message from one of Pete Buttigieg’s campaign organizers led to a one-on-one phone call with the candidate himself and a chance for Cassidy to influence his disability platform.

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QUESTIONABLE JUDGMENT: I went to this apple orchard that had the steepest gravel driveway. When I came back to it and saw just how steep and tall it was, I was like, “That’s one of the dumbest things I’ve ever done.”

WHY I JOINED UNITED SPINAL: I wanted to get more involved and be more engaged with the disability community. Being a member has allowed me to network with others with disabilities and see what we have in common.
In 1969, the eyes of the nation focused on rural Woodstock, New York, as thousands of people from all across the country descended on a farm for what would become arguably the biggest concert of the century. Around the same time, just over an hour away in Rock Hill, New York, a bunch of disabled kids were enjoying an equally transformational moment at Camp Jened, a small summer camp.

The friendships and mutual understanding those campers developed would go on to serve as key pillars in the nascent disability rights movement, with the campers leading the way as the movement’s architects. The camp, the campers and their legacies are the subject of the documentary, Crip Camp, which was produced by Barack and Michelle Obama for Netflix, and featured at the 2020 Sundance Festival, where it won the Audience Award.

In “Crip Camp,” David Radcliff talks with the film’s co-directors, Jim LeBrecht and Nicole Newnham, about why this documentary of a long-ago counter-cultural time is the movie we need today. Then, Radcliff takes us “Behind the Scenes at Sundance,” reporting on the festival’s efforts to embrace the disability community and the work that still needs to be done.

Though it now boasts President Barack Obama as one of its executive producers, the powerful Netflix documentary Crip Camp wouldn’t have happened at all, if not for co-director Jim LeBrecht’s cherished memories of Camp Jened, a touchstone of his young adulthood.

Located just down the road from the Woodstock experience that rocked Northern New York in 1969, Jened offered disabled teens of the late 1960s and early 1970s a unique oasis of both independence and community. For LeBrecht, who grew up often feeling isolated by his spina bifida, that was a potent combination.

“Jened was the first time in my life I felt like I wasn’t a burden,” LeBrecht said. “It was a place where I could actually be one of the cool kids.”

At Jened, campers like LeBrecht weren’t defined by the constraints of their various disabilities, but by the shared power of their teenage dreams and ambitions. They cooked meals, played musical instruments, hooked up and smoked dope, all under the watch of camp counselors who essentially treated their charges as peers.

In other words, this ramshackle camp laid the perfect foundation for a revolution.

“It became an important part of the disabled civil rights movement,” LeBrecht said. “It wasn’t the start of it, as things had been percolating throughout the country. But what happened at that camp — each of us learning our lives could be better — was so motivating that a lot of us went on to get involved politically.”

That wave of political involvement would ultimately shift the United States in radical ways, helping to usher in not only enforcement of Section 504 of the 1973 Rehabilitation Act but also the landmark Americans with Disabilities Act of 1990. Judy Heumann, a Jened camper and counselor who formed a close friendship with LeBrecht in their teenage years, would go on to work for two American presidents and to become a world-renowned advisor on international disability rights.
Digging Up Memories

The spirit of Jened was a countercultural force with which to be reckoned. Even in adulthood, having secured a career as a film and theater sound designer, LeBrecht retained a powerful love for his Jened cohort. In 2015, he turned to his friend and colleague, documentarian Nicole Newnham who won an Emmy for Collisions, with an interest in channeling those formative memories into a feature-length documentary film.

“Jim sent me a Facebook page where campers and counselors from Jened had collated photographs,” Newnham said. “Just the still photographs were such eye-openers for me, because they showed kids with disabilities in a different light than I was used to seeing them in the media. I thought, if these still pictures of the camp could be that transformational, what could a film be?”

At Newnham’s suggestion, the pair agreed to serve as co-directors on what would reveal itself to be a sprawling and ambitious project. Their research required not only interviewing numerous alumni of the Jened experience but also diving deeply into a civil rights movement that isn’t typically covered in schools. Throughout it all, LeBrecht’s intuitive understanding of Jened and of life as a disabled American provided what Newnham describes as the project’s “north star.”

“It was apparent to me that what was really different and exciting about this was Jim’s personal perspective,” Newnham said, “and his being able to do for other people, through this film, what he has done for me over the years: introduce me to this community and to its experiences and even shift the way I might have [otherwise] thought about disability.”

“The film is a blueprint of what inclusivity and belonging looks like.”
— Denise Sherer Jacobson (center in photo above)
But it wasn’t until they happened to uncover handheld documentary footage, archived by a Northern California collective known as The Peoples’ Video Theater, that Newnham and LeBrech realized just how personal LeBrech’s relationship to the film was likely to become.

“Somehow I had remembered this group of hippie videographers had come to camp,” LeBrech said. One of them, Howard Gutstadt, handed LeBrech a camera. “We had strapped it to the back of my wheelchair and we went on a camp tour.”

That specific memory, coupled with the remarkable discovery that Peoples’ Video Theater still retained a treasure trove of handheld documentary footage of 1970s Jened, expanded not only the scope of the Crip Camp project but also LeBrech’s own sense of nostalgia. Suddenly he found himself face-to-face with the people and the moments that had shaped his young adulthood — oftentimes filmed by teenage LeBrech himself.

“Those videographers, and the sense of agency they gave us, was something pretty extraordinary,” LeBrech said. “They just handed us cameras and treated us like who we were: teens and young adults, not patients.”

Armed with footage shot by the Jened campers themselves, and with a narrative arc that would take its teenage protagonists from mischievous campers to world-changing advocates, LeBrech and Newnham were even more convinced of their unique opportunity to illuminate a complex view of disability.

“We had a sense that, hey, maybe something is really happening here,” LeBrech said. “Maybe we can actually open up minds and change some of the narrative.”

‘Piss on Pity’

Seeking to sidestep typical problematic tropes, the filmmakers pledged to focus Crip Camp on the dynamic relationships between the campers rather than take cheap tugs at audience heartstrings.

“Jim wore a T-shirt, during the making of the film, that said ‘Piss On Pity,’” Newnham said, “and that was our ethos. These stories are all delivered in such an empowered fashion by [the interviewees], in a spirit of not being passive and of not accepting ‘no’ for an answer. That’s not pity. We really didn’t want to make inspiration porn.”

In its commitment to eschew cheap emotional ploys, Crip Camp found an ideal central figure in the sharp-witted and morally unshakable Heumann. Introduced in the film as a Jened camp counselor who draws upon her natural community-organizing instincts to plan a dinner menu, Heumann ends the film having led over 100 disabled protestors in the longest sit-in at a federal building in American history.

“It was exciting to learn from [Jim and Nicole] about the footage they were finding and to help them look for things and gather things,” Heumann said. “It was really a process of something being born or created, but in a very non-traditional way. And it’s powerful to get those real stories out there that can go pretty deep.”

As it was for LeBrech, the process of diving back into the footage of Jened was an invigorating experience for Heumann. Though she has been written about and filmed for other projects, the life-long advocate recognizes a clear link between her coming-of-age at Jened and her current significance on the world stage.

“My camp experiences happened at times I was realizing my friends who didn’t have disabilities were able to do things I couldn’t do,” Heumann said. “[Nondisabled] friends were going out on buses or trains, or getting in and out of cars, or visiting people’s homes. So with the friends I made at camp, we were able to talk about real barriers we were experiencing. … We were really talking about our goals and aspirations, and we were talking about discrimination. These were less likely to be the kinds of conversations [other] kids would have had.”

Like Newnham and LeBrech, Heumann is hopeful the existence of Crip Camp will elevate not only an awareness about the civil rights struggles of the past but of the day-to-day struggles, both physical and interpersonal, that continue today for members of the disabled community.

“Not knowing the story [of Jened] is one thing,” Heumann said, “but not knowing the story of your neighbor
who has a disability, or not recognizing it as a denial of rights if he can’t do the same things you’re able to do — that’s different. Because this isn’t just about the lack of an accessible bus; it is about the question of why that bus is not accessible. It’s about whether [nondisabled] people are ready to acknowledge they view us in a non-equal way.”

Whatever shift in perception Crip Camp might prompt after its global Netflix release, LeBrecht says he feels bowled over by the enthusiastic response his passion project — his own coming-of-age story — has already received.

“It’s hard to put into words my feelings about that first night [at Sundance],” LeBrecht said. “The applause, how loud it was, and knowing the audience was seeing all these incredible people on stage, many of whom have obvious disabilities. It really felt like something like this had never happened before. That kind of positive reception — it really gives everything even greater weight.”

“I loved Crip Camp so much. It was just beautifully done. I wasn’t expecting to be so moved by it, honestly. It was just such a relief that it wasn’t inspiration porn, you know? To see that this film was possible, and that it had approval from Sundance and from the Obamas, was so important. It never turned into a [typical disability] story of ‘Oh, we hate ourselves’. Usually these kinds of movies are just chock-full of hot messes, but this one was really something different.”

— Keah Brown, author of The Pretty One and creator of #DisabledandCute

**Crip Camp Reflections**

An Interview with Former Jened Camper Denise Sherer Jacobson

Author Denise Sherer Jacobson is one of the campers featured in Crip Camp. She recently completed her memoir, My Camp Jened Summer: A Teenage Misfit’s Tale of Love, Heartache, and Belonging. Her first book, The Question of David: A Disabled Mother’s Journey Through Adoption, Family, and Life, documents how she and her husband, both of whom have cerebral palsy, became one of America’s first couples with significant disabilities to adopt and raise a baby. We asked her to share her thoughts on Crip Camp.

**New Mobility:** When did you and Jim LeBrecht, the director of Crip Camp, first talk about his documentary idea?

**Denise Sherer Jacobson:** That conversation began around 2011 when Jim and I bumped into each other on the street. He asked what I was up to and I told him I was working on my second book, which is about my first summer at Jened. His eyes lit up and he said he always dreamed of making a film about Jened. That’s when we started getting together from time to time to talk about what that might look like.

**NM:** What was it like to see your transformation from a teenager to an adult on the big screen?

**DSJ:** As a teen, I had so many doubts and fears about my future because of the messages I got [about disability] from family and society that painted a very grim reality. Before Jened, I was just an observer. At Jened, I became a participant! I felt very alone in my feelings until I went to Jened. Jened helped me find validation and confidence, compassion, and resolve that empowered me. I figured if I could feel valued at camp, then I could feel valued in the outside world. The film proved I was right.

**NM:** What do you think of how the movie turned out?

**DSJ:** I’m just awed. I really believe it will have a far-reaching impact beyond the obvious disability-related issues because it clues people in on how we readily dismiss and devalue “the other.”

**NM:** What was the response to the movie at Sundance?

**DSJ:** The response has been incredible! At Sundance, people came up to me in tears sharing they had never seen a film like Crip Camp. Many said that they had no knowledge that there even was a disability movement. The film is a blueprint of what inclusivity and belonging looks like.
It’s no secret most paid film journalists tend to be of the white, straight, male and non-disabled varieties. This year, however, the Sundance Film Festival’s new Press Inclusion Initiative offered stipends to help load Park City, Utah, with journalists that looked and lived a bit more like the diverse filmmakers, characters and documentary subjects they’d be covering.

According to the Sundance Institute, 317 journalists and freelancers applied for this inaugural stipend program, and 14% of those applicants were people with disabilities. Among the 51 writers approved for stipends, 25% identify as disabled.

I was among that 25%.

“I hate to tell you,” a Sundance-savvy friend of mine wrote me shortly before my Utah trip, “but it will be a bit of a challenge to get around town. Main Street is at the top of a steep hill, and that’s where most of the receptions and parties are.”

Oh, boy.

“Main Street is at a little bit of an incline,” wrote another friend, “which may be an issue in either your wheelchair or on your crutches, especially if it all ices over.”

Of her own volition, my step-grandma in Omaha began researching Park City, even calling her own sister who lives near the area. A wheelchair-using friend of mine loaned me new (and thicker) tires. Crutch tips capable of cutting through ice suddenly appeared in my mailbox.

And I bought myself a new and probably unnecessarily large winter coat, only because it felt like, well, I should do something. A world of other people’s concerns had managed to burrow its way into my head: Was I visiting a film festival or summiting Mount Kilimanjaro?

My first night in Park City left me wondering, with some amusement, if all that commotion had been necessary. The rideshare from the Salt Lake City airport to the Rey Theater in Park City was easy enough. The already-fallen snow seemed more picturesque than menacing, and I arrived at my destination with plenty of time before the world premiere of Crip Camp lit up two simulcast screens.

That documentary film — with its powerful story of disabled people forming friendships, sharing grievances and then turning their relationships into a platform for advocacy — reminded me that routinely proving our own capacity for ingenuity and survival is simply a function of disabled life.

But that same night, the film also reminded me of the importance of community. After all, the fact that so many people wanted me to have a great and safe time at Sundance is just as meaningful to me as making it understood I can create such an experience without risk to myself.

So, let me pause here to recognize that I did have a great time at Sundance. In fact, as I think back to the four days I spent in Park City, my thoughts are filled not with the topographic challenges I
expected to encounter, and not even with the stories of personal triumph I’d perhaps expected to write about here.

Instead, what I remember are the days spent surrounded by friends, many of whom are themselves disabled, and many of whom benefited from the same press stipend program that had brought me to the festival. In few other places would our voices be collected and amplified for the benefit of an industry. All too often — on-screen and behind the scenes — we are left somewhere in the margins if we’re anywhere at all.

**Meaningful Moments**

Thanks to Sundance, I met voices and writers from the disability community whom I’d long admired only through Twitter. I partied with disability-rights activist Judy Heumann, herself a central figure in *Crip Camp*. I conspired with Lawrence Carter-Long of the Disability Rights Education and Defense Fund. I unexpectedly ran into a nondisabled friend from Chicago while inching my way down the (yes, very steep) slope of Main Street, then bumped into another friend from Austin, Texas.

I wheeled past the snowbanks in Park City alongside Nic Novicki and Teale Sperling, two friends who are little people — each of us realizing how nice it was that none of us had to crane our necks to talk as we pressed forward.

For me, Sundance 2020 provided a well of small but meaningful moments like these. But it was also a reminder of my own privilege — my own ability to speak and to hear and to see. It was a reminder that there is still a lot of work to be done, at this festival and elsewhere, to make these spaces truly equitable and inclusive. And while there are several events I was able to attend, there were several others I avoided simply because of clear access oversights.

We all know the kinds of events I mean: mixers held at the top of two flights of stairs. Press screenings or parties situated in the middle of a hill. Industry conversations without a curb cut in sight.

And the irony of Sundance’s “Equality Lounge” — an ongoing salon highlighting issues of inequity across race, gender and disability — being at the summit of that infamously treacherous Main Street should, hopefully, be lost on no one.

The truth is stark: Many of the fights highlighted in *Crip Camp* — struggles for true access and inclusion and visibility — are still being fought today and sometimes even in spaces that may be, in all other ways, well-intentioned and thoughtful.

Perhaps nowhere was this reality more clearly underscored than in a morning screening of *Crip Camp*, at which the theater’s CaptiView, a portable viewing system used by Deaf patrons, malfunctioned. This technological failure was a moment of heartbreak for Michael McNeely, a Deaf-blind law student and film critic who attended the festival with a passion for *Crip Camp’s* story of disability rights. In his opinion, the CaptiView system, which is vulnerable to interfer-
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to follow robust conversations with ease but also to enthusiastically add their own voices to later Q&As.

Keah Brown, an accomplished disability advocate with cerebral palsy and the author of The Pretty One, had similar feelings of ambivalence about her Sundance experience. As she doesn’t use mobility aids, Brown knew Park City would likely present her with some “pretty rough” ambulatory challenges but was heartened that Sundance liaisons were “so wonderful and helpful” in fielding her questions prior to her visit.

What Brown wasn’t prepared for, she admits, was the mood of indifference she encountered from some Sundance volunteers once she was in the thick of the festival action. “It had always been a dream of mine to go to a film festival,” Brown admits, “and the movies and the panels were the aspects I thoroughly enjoyed. But there was such a disconnect between the people I’d been talking with [before the festival] and the people on the ground.”

Inconsistent Access

While Brown hoped there’d be options available to help transport her up and down the steep Main Street artery that cuts through the festival, she instead found herself endlessly sinking money into rideshares just to keep her body from collapsing — all because the free Sundance shuttles that were available would

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drop her only at the bottom of the hill.

“I walked up and down Main Street that first night,” she remembers, “and I thought, there’s no way I can do this for four days. Eventually, I was telling the rideshare drivers, ‘I’m desperate. Please just drop me as close as possible.’ It was just frustrating that there didn’t seem to be a true disability plan in place once we got to the festival. The stipend is wonderful, but what is being done for people once the festival is going on?”

Mel Addington, a film festival programmer who attended Sundance prior to acquiring multiple sclerosis three years ago, echoed similar concerns this year.

“The pre-festival team was super-nice and communicative,” Addington said. “I can’t stand for long periods, but they said, ‘Just let people know you’ve requested in advance to sit in the lobby.’ But the people at the venue weren’t reading the notes that were given to them. I felt like I had to explain my life history 50 times.”

Addington also noted a friend of hers who is a wheelchair user couldn’t enter a tent for press and industry screenings because the entryway was too narrow—a fact that was, unfortunately, only discovered at the moment of their arrival.

“It was like every day the rules changed,” Addington said, “and some of the volunteers were great, but others always wanted to make sure I understood how accessible they were being to me.”

Nevertheless, Addington, Brown, and McNeely all indicated willingness to return to Sundance in the future, perhaps to help keep this world-renowned festival progressing toward a truly equitable experience.

“[As a festival organizer], I know Sundance is trying really hard to get a lot of things right,” Addington said. “Often if you’re running an event like this, you’re not even thinking enough about these disability equity issues, which sucks because that’s such a big part of the population that you’re leaving out. It’s so important.”

“Watching Crip Camp for the first time, I was reminded of how rare it is to see teenagers with disabilities on a big screen being just that — teenagers. Laughing and smiling, with sweet summer crushes and streaks of fierce independence. Crip Camp captures the complexity and humanity of living with disabilities, and it honors this community of young people who would go on to lead the disability rights movement.”

— Michelle Obama, executive producer of Crip Camp and former first lady of the United States
Arizona athlete Tim Surrey uses a Top End Pro basketball chair to play lacrosse. Photo by Loren Worthington.
wheelchair court sports are a blast. And modern sports chairs are built to be faster and more agile than ever, making them even more fun to use and very exciting to watch in action.

For athletes, putting one of today’s sports chairs through its paces results in a rush of acceleration, velocity and snappy turns — it’s a cool synergy of human and machine. Constructed of high-strength alloys, these chairs are lightweight, strong and rigid. They have high-cambered wheels and aggressive seating positions combined with anti-tip casters for rear stability, allowing athletes to get the most out of their bodies.

Here is a look at the current crop of specialized sports chairs, the sports they’re designed for and the players who use them.

Above: Ryan Baker (in the white shirt) rocks a Melrose Wolverine sports chair.
Wheelchair lacrosse is the newest, and arguably fastest-growing, court sport, having expanded to over 20 programs across the U.S. since its debut in 2009. It’s played on a roller hockey rink that is approximately twice the size of a basketball court, and a majority of lacrosse players use basketball chairs since the rules governing chair specifications are identical for both sports.

“I’ve played a lot of adaptive sports and I like how well wheelchair lacrosse translates from its nondisabled counterpart,” says Ryan Baker, a 47-year-old T6 para who co-founded the sport. He fields the attack position for the San Diego Seals wheelchair lacrosse team using a Melrose Wolverine sports chair.

“It is one of the few chairs made specifically for lacrosse,” says Baker, about the Wolverine. “I like it because it has a custom-welded frame that’s light and very strong.” Baker runs 17 degrees of camber on 26-inch Spinergy wheels. “I find that 17 degrees is the sweet spot for stability, quick turning and not losing energy when the front wheels come up. This is important in lacrosse because we are sprinting almost twice the distances as wheelchair basketball players.”

Camber refers to the side-angle of the rear wheel, and the average sports chair camber ranges from 15 to 20 degrees. Greater camber enables quicker turns and better stability, which is especially important at high speed. Trade-offs for greater camber, especially when you go up to 20 degrees, are wheels that stick out, which makes the chair quite wide, and drag caused by additional toe-out — meaning the backs of rear wheels are closer together than the front — when the front casters lift up. Optimal camber depends on the sport, position played and athlete preference.

Baker is the customer service manager for Spinergy wheelchair wheels and says that most players in court sports use Spinergy wheels because of their combination of strength, stiffness and light weight. He adds that quad rugby chair manufacturers are incorporating thicker 5/8-inch rear-wheel axles versus the standard half-inch size for added strength. “This is frequently an option when ordering basketball and lacrosse chairs,” he says.

Once a player knows what their needs are, a custom-welded fixed frame sports chair is preferable because they can be made lighter and stronger. However, most sports teams use adjustable chairs for their ‘club chairs’ — team chairs for new players to try or use as backups — because they are generally less expensive. And more importantly, it takes most players a couple years of experimenting with different adjustments to find the optimum chair configuration.

“I was focused on playing nondisabled sports after my injury until I saw wheelchair lacrosse in 2014,” says Chris Van Etten, 29, a Marine Corps veteran who lost both legs in Afghanistan. “I realized I was letting the stereotype of disability get in my way, so I tried lacrosse, loved it and have been playing since 2014.”

The PER4MAX Thunder Basketball chair is Van Etten’s choice for lacrosse. “It fits great and is tough,” he says. “My original PER4MAX is four years old and has never broken. I got it through a grant from the Semper Fi fund for veterans, and just got a second one through the VA.” Van Etten says the key for lacrosse chairs is setting them up with a lower center of gravity than you would for basketball. “Not too low, but low enough so when you get hit you stay upright.”

Although “center of gravity” can mean how high or low a player sits in their chair as in Van Etten’s reference, most of the time it refers to how close the rear wheel axle is mounted to a player’s center of mass. The closer that axle is to a person’s center, the quicker the chair turns and the longer a player’s push stroke can be. This also makes a chair extremely tippy, which is why sports chairs incorporate one or two anti-tip bars with high-performance casters.
ty-nine years later, rugby is just as important. It keeps me in shape, plus the only time I’m free from my intense neuropathic pain is when I’m training or playing and so focused that I don’t feel it.” McGuirk says other benefits of the sport include hanging with the team and sharing “SCI life hacks” that range from sex and transfers, to managing bowels and bladder, to travel tips.

McGuirk was injured in 1990 and started playing nine months after acquiring his C7 SCI. Since then he has amassed an impressive resume that includes playing for Team USA in the ’95 and ’98 World Championships and in the 2000 Paralympics. Although he has retired from tournament play, McGuirk still coaches a local team and also plays in pick-up games on weekends.

In quad rugby, players are assigned a point value ranging from 0.5 to 3.5 based on their level of injury or amount of upper limb control — the more muscle/limb control they have, the higher the point value. Each team must not let the total point count of their four players on the court exceed eight. Higher-point competitors play offense. They wheel the ball toward the goal while lower-point players are on defense, trying to guard and hook offensive players. Offensive chairs have smooth impact guards for movement, and the impact guards on defensive chairs, known as pickers, are designed to try and hook an opposing player.

The Vesco Hi-Point Offensive is McGuirk’s choice for a quad rugby chair. He is also a Vesco sales rep, a job he has been doing for 10 years. He was hired because he knows the teams and players, and he has a deep knowledge of how to fit and adjust rugby chairs to enable maximum performance.

“A lot of times I’ve been able to help a player dial in their chair by making a simple upholstery adjustment, which is easy to do, but can make a big improvement in performance,” he says. “I like Vesco chairs because they are custom built for the player and are made out of heat-treated aluminum that makes them both extremely strong and one of the lighter quad rugby chairs on the market. I’m classified as a three, so the light weight is important for speed.”

In quad rugby, offensive players generally push 25-inch wheels that provide better top speed, and defensive players run smaller 24-inch wheels that are better for short, quick bursts of acceleration.

“I was mainly using a power chair until a friend invited me to check out a quad rugby scrimmage,” says

**SPORTS CHAIR MANUFACTURERS AND MODELS**

**Melrose** makes a complete line of sports chairs using high-quality aluminum, manufactured with the latest CNC technology. Its sports chairs are also available in titanium. Of special interest is the Melrose Rhino, a custom-built offensive and defensive quad rugby chair. MSRP for quad rugby chairs, without accessories, starts at $3,600. The titanium chair base price starts at $6,545. [melrose-wheelchairs.com](http://melrose-wheelchairs.com)

**PER4MAX** manufactures Thunder elite performance sports chairs. The Thunder series includes basketball, tennis, mini and adjustable chairs. The MSRP is $2,995 for all of these except the adjustable, which has an MSRP of $3,295. Standard weight is approximately 19 pounds. For an upcharge of $400, many of its chairs can be made from 700 series aluminum to reduce weight and increase rigidity. [per4max.com](http://per4max.com)

**Quickie** by Sunrise makes high-performance, lightweight wheelchairs for basketball and tennis out of top quality aluminum. The MSRP for both the All Court Basketball and Match Point Tennis chairs is $2,950 and titanium versions of each chair are available at an MSRP of $4,075. [sunrisemedical.com/manual-wheelchairs/quickie/sports-wheelchairs](http://sunrisemedical.com/manual-wheelchairs/quickie/sports-wheelchairs)

**Spinergy Wheels** can be found at [spinergy.com/content/wheelchair](http://spinergy.com/content/wheelchair)

**Top End** by Invacare’s flagship chairs, the Schulte Series 7000 Basketball, and T-5 7000 Series Tennis chairs are custom-made, custom-fixed sports chairs made out of heat-treated 7005 aluminum, which enables strong chairs that are lighter weight. The MSRP for the Schulte Series 7000 Basketball Chair is $3,149 and is $3,295 for the T-5 7000 Series Tennis Chair. Top End offers Pro Basketball and Pro Tennis adjustable sports chairs for players who are still making adjustments and learning to dial in their chair for maximum performance. Its Pro Basketball chair’s MSRP is $2,795 and its Pro Tennis chair’s MSRP is $2,595. [topendwheelchair.invacare.com](http://topendwheelchair.invacare.com)

**Vesco Wheelchairs** specializes in custom quad rugby chairs that are available in offensive and defensive models. Vesco chairs are made from ultra-strong, lightweight, heat treated aluminum. The MSRP for both chairs is $6,600. [vmcrugbychairs.com](http://vmcrugbychairs.com)
If you’ve found the sport for you and are ready to get a chair, here are a few tips to make sure you wind up in a setup that works for you:

- Sit in as many different chairs as possible. Go to practices with your local adaptive sports teams and programs and ask people with similar levels of function if you can try their chair. Small changes in seat height, dump, center of gravity and footplate position can make a big difference in stability and performance, so it’s a good idea to try a variety of setups before you commit to measurements.

- If you’re just starting out, consider buying a used chair. It’s nearly impossible to get the measurements of your first chair perfect, so while you’re learning and getting stronger, save some money by buying a used chair. Spending big on a shiny new ride usually isn’t worth it until you’re sure you are in it for the long haul and you have your measurements dialed in.

- Once you have a chair, don’t be worried if it doesn’t feel perfect right away. Even with a non-adjustable sports chair, you’d be amazed how adjusting the seat sling and backrest upholstery, changing your cushion or changing your footplate position — these usually are adjustable — can have a big impact on fit.

- No sports chair is complete without the proper strapping. Many manufacturers offer options with click-tight hip and foot straps (if you’re looking to save money, snowboard binding straps can be used as well). Depending on function, athletes will often use weight lifting belts as chest straps, and Velcro webbing to secure their legs against the chair. Generally, the less function you have, the more strapping you’re going to need to properly secure and stabilize yourself in a chair.

- Don’t be in a rush. Getting the perfect chair setup can take years of small adjustments, but it’s worth the effort. A proper chair setup can minimize whatever functional deficits you have and allow you to maximize your remaining musculature — it lets you do you, only better.

Todd Wolfe, a C5-6 incomplete quad who was injured 14 years ago. He figured he would just watch, but the team got him transferred into a club chair, put some sticky quad rugby gloves on his hands and sent him out onto the court. “All of a sudden I could push! I felt like a superhero and liked it right away. I started going to practices and scrimmages, built up my arm strength and transitioned to using a manual chair full time.”

Wolfe uses the Melrose Low-Point Defender chair in titanium as a player and coach for the Cal/Nevada High Fives. He is also a sales rep for Melrose. “After playing for a while I got to know the players as well as the various funding and grant organizations, and I was offered a rep job at Melrose,” says Wolfe, who also owns a tree service company.

Wolfe likes Melrose chairs because they are custom built to the player’s specs and have a fast delivery time of about six weeks. “I especially like Melrose’s titanium chair because it’s super light and super strong. After three years of hard hitting, plus travel, my chair still looks as good as new,” he says. “The light weight of titanium is also an advantage for a low-point player because it enables me to accelerate quicker. The downside is it is much more expensive, almost twice the price as aluminum.”

Josie Portell, 12, is a point guard with the Rolling Rams wheelchair basketball team and uses a PER4MAX Thunder basketball chair that was paid for through a grant from the J-Rob foundation. Portell, who has spina bifida, started playing basketball at age 7 in a local team’s club chair, which worked well until she outgrew it. “What I like about my PER4MAX Thunder is the custom fit. It is super light, turns quick and is really stable, which allows me to go fast,” she says. Always trying to up her game, Portell is running 25-inch Spinergy 24-spoke wheels and finds that 18 degrees of camber is the sweet spot for quick turning and lateral balance, yet narrow enough to get her in close under the boards.

Portell’s favorite things about basketball are making new friendships, practicing her moves and experiencing the payoff when hard work leads to improved skills during a game. Portell is also a dedicated student and has her sights on playing basketball at the collegiate level.

The Top End Schulte 7000 by Invacare is Myreo Dixon’s chair of choice for basketball. Dixon, 49, is in his 31st year as a T11 para, and has been playing the sport for 22 years.

“This is my first season playing in the 7000 and I love it,” says Dixon, who played in the previous Schulte model for eight years. “It’s everything I want. It’s custom made for me — light, strong, quick and smooth. I’m running 20 degrees of camber, which really makes for snappy turns, and using 25-inch Spinergy 24-spoke wheels.” In basketball, the advantage of 20-degree camber...
is quicker turning. But a disadvantage is the wheel slants out so far that it makes the chair wider, which can interfere with ball handling and squeezing between players to get to the hoop.

Dixon was able to get his chair through a grant from the Rehabilitation Institute of Michigan Foundation, where he is the coordinator for the Adapted Sports Program. Dixon also uses his Top End Schulte 7000 to play tennis and lacrosse.

For Zack Wentz, 26, the Quickie All Court by Sunrise Medical is perfect for recreational basketball. “I like playing basketball with friends and in fundraiser games, but with my level of injury, I’m not competitive at the elite level,” says Wentz, who in his 11th year as a C7-T1 quad. He uses his All Court to play in an annual basketball tournament fundraiser he founded at University of Southern California six years ago to raise money for ‘Swim With Mike,’ a national campaign that provides scholarship funds for athletes with disabilities.

“What’s cool about the All Court is it’s fast and agile. It is great for basketball yet has the flexibility to be good on the tennis court,” says Wentz. He says it accelerates and turns so fast that it’s elevated his tennis game. “Now I’m hooked and am going to purchase a dedicated tennis chair, thanks to a grant from the Kelly Brush Foundation. And the All Court is also good for working out in the gym.”

Letherbee increased the camber on his current Match Point to 20 degrees, which he says really makes a difference in snappy turns. He had been using everyday 12-spoke Spinergy wheels and recently upgraded to 24-spoke Spinergy Spox. “My game really improved with the much stiffer wheels. I didn’t realize how much energy I was losing to the flex of the 12-spoke rims,” he says.

Letherbee also likes the Match Point because it is strong. “I’m 6-foot-1-inch tall and weigh 220 pounds, so I put a lot of force on my chairs, and the Match Point holds up.” He chose the option of a folding back rest, which makes it easier to transport the chair in his convertible car.

For more information, or to try one of these sports, contact one of the national associations below. Some local park and rec departments sponsor wheelchair teams and your Center for Independent Living may know if there is a program or team near you.

**RESOURCES**

- Challenged Athletes Foundation, challengedathletes.org
- High Fives Foundation, highfivesfoundation.org
- J-Rob Foundation, jrobfoundation.com
- Kelly Brush Foundation, kellybrushfoundation.org
- Melrose Wheelchairs, melrosewheelchairs.com
- Rehab Institute of Michigan Adapted Sports Program, rimrehab.org/services/adapted-sports-program
- Semper Fi Fund, semperfifund.org
- Swim with Mike, swimwithmike.org
- US Tennis Association, uspta.com
- United States Quad Rugby Association, usqra.org
- Wheelchair Lacrosse USA, wheelchairlacrosse.com
he athletes wait on the court. With their power chairs charged and their fingers on the joysticks, they are poised and ready to take their shot.

A teammate positions himself next to the oversized soccer ball just so. Then he spins full speed, 360 degrees, and strikes the ball with a “thump” that sends it far down the court. Another teammate surges past a defender and hits the ball with her front chair guard, shooting it through the goal posts, just inches beyond the reach of the goalie’s chair.

Goallllll!!

This is power soccer. And it’s much more than just another game.

A PASSION FOR THE SPORT

In the 11 years or so that Tony Jackson, 43, has been involved with power soccer, he’s been a player, a coach and an internet broadcaster.

He’s passionate about power soccer, but he didn’t always feel this way. He wasn’t even interested when he first learned about the sport. “I didn’t think it was competitive,” says Jackson, who has arthrogryposis and lives in Phoenix, Arizona. “I wanted high-level competition, and my perception of adaptive sports at the time was that they were not challenging.”

Then someone shared a highlight video of the 2007 Power Soccer World Cup with him. “Wow, this is really, really cool,” he remembers thinking. “These players are driving their chairs in ways I’ve only ever dreamed — they are whipping them around, hitting the ball.”

When he finally started playing, he realized how intense the sport is for both body and mind. “It takes a lot of
energy to compete,” he says. “Mentally it’s draining and physically you can get a little sore because that chair is moving at a rapid rate. It’s taxing.”

Ryan Kenneally, 38, who has Becker muscular dystrophy and lives in Portland, Oregon, had a similar experience. “I showed up to a practice and watched other people in wheelchairs just like me out there moving this ball,” he says. “Seeing those other athletes who had way more severe disabilities than mine out there on the court kicking people’s butts right and left? That blew my mind.”

Kenneally realized power soccer was something he wanted to try. “When I had a chance to do it, I was hooked on it, and I’ve never stopped,” he says. Now he’s a coach as well as a player.

It’s not just the athletes who get hooked. Karen and Dominic Russo have two kids, Natalie and JC, who first played power soccer at a Muscular Dystrophy Association summer camp in the early 2000s. When they found out there wasn’t a program where they lived in Indiana, they started one so their children could keep playing.

“The kids felt passionate about it so Karen organized the first clinic,” says Dominic. “When we realized what it is all about, we got behind it 100%,” adds Karen. And now? “We eat, live and breathe power soccer,” she laughs.

She’s not kidding. Their daughter, Natalie, won six national championships and played on the 2007 and 2017 U.S. National Teams, while their son, JC, won four national championships and played on the 2007 and 2011 U.S. National teams. Together the family runs the Power Soccer Development Group, a volunteer-run nonprofit dedicated to starting programs across the U.S. and around the world.

THE FIRST SPORT FOR POWER CHAIR USERS

Power soccer was the first competitive team sport designed for athletes who use power chairs and has been around since the 1970s. There were four major variations of the game across the globe until 2006, when several nations came together and standardized the rules and equipment, which allowed for international play.

Today the rules and structure of power soccer are similar to nondis-
abled soccer and there are teams for all levels of competitors, from recreational up to international.

The sport is played on an indoor basketball court, and each team fields four players — three fielders and one goalie. Offensive players use the bumpers on their chairs to control and strike the ball to score goals while defensive players use theirs to prevent goals against their side.

To ensure the competition is between the athletes and not their equipment, players must keep their top speed capped at 6.1 mph. But they are permitted to spin their chairs as fast as they can. Why is this a benefit in competition? Spin power!

“Everyone has their own technique, but some of us are really able to strike the ball with a lot of force,” says Jackson. “Some players can hit the ball as fast as 35 or 40 mph.”

Like all competitive sports, elite level play doesn’t just happen. Athletes need to put in the work to gain the skills to compete at a high level.

“It took easily a year for me to be able to learn to control the chair and hit the ball where I wanted it to go,” says Kenneally. “It’s definitely a skill that is gained over time. It takes quite a bit of practice.”

“It’s very skilled,” agrees Karen, “and there is a place for people of all levels, whether you want to play recreationally or travel the world and play for your country. There is a place for everybody.”

The teams can be made up of a diverse group of power chair users. So who can play power soccer? “As long as you can drive a power wheelchair you can play,” says Jackson.

Teams are composed of athletes of all genders, with all sorts of disabilities and of all ages from 6 to … well, there is no upper age limit. “I have a guy I coach who is in his 70s, and this is his first team sport ever,” says Jackson. “He’s super-thrilled about it. He loves it.”

IT’S ABOUT INDEPENDENCE

Sure, power soccer is a fun game to play, being both strategic and fast-paced. But what is it about power soccer that inspires such commitment?

For Jackson, it’s about independence. “A lot of us who play power soccer have a severe disability, and the vast majority of us need help to live,” he says. “But once we’re strapped into the power chair and ready to go, we don’t need help anymore. It’s very liberating for a lot of people and provides a great deal of independence.”

For Kenneally, it’s the camaraderie. “The whole experience of being part of a group of people with similar disabilities connected with me,” he says. “Prior to power soccer I didn’t really involve myself in the disabled community. The community side was huge for me — it was one of the things that got me hooked into the sport.

When Kenneally joined a traveling team, he learned from his fellow athletes that the world holds more possibilities than he ever imagined. “Traveling and playing other teams — that
experience is what really drove it home,” he says. “The abilities these different athletes had outside of power soccer blew my mind. They were going to four-year colleges and one was in law school.”

Kenneally continues, “Seeing the lives of other people in the disabled community opened up my eyes to the fact that anything is possible. It doesn’t matter that I use a wheelchair — I can still achieve goals in life, be successful, have a job, go to college. A wheelchair doesn’t define me as a person at all.”

RESOURCES:

• US Power Soccer Association, powersoccerusa.net
• Power Soccer Development Group, powersoccergroup.org
• Power Soccer Shop, powersockershop.com

ABLE ACCOUNTS HELP YOU SAVE MONEY WITHOUT LOSING BENEFITS. HOW CAN WE MAKE THEM BETTER?

United Spinal supports the ABLE Age Adjustment Act, which would expand eligibility for ABLE accounts to allow people whose disability occurred before their 46th birthday to sign up for these life-changing savings plans. This would allow another 6 million Americans the opportunity to open an ABLE account.

To contact your members of Congress, please visit unitedspinal.org/save-the-able-act. To learn more about ABLE accounts, visit ablenrc.org/get-started.

GETTING STARTED

The U.S. Power Soccer Association website allows you to search for teams in your area. Not all recreational teams are listed there, so if you don’t find one, give your local adaptive recreation group a call to see if they know of any.

If there isn’t a program close by, your local adaptive recreation group may be able to help you start one, or at least support your efforts. You can also contact the USPSA’s regional director for your area, or the Power Soccer Development Group to get a clinic held in your community, which they’ll often do for little or no charge.

To play power soccer, you need chairs with front guards, a power soccer ball, an indoor court and some pylons, or other vertical structures, for goals on both ends of the court. Power soccer chairs for competitive leagues can be quite expensive, but many recreational players use their everyday chairs and low-tech solutions when they start out.

Ryan Kenneally has been developing a new team for the last four years. It’s a recreational team now, with aspirations of becoming a competitive traveling team in the future. “In the very beginning we started out with everyone using their everyday chairs. We were literally using milk crates on the front as guards,” he says. Today his team has a group of dedicated power soccer chairs with custom metal guards on them. They built their fleet with donations, grants and fundraisers.

What’s Kenneally’s advice for newbies? “You need to start out with baby steps and work your way up,” he says. “You can start out with your everyday chair and then begin thinking about opportunities to get a dedicated chair. You need to learn practical skills first. Don’t stress about the entry barriers.”

Tony Jackson waited a few years to play after he heard about the sport. But once he got into it, he began traveling the country and the world playing, coaching and broadcasting the sport. His advice? “Don’t wait as long as I did. If you have an opportunity, go out and do it. Power soccer has opened up so many opportunities that I never thought of pursuing. It’s really altered what I’m doing with my life. I don’t even know what I’d be doing if I didn’t have power soccer.”
MOROCCO

FROM A WHEELCHAIR (AND A CAMEL)

BY CORY LEE WOODARD

Top: Majorelle Garden
Left: Chamber of the Twelve Pillars
Right: A donkey pauses from grazing on desert flora.
Riding a camel in the Sahara Desert has been on my bucket list since I watched the 1999 film *The Mummy* for the first time. It seemed so exotic and struck me as something I needed to try at least once. And let’s be honest, I really wanted to be a newer, wheelchair-using version of Brendan Fraser — hunting treasure and defeating evil on camelback.

When dreaming of being an adventurer, I imagined myself on a camel in front of the pyramids of Egypt (à la Brendan). However, after hearing of an adaptive camel saddle in Morocco, I knew that if I was going to check camel-riding off the bucket list, I needed to swap out Egypt for Morocco and travel to northwestern Africa. After many emails back and forth with the kind folks at Morocco Accessible Travel Consultants, the trip was planned.

Fast-forward a few months and I was in Morocco. I didn’t know very much about the country before arriving, but in just eight days, it unexpectedly became one of my favorite places on the planet. Whether I was devouring tagine, an authentic Moroccan stew that is cooked in a conical shaped dish, or rolling through a UNESCO World Heritage Site in an off-road wheelchair, I found Morocco to be full of accessible adventures. It blew me away.

**MAD ABOUT MARRAKECH**

The starting point for my journey was Marrakech, a former imperial city that is located about 350 miles from the Sahara. I only had a few days there before I planned to venture into the desert, so I tried to see as much as I could. Marrakech might be known for its snake charmers, but I learned there are plenty of sights to see without having to get close to any serpents.

It took Jacques Majorelle, a French painter, nearly 40 years to complete the botanical garden that bears his name, but I was quick to make the famed garden my first destination. In 1980, fashion designer Yves Saint Laurent bought the garden and eventually turned it into one of Marrakech’s most popular and accessible attractions. The paved paths made it easy for me to roll around Jardin Majorelle’s two and a half acres in my powered wheelchair and enjoy the surrounding palm trees, bamboo and birds.

Majorelle’s former studio now doubles as The Berber Museum. The Berber people are indigenous to Morocco and this small museum’s displays of clothing and jewelry gave me a better understanding of their history and daily life.

Next on my itinerary was touring the Saadian Tombs in central Marrakech. Visiting tombs might not sound like an idea of a good time, but I think their beauty surpassed that of the botanical garden.

Toward the end of the 16th century, Ahmad al-Mansur, sultan of the Saadian dynasty, ordered the ‘Tombs’ construction on the site of the royal necropolis. The Tombs were sealed off after the fall of the dynasty in the 17th century and rediscovered in 1917. Today, the Tombs are the final resting place to over 200 members of the Saadian dynas-
ty, including al-Mansur and his family, who are buried in a mausoleum known as the Chamber of the Twelve Pillars.

The mausoleum is famous for its intricate design, but in order to see it, I had to go down one step. Luckily, MATC was prepared with a portable ramp that worked perfectly. I was able to view the mausoleum in all its glory, complete with Italian marble and an immense attention to detail. Visiting this one mausoleum was worth the trip to the Saadian Tombs in itself.

I know I said there’s plenty to do in Marrakech aside from seeing snake charmers — and there is — but to truly understand what makes the city unique, you have to visit Jemaa el Fna, Marrakech’s wild public square.

Rolling through Jemaa el Fna is an overwhelming experience. From henna tattoo artists to monkey handlers and the ubiquitous snake charmers, there is something going on in every direction. Don’t be surprised if someone suddenly puts a snake around your neck or a monkey on your shoulder while you roll through the square. I avoided the area with the snakes like the plague, but someone did come up behind me to sit a monkey on my shoulder. I hadn’t asked him for anything, but he demanded a small amount of money for letting me get a picture with his pet. I figure those encounters are all part of the experience.

JOURNEY TO THE SAHARA

After a spectacular few days in Marrakech, it was time to make my way to the Sahara. MATC had a wheelchair accessible van with a driver for me, which worked perfectly.

It is only about 350 miles from Marrakech to Merzouga, which is known as the gateway to the Sahara, but because much of the eastward journey traverses the rugged Atlas Mountains, it takes around nine hours to drive. The drive was stunningly beautiful, with snow at the higher elevations and dry desert-like conditions at the bottom. I was astounded at how quickly the climate in Morocco changed.

I highly recommend stopping at Ait-Ben-Haddou, a UNESCO World Heritage Site in the Moroccan province of Ouarzazate. It is about four hours from Marrakech on the drive to Merzouga.

Ait-Ben-Haddou is an ancient fortified city with unique castle-like buildings that are made of mud and straw, and yet are still standing, centuries after being built. If you’re a TV or movie buff, you might recognize Ait-Ben-Haddou, as it is featured in the movie Gladiator and in the popular show Game of Thrones.

On its own, Ait-Ben-Haddou isn’t wheelchair friendly ... at all. In the 8th century, they weren’t too concerned about accessibility, unfortunately. However, a wheelchair user can tour the heritage site with a bit of help.

MATC has a Joelette, a one-wheeled chair maneuvered by volunteers, which can be used in rougher terrain where a regular wheelchair can’t. I transferred from my powered wheelchair to the Joelette, got strapped in and was ready to wander around Ait-Ben-Haddou. There were multiple people assisting with the Joelette and it worked like a charm. It was more comfortable than I expected, as well.

During the tour, I enjoyed getting souvenirs from vendors throughout the fortified ancient city and admiring the architecture. I marveled at the spectacular mud structures.

SITTING ABOVE THE SAHARA

While I had an absolute blast in Marrakech and at Ait-Ben-Haddou, the best part of my Moroccan trip came last. After the long drive from Marrakech, we arrived in Merzouga, where we were booked to stay at a desert luxury camp. To actually get to my tent took a bit of work, but MATC was there to help every step of the way.

To get to our campsite, I had to transfer into a Toyota Land Cruiser because the wheelchair accessible van couldn’t drive over sand dunes. A few people physically lifted me from my wheelchair into the LandCruiser and then put my heavy power wheelchair in the back of the vehicle. It took some time to load it, and I’m still not entirely sure how they did it, but eventually it fit perfectly, and I was off to the desert!

After 10 minutes of driving, I started noticing a few signs of the desert. Within 10 more minutes, the desert surrounded us. There were camels, donkeys and majestic sand dunes unlike anything I’d seen before. The dunes stretched toward the clear blue sky for what seemed like an eternity.

“Want to go over some dunes?” our
As a wheelchair user, and as a traveler in general, I consider myself pretty adventurous. I’ve gone hot air ballooning over the Negev Desert in Israel, hiking in the Amazon rainforest and even rock climbing in Utah, but for some reason this camel ride felt like my biggest undertaking yet. Perhaps it was because I had no control over what could happen. I was letting go and handing over the reins to the camel. After all, riding a camel in the Sahara Desert had been on my bucket list since before the term “bucket list” was even a thing.

As the camel approached me, I tried to push the fear away. It seemed much bigger in reality than I imagined it would be. As it got closer, I looked in its eyes. I tried to telepathically let it know that it was the best camel in the whole desert, in hopes it would spare me from face-planting in the sand. Not seeming too enthused by my efforts, the camel gave me a look like, “Can we please get this over with so I can go back to my nap?” And then it promptly sat down.

As the camel sat down beside me, I noticed the adaptive saddle on top of it. MATC realized how difficult riding a camel would be for someone with poor upper body control, so they went on a mission to create a saddle that anyone could use, regardless of their abilities. It’s basically a seat with a full back and headrest — like half a wheelchair sitting on top of the camel. It also has a seatbelt, so I couldn’t fall. After I inspected the adaptive saddle, I felt more confident that this ride might actually be possible.

Within seconds, I was lifted out of my wheelchair into the seat on the camel’s back. The saddle was quite comfortable, but it did take a few minutes for me to get perfectly situated. One of the men from MATC helped secure me by wrapping some straps around my chest and my forehead, to keep my head from falling forward or sideways during the ride. It took some work, but I was finally stable and ready for liftoff.

When camels stand up, they raise their back legs first, so for a moment it felt like I was falling forward. However, once the camel was completely upright, I took a sigh of relief. I could not believe I was officially riding a camel in the Sahara.

As the camel took its first steps with me on its back, my fear subsided and I became overwhelmed with gratitude. I was thankful to be riding a camel in the Sahara, for MATC’s ingenuity that made it possible, and for everything that led me to that moment.

The ride lasted for a surreal 15 minutes. I kept looking out at the sand dunes and then down at the camel, trying to take it all in. “Why did I almost face-plant?” I thought.

Sometimes fear is a good thing and keeps us from picking up a rattlesnake and making it our pet, and sometimes fear keeps us from truly living life to the fullest extent. As I sat on that camel in the Sahara Desert, I decided that I will be the orchestrator in deciding which version of fear I let play out in my life. I had realized my dream of riding a camel, and now you can officially call me Mr. Fraser.
MULTICHAIR Slider Systems

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MY SMART FRIENDS

Let me introduce you to my friends. They are so smart, and I know you will love them.

My favorite friend is Nestor (Nest Smart Thermostat). He knows when to keep me warm and when to cool me down. He just picks up on what I like and does it — so considerate. When I am away for a while, he doesn’t get cranky with me. On the contrary, he receives me with warmth.

Then there is Yolanda (Yale Smart Door Lock), my newest friend. She is safe, reliable and protective and doesn’t just let anyone come and go into my life. I can trust her.

Hector (the space heater) is my longest and most loyal friend. I hate that I need him so much but love that he is always there when I do. We are together every single day in the winter, so we definitely need a break from each other during summer months.

Then there’s Roberto, or Bob for short (the knockoff Roomba) — what a guy! Bob is always cleaning up my messes. He isn’t afraid to get dirty even when the situation gets hairy. Plus, the cat and the dog love him.

I suppose I want you to know my friends because friends are the ones that support you and your lifestyle choices. As much as we like to be independent individuals, we all know that as people with disabilities it sometimes takes a village of humans and gadgets combined to ensure different levels of independence in our homes and lives.

If you must know, I do have wonderful human friendships that make my life fulfilling and enjoyable, but these four gadgets help me around the house, are familiar with my habits, and keep me safe and warm. Isn’t that what friends do?
Most of us come to believe that we really know nature and the outdoors by experiencing it for an hour or two every now and then. In reality, there is much more going on out there the 99% of the time that we are not present, and wild creatures are very good at hiding themselves while watching us pass by. A great way to look deeper into their world is to set up trail cameras.

Also known as game cameras, trail cameras are self-contained, battery-powered devices that take a picture or video when motion sensors are triggered. They are often used by hunters to see what wildlife is in the area and are useful as surveillance cameras in remote situations where Wi-Fi is out of range.

Some cameras use cell phone technology to automatically send you pictures when triggered. These are great for hard-to-reach areas and even better for people with mobility issues. They also allow you to check images without disturbing the area or leaving your scent behind and possibly discouraging wildlife from returning. The disadvantage is they come with a cell phone bill.

My friend Dave and I initially used cameras to assist with hunting here in Alberta, Canada, but we soon learned that, beyond helping with hunting, setting up game cameras is a fun, year-round hobby on its own. Replacing the SD cards in the game cameras is a bit of an event here. When Dave comes over for our weekly “tinker-bleep-day,” one of the first things he does is to collect the SD cards from the cameras to see what is living just over the hill. It’s always thrilling, like opening a present every time.

"Let’s see what we’ve got," I say excitedly.

"Small one, small one, there’s a big one!" says Dave, pointing at a nice 4x4 whitetail buck on the monitor. Bucks are measured by how many points their racks have, and this guy has four on each antler.

"Wow! There’s a 6x6, silhouetted in the moonlight!"

We can’t believe our luck. There are several pictures of a very large whitetail buck from different angles and with the moon behind him. We couldn’t have gotten a nicer picture if we tried.

Placement

One of the issues you’ll deal with when using these cameras is false triggers, or pictures taken with no animal present. It is important not to have tall grass or trees nearby in the field of view, as wind will move them and cause a false trigger. If possible, point your camera north. You want to avoid the rising and setting sun, which will cause washed-out pictures and false triggers, as will a low south sun.

You’ll want to place your camera where the animals are, or where they travel. A leaky grain bin with lots of deer tracks nearby turned out to be a great place for a camera, as did the point where a game trail entered a farmer’s field. Deer often get into established patterns and use the same place to exit the trees when they come out to feed for years, even generations, and these are great camera locations.

We simply set a camera at about chest height in a tree near the trail mouth where deer walk past nearly every day as they enter or exit the woods. You can use swivel mounts to place the camera.
straight in a leaning tree or to mount it high and pointed down for a larger field of view. The cameras work best for animals that are 10 to 20 feet away, so try to place them about that distance from where the animals are expected to be. Animals, it seems, can see the infrared lights on the cameras, as we’ve had several of them lick the camera, and moose seem to enjoy standing with their eye very close to the lens. Hiding your camera well prevents these awkward shots and decreases the chance it will be stolen by a keen-eyed and unscrupulous passerby.

A good way to have game stop and have their picture taken is to place some bait in front of the camera. In our area, the deer have an abundant supply of grain and hay. Barley, oats and bird seed seem to attract them. Once they know food is there, they keep coming back to see if there’s more. You need to check the regulations on feeding wildlife in your area, as it may be illegal. In our area we can put bait out, but it is illegal to hunt with it. We tried using apples as bait, and it seems that coyotes love them more than deer do.

With the help of cameras, we now realize there is much more going on in the wild when we are not around, especially at twilight and after dark. The wildlife seems to come out of nowhere and in surprising numbers. I usually see a deer or coyote a few times per month with my own eyes, but placing three cameras within a mile of my home has revealed that there are at least five or six whitetail and mule deer bucks and many more does, at least two moose, and many coyotes, rabbits, porcupines, ruffled grouse and more.

When we see the nearby life on the cameras, we’re reminded that we are a piece of a much larger puzzle. We may have our name written on the title of a piece of land, but it only guarantees that we get to be its caretaker for a short period of time. There are so many other pieces of the puzzle that run the show when we aren’t out there, as they have for thousands of years.

Get a game camera and see what owns the world when we have our backs turned. It’s truly amazing.
I broke my left femur when I missed a transfer to my chair. The fracture runs straight across and the bone is lined up, but my orthopedist doesn’t want to fix it surgically because the break is too close to the knee to repair with a rod, and screws with a plate would likely pull out of my osteoporotic bone. Instead, he prescribed a soft splint that keeps my fracture aligned and enables me to check my skin.

An eight-week follow-up X-ray didn’t show any signs of healing, so my orthopedist wrote a prescription for a PEMF bone growth stimulator. He said sometimes bone growth stimulators will jump-start the healing process. Now I’m waiting to see if my insurance will cover it.

What is a PEMF bone growth stimulator? How does it work? Have you heard of other people with SCI using one to heal fractures?

— Sarah, 47, T6 complete para for 30 years

Sarah, I had a similar fracture 22 years after my T10 complete SCI. While throwing a tennis ball for my dog, I took a forward tumble out of my chair. It was the kind of tumble I’d taken hundreds of times over the years — only this time it resulted in a fracture just above my right knee. When a follow-up X-ray six weeks later didn’t show any healing, my orthopedist said, “Sometimes these fractures in SCI fail to heal, and you might end up with an extra knee joint.” This was not an option.

He said a bone growth stimulator might help and wrote me a prescription. After using the stimulator for eight weeks, another X-ray showed the fracture had completely healed.

Unfortunately, leg fractures are common for those of us with long-term SCI. Many studies, including one from 2015 published in Spinal Cord, found that chronic SCI often leads to long bone fractures of the lower extremities, which are often the result of a “low energy insult,” such as a fall out the chair while wheeling or a failed transfer.

For in-depth answers to your questions, I turned to Dr. Douglas Garland, a retired orthopedic surgeon and former director of neurotrauma at Rancho Los Amigos Rehab Center. He spent over 20 years researching osteoporosis and fractures in SCI and has many peer-reviewed papers on the subject. Garland has also studied and published research on PEMF and fracture.

When a bone breaks, the body sends out a low-level electrical field that signals the immune system to deliver healing materials to the area of the fracture. PEMF stands for “pulsed electromagnetic field,” and a bone growth stimulator is an external device that sends pulses of electromagnetic frequencies to stimulate production of the proteins and growth factors needed to heal bones. In essence, it is like a loudspeaker telling the body, “We need healing materials here, now!”

The portable device is about the size of a TV remote and has a wire that goes to a pad shaped to fit over the fracture area. The pad is held in place with a Velcro strap. The device is used for approximately four hours a day until the fracture is healed.

Added Complications

Garland suggests that the prevalence of low energy fractures goes hand-in-hand with the prevalence of progressive osteoporosis among those with chronic SCI.

Osteoporosis starts when a person loses 32% of their bone mineral density. On average, a person with a complete SCI injury loses 28% of the BMD in their legs within the first year and a half of their injury. By two years post-injury, BMD decline slows to a loss of 1% a year. After 20 years, the legs of the average person with SCI have lost 46% BMD. This is close to the “fracture breakpoint” of 50% of BMD loss, after which a simple twist or fall is likely to break a bone.

Garland’s early studies found that lower extremity fractures have a significantly higher rate of delayed union for people with SCI, meaning the fracture takes longer to heal or fails to heal.

A 2018 study in the Journal of Spinal Cord Medicine found similar results. Depending on the fracture, surgery on osteoporotic bones is difficult because screws and hardware don’t get a solid fixation and can loosen and pull out.

“This is where a PEMF bone stimulator is a very viable alternative,” says Garland.

In a 1991 study on PEMF, Garland followed 139 people with established non-union fractures and found that using PEMF at least three hours or
more each day produced an 80% success rate of healing. A 2012 study in the Journal of Orthopedic Research reports similar results. Other recent studies support the use of a bone growth stimulator for healing and point out the need for conducting larger and more definitive trials. Garland explains that doing larger trials is difficult because most orthopedists operate on these fractures in spite of the complication risk.

Because of the added complications that come with SCI and osteoporosis, sometimes a bone growth stimulator is used at the onset of a fracture. Five years ago, Candace Cable, then 60, had a slow-motion fall into a kneeling position while transferring out of a friend’s car. After 40 years with a T10 complete injury, she knew the signs of a leg fracture. “At first, I thought I was OK, but within two hours I felt sick, my heart was racing and my blood pressure spiked,” she recalls.

A trip to the ER and X-rays confirmed a hairline fracture in the top of her shinbone. X-rays done at her orthopedist’s office a few days later showed the crack was widening, so she was prescribed a straight splint. Cable suggested using a bone growth stimulator, and her orthopedist agreed. Once she got the stimulator and started using it, her fracture healed in two months.

Although research on the benefits of bone growth stimulators is inconclusive, the evidence for healing non-union fractures is strong enough that they have been covered by Medicare since 1999. Remember that, like many specialists, orthopedists may not have experience in treating people with SCI. So it benefits you to know treatment options, including bone growth stimulators, to present and discuss. That way you can ensure you have the best odds of healing successfully.

Resources
Bone Growth Stimulator Manufacturers
- Biomet-EBI, zimmerbiomet.com
- Orthofix, orthofix.com

Articles
- Bone Loss at the Knee in Spinal Cord Injury, archive.scijournal.com/doi/abs/10.1310/KP8E-K7H7-6072-G8GB
- Long bone fractures in persons with spinal cord injury, ncbi.nlm.nih.gov/pubmed/25987003
- Lower extremity fractures in patients with spinal cord injury characteristics, outcome and risk factors for non-unions, ncbi.nlm.nih.gov/pubmed/28545316
- Pulsed electromagnetic fields for the treatment of tibial delayed unions and non-unions. A prospective clinical study and review of the literature, ncbi.nlm.nih.gov/pubmed/22681718

New Mobility Coverage
- Fracture Risk and Treatment Options with SCI, newmobility.com/2016/04/fracture-risk-treatment-options-sci
- Osteoporosis: Avoiding the Breaks, newmobility.com/2009/12/osteoporosis-update

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I’ve taken part in so many cripple political protests that I’ve run out of appendages on which to tabulate them (which means it’s more than 21). I’d say that at least 70% of the time, the first reaction of the police and/or other security personnel who are dispatched to deal with us is to play a game I call Grab-A-Vert.

It’s an amazing phenomenon to observe, and it plays out pretty much the same way every time. The police arrive. They see a pack of raucous cripples chanting. They look flummoxed. They huddle and come up with an action plan. They break the huddle and move in on us. They grab everyone who is standing, or not sitting in a wheelchair, and haul them away.

They grab everyone they perceive to be a vert. Sometimes they grab deaf people. They might even grab a blind person who doesn’t have a white cane or guide dog nearby to clearly identify them as blind. One time when we protested in the lobby of a hotel where an evil conference was taking place, hotel security manhandled a guy with hemophilia, dragging him out onto the sidewalk and leaving a bruise shaped like a handprint on his ribcage.

When the cops huddle, no doubt one says, "Well, what do we do now?" And then another one says, "Hey, I’ve got an idea!" And that person feels full of pride because they think they’re the first person to come up with this brilliant Grab-A-Vert approach.

The success of this strategy relies on the premise that the verts are our Svengalis who have hypnotized us into protesting. The cops must picture these verts having a big meeting where they all decide to organize a cripple protest for some reason. And then the verts set about the business of recruiting innocent cripples to join. I bet the cops picture these sinister verts cruising nursing homes in search of vulnerable, impressionable cripples to lure in. After all, some cripples will do anything if it’ll get them out of the nursing home for an afternoon.

And so, the Grab-A-Vert logic concludes that if the vert ringleaders and instigators are removed, their poor, frightened crippled dupes won’t know what to do. And we’ll probably break down crying and run away.

After encountering crippled protesters for the first time, cops new to Grab-A-Vert stand there with their arms folded, looking all badass, waiting to see what happens next. And not once has it ever played out the way they hope it will. They soon realize that all they’ve managed to accomplish was to make the cripples chant louder. The cops look forlorn. They huddle again to figure out a plan B.

I used to be insulted by Grab-A-Verting. How dare the cops assume that cripples are all a bunch of passive Tiny Tims! How dare they assume that cripples can never be pushy, rude and out-of-line without outside agitator verts putting us up to it! This is the 21st century, dammit! Hasn’t everybody learned by now that cripples are perfectly capable of being pushy, rude and out-of-line on our own? It just goes to show that even 30 years after the signing of the ADA, we still have a long way to go to properly change people’s hearts and minds.

But as I think about Grab-A-Vert more, I’m starting to believe that maybe I’m reading too much into it. Maybe the cops don’t think the whole Grab-A-Vert thing through nearly as much as I give them credit for. Maybe it’s all just instinct and reflex. The gut response of a lot of cops when confronted with a rowdy mob is to manhandle everybody into submission. So maybe Grab-A-Vert is just their way of satisfying that burning urge in a measured manner that doesn’t create video of cops giving cripples whiplash. Maybe it’s manhandling done purely for the joy of manhandling, with no other particular outcome sought.

Maybe I shouldn’t take Grab-A-Vert so personally. It’s probably just cops being cops.
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MEET NEW MEMBER DONNA GIBBS

Age 62, from Middleton, Massachusetts
SCI paraplegic

Why I joined United Spinal: I first learned about United Spinal at an Abilities Expo event. I was impressed with the work and service United Spinal provides to members of the disabled community, and I wanted to be a part of this association.

Can’t live without: My Permobil chair, which can be raised and lowered. It is a game-changer for me because it allows me to feel independent. I can now select products at the grocery store without having to ask for help.

What I would change: Accessibility because accessibility results in sociability. The two go hand-in-hand — if more places were accessible, I could meet and interact with people and regain the independence I’ve lost since my injury.

Meet other members or join United Spinal at unitedspinal.org
My post-shower routine is to sit on my clothes hamper, wearing a short nightie while I pull my jeans and braces on, and then transfer into my power chair. One morning I needed to change the shoes on my braces, so I set a brace on my power chair and removed the screws and nuts from the ankle joints. I fumbled one of the nuts, and it rolled under the chair. No problem, I thought, and I used the brace to turn the power button on, operate the joystick and carefully guide the chair so I could retrieve the nut.

As the chair rolled backwards, I lost control of the brace and it fell onto the joystick. Before I knew what was happening, the chair jetted forward and almost took off my toes before it did an immediate 180-degree spin and careened across the room. It smashed into the far wall, brace stuck on the joystick, tires spinning and motor whining.

There I was, barely dressed and sitting on my hamper without my braces or chair. I didn’t want to call for help, so I gathered my thoughts. Luckily, my trusty reacher and some impressive stretching allowed me to free the brace from the joystick. I put both my braces on and then retrieved the chair. A lesson was learned and no one was the wiser. Well, unless they noticed the telltale dent in the wall.

Rhonda Rome
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