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**39 FASCIA RELEASE** LILLY LONGWORTH introduces you to fascia, the fibrous tissue around muscles and organs, and explains how it just may hold the key to relieving your pain.



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You may have never heard of Rory Cooper, but if you use a wheelchair or have a disability, there is a good chance you have used or benefitted from a product or invention he has been involved with. IAN RUDER profiles Cooper and HERL, the world-class research engineering facility he has built from the ground up at the University of Pittsburgh.

Cover and Contents Photos by Joe Appel Photography



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## ( BULLY PULPIT )



### Opioids: The Beauty Within the Beast

Not a day passes that I don't hear a reference to the burgeoning opioid crisis — way too many people dying from overdoses. Yet the primary source of this life-threatening pandemic is the beautiful and innocent-looking opium poppy, and the history of civilization is rich with stories of opium or its derivatives being used for beneficial medicinal and other health-enhancing purposes.

I have always had an affinity for opium-derived medicines, beginning with the morphine injections that made life bearable when I was hospitalized following the traumatic plane crash that paralyzed me in 1965. Not only did morphine relieve my pain, it also calmed my anxiety and fear of an uncertain future. But I became addicted while hospitalized. Twice. Each time, however, I was able to gradually wean myself prior to being discharged.

During the drug-laden late 1960s, when I was struggling to find my way as a paraplegic in a wheelchair-unfriendly culture, an acquaintance of mine offered me opium, a dark, tar-like substance the size of a golf ball. We smoked some, and I immediately felt its effect, which was similar to morphine. Under its influence, all seemed well with the world.

Opium has been around for thousands of years. Today dozens of products derived or synthesized from opium are available, almost all of them legal. Got a toothache? A dentist will prescribe Norco or Vicodin (hydrocodone). Oxycontin (oxycodone) is also popular and available. Headache or cough? Codeine comes to the rescue with no prescription. Diarrhea? The over-the-counter product of choice is the opioid Imodium. Even those poppy seed muffins you buy at Costco get an assist from opium. Eat enough seeds, you can get high.

Then there are the heavy hitters: heroin, morphine, fentanyl, meperidine, methadone.

Due to hospitals and doctors routinely overprescribing opioids, there are now numerous initiatives aimed at making opioids harder to get. Unfortunately, those of us who

**Pain pills provide needed daily relief, and we know how to use them safely. But do we, really?**

have chronic pain and know how to use these drugs responsibly have been caught up in the rush to demonize opioids. For us, they provide effective and inexpensive (mostly) relief. A bottle of 50 hydrocodone-acetaminophen tablets, for example, costs \$6 on my Medicare Advantage plan. That's 12 cents per pill.

The truth is many of us feel entitled to our pain pills. They provide needed daily relief, and we know how to use them safely. But do we, really? Most medicines, when taken several times a day, tend to build up in your bloodstream. And continual opioid use does lead to dependence and addiction.

Before long, we want stronger doses, more pills per day, relief now. Do you find that your mind wanders to the pill bottle in anticipation of pain, even when you know it may be temporary? We are the quick-fix culture, smart phone addicts who demand results with one click. But our pain is here to stay, and we must learn to accept it.

If you are maxed out on pills, cut back now. Take a break from thinking you must always be pain-free. Maybe today's the day you can be satisfied with less, rather than no pain.

— TIM GILMER

## ( CONTRIBUTORS )



A T10 para since 1985, Bob Vogel has been writing for NM for more than 20 years, covering adaptive equipment, sports and recreation, travel, and more. He also writes *NEW MOBILITY*'s Para/Medic column and manages the magazine's Facebook site. Bob took to extreme adaptive sports in the late 1980s and has written about scuba diving Spanish Galleons, hang gliding at 20,000 feet above the San Juan Mountains of Colorado, and mountain biking to the bottom of the Havasu Canyon. He lives in Loomis, California, where he spends time with Sarah, his 16-year-old daughter, and Killy, his German Shepherd service dog.

Alex Bennewith is United Spinal's vice president of government relations and directs the organization's advocacy strategy for legislation and regulations regarding health and disability policy at the federal level. She has close to 20 years of government affairs and public affairs experience. When she's not working, Alex and her husband, David, try new restaurants and go on weekend bike and food trips in Northern Virginia. They also love to travel — especially internationally — and are excited about visiting Costa Rica and Jamaica.



Senior editor Ian Ruder finds it hard to believe that he has been with United Spinal for almost six years. He has enjoyed watching United Spinal blossom into the multi-faceted organization it is and appreciates the support the *NEW MOBILITY* staff provides him. He enjoys writing about technology and sports and is continually amazed by the people he gets to meet through his job. When he is not working, he is probably watching his San Francisco Giants or out on the town trying Portland's latest and greatest restaurants.

## ( COMMUNITY PARTNER )

*NEW MOBILITY* community partner Christiaan "Otter" Bailey is a professional adaptive surfer and chairskater from Santa Monica, California. Since his 2006 injury, which happened during the filming of a skateboarding video at Derby Park in Santa Cruz, his sponsors continue to support him. This allows him to surf and chairskate in expression sessions on various pro and semi-pro tours worldwide. He also serves as executive director of Ocean Healing Group, which provides once-in-a-lifetime adaptive sports excursions to Costa Rica for young people with disabilities and their families.



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A new fashion conversation that fashion is for everybody. Keep this conversation trending.



### Exciting Fashion Movement

This article is so exciting for the newest movement in fashion ... a new fashion conversation that fashion is for everybody. Keep this conversation trending ["Adaptive Clothing Shakes Up the Fashion World," March 2017].

*Sharae Moore Myers*  
Via [newmobility.com](http://newmobility.com)

### Promising, but Affordable?

As a quad for the last 34 years I've seen various adaptive clothing companies come with great promise and then disappear a few years later. Even though I've liked some of the designs and adaptations, I can't afford the prices. My budget simply doesn't allow spending \$60 or more for a pair of pants or \$50 for a shirt.

*Matt Grillot*  
Via [newmobility.com](http://newmobility.com)

### It's Coming

Our less expensive adaptive jean for Walmart.com re-order is in process, and will be re-stocked there in a few months. In the meantime, stay tuned for new styles and fabrics!

*Stephanie Alves, Abl Denim, abldenim.com*  
Via [newmobility.com](http://newmobility.com)

### Operation Needed for Pain

My fiancé's neuropathic pain is so constant and strong (over 15 years of his C5 incomplete injury) that none of the meds mentioned in the article have helped him ["The Pain That Never Stops," March 2017]. For the past few years he's been on methadone and fentanyl patches, but even with these not being enough to calm the pain, he will be getting a spinal cord stimulator surgery in three weeks. Let's hope this works!

*Paula Andrade*  
Chester, Virginia

### Opioids Do Work

Thanks for the story on finding pain "cocktails" that work ["The Pain That Never Stops"]. I am a T7 incomplete para who experiences all the types of pain described in the article, thankfully usually at different times. I have a mix of drugs that I take and find I can usually get the pain to a three [on a scale of 10]. Right now there is so much news about opioid dependence that it has many doctors unwilling to prescribe them on a regular basis. I am taking this article with me to my next appointment with the "pain specialist" I must see in order to continue the prescriptions that I have been taking for 10 years. This industry has many newcomers to the field who are so intent on lowering or discontinuing every patient's dosage. They don't seem to understand some people live with, and will always live with, continuous pain. I hope that by having them read this article they might understand the situation for people with SCI.

*Sandra Sory*  
Greeley, Colorado

### Sharing Info Helps

The article on pain was informative and therapeutic. Hearing stories similar to mine (C6-7 incomplete injury for 25 years) was a great way to commiserate, which is something I don't get to do often, as I've had only a small number of friends with SCIs. I look forward to reading NM just for those reasons.

*Bryan Wynacht*  
Via [newmobility.com](http://newmobility.com)

### Outrageous Cost

You have got to be pulling my leg! \$3,000-plus for a seat cushion? ["Cushion Options for Severely Compromised Skin," March 2017]. If you don't know it, stealing from disabled people is illegal.

*William Durham*  
Via [newmobility.com](http://newmobility.com)

### Pricey but Worth It

I have been using the Ride cushion for more than 15 years, after having many problems with pressure sores (40 years in a wheelchair), and I have had absolutely no problems since I started using the Ride. It's custom made, ischials are suspended, and weight is distributed throughout the seating area. I have a cushion/back that helps prevent scoliosis issues. Yes, it's very expensive — equal to about two days in the hospital. [But] with the cost of one butt surgery, you could buy about 100 Rides.

*Richard St. Denis*  
Via [newmobility.com](http://newmobility.com)

### Another Airlines Atrocity

My wife and I were flying New York to Chicago. I watched from the plane as American brought her 400-pound power wheelchair to the plane in a flatbed truck literally upside down, resting on the arms and the controls ["New Mobility Contributor Removed from American Airlines Flight," March 31 News, [newmobility.com](http://newmobility.com)]. I spoke to the captain who went down to the tarmac (he was told that was the proper way to handle a wheelchair). We arrived in Chicago with a totally destroyed control panel. We spent two hours in the airport arguing with American Airlines personnel that we would not leave the airport until we had a signed resolution regarding repair. They did not want to sign anything and only wanted us to leave. Finally a Chicago police officer suggested strongly that American Airlines sign off for repair. This was six years ago and we immediately switched to Delta and have averaged six round trips a year with never a problem and the most courteous people you can ever imagine.

*Bobby V*  
Via [newmobility.com](http://newmobility.com)



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## NM Contributor Removed from American Airlines Flight

On March 27, American Airlines removed *NEW MOBILITY* columnist and seasoned air traveler Mark E. Smith from his flight home to Philadelphia from Los Angeles without giving him an explanation. Weeks later, Smith, who has severe cerebral palsy, was sent several unsatisfactory explanations in an email about why he was involuntarily removed.

As reported on April 11 by WNEP-TV, which covers Smith's home county of Luzerne, Pennsylvania, the airline's email to Smith claims he voluntarily chose to leave the airplane, which he says was not true.

As recounted in a March 29 entry to his *Powerchair Diaries* blog, Smith saw "a large group of American Airlines' flight attendants, gate agents and ground crew — a sea of varying uniforms and two-way chatter — coming up the aisle." Without speaking to Smith, they asked the two



women sitting next to him to move from their seats, explaining they were removing Smith from the plane.

He was then strapped into an aisle chair and wheeled out of the plane, past most of the passengers, who watched in silence. "No one — flight attendants, ground crew — gave me a direct answer

as to why I was being removed," says Smith. "Someone in the group mentioned 'getting me off of the manifest.' I'm not sure what that meant."

The airline's email also says Smith had to leave the airplane because his wheelchair would not fit in the cargo hold. "The aircraft's cargo door opening on this particular aircraft is 33 inches tall and 48 inches wide," read the email. "While our ground staff tried on several occasions to load your wheelchair into the cargo hold, they were, unfortunately, unsuccessful."

However, WNEP measured his chair and says its dimensions are "wheel to wheel, 24 inches, height 29 inches." Smith told WNEP that the dimensions of the cargo hold "well exceeded" his power chair's dimensions.

Nonetheless, Smith was involuntarily ejected from the plane and had to wait half an hour for his chair to be removed from the hold and brought up to him.

The American Airlines email also told

## People in the News: Lenin Moreno Elected President of Ecuador

Lenin Moreno was declared the winner of Ecuador's April 2 presidential election, becoming the first person with paraplegia to be elected as a head of state in Latin America. Moreno, who served as vice president of Ecuador under Raphael Correa from 2007-2013, narrowly defeated banker Guillermo Lasso to become president-elect of the South American country.

Moreno, the candidate for the ruling populist party, had campaigned on the promise to continue the social and poverty-reduction programs of Correa's "Citizen's Revolution." The victory comes as something of a surprise in South America, where leftist leaders across the continent have been swept from power in recent years.

Moreno began using a wheelchair in 1998 after assailants shot him in the back during a botched robbery attempt. At the time he was already an activist and involved with Ecuador's political left before the shooting. Afterwards, disability rights became central to his political career. While serving as vice president, he helped implement a variety of programs



for people with disabilities, passed inclusive labor laws, began installing curb cuts and accessible crosswalks throughout the country, and created a fund to pay monthly stipends for people with disabilities who are unable to work.

Solidarity and social justice have been a guiding principle of Moreno's political life. "Solidarity — not as charity, but rather as recognition of others as equals — is the basic pillar for initiating social inclusion," he wrote in 2012.

In 2012, Moreno was nominated for the Nobel Peace Prize for his work in bringing Ecuador's disabled population out of the shadows. From 2013-2017 he served as the U.N. special envoy on disability and accessibility rights before returning to politics to campaign for president.

Selena Flores, paraplegic for 27 years as a result of a traffic accident, received her first wheelchair as a result of one of Moreno's recent programs. "He's helped bring us out of our isolation," she told the *Miami Herald*. "We're no longer the shame of our families. We're not just a statistic."

Smith that he had “the option of traveling on your original flight with your wheelchair following on another flight, or that you could travel with your wheelchair on the next available flight that could accommodate your wheelchair. Our records show you opted to travel with your wheelchair and therefore deplaned with assistance from our ground staff.” Smith denies this.

He has filed a complaint against the airline with the U.S. Department of Transportation.

### **FDR Four Freedoms Memorial Park Faces ADA Lawsuit**

On March 16, the nonprofit legal center Disability Rights Advocates filed a class action lawsuit in federal court on behalf of individuals with mobility impairments, alleging that the New York State Department of Parks, Recreation and Historic Preservation and the Franklin D. Roosevelt Four Freedoms Park Conservancy are in violation of the Americans with Disabilities Act.

The plaintiffs, who include the Brooklyn Center for the Independence of the Disabled and several New York City wheelchair users, allege the park is inaccessible due to a number of architectural barriers. Those include a large flight of stairs leading up to the monument, paths of gravel and uneven stone that bypass a majority of the memorial, and steps that inhibit access to a sunken terrace with a view of the city and East River. The lawsuit also claims a lack of accessibility in the gift shop and restrooms.

“The memorial was built very recently, decades after the ADA, and New York State should know better,” said Michelle Caiola, litigation director at DRA. “We can’t figure out what they were thinking, but to leave it as is would give unfettered license to continue building important public spaces with no regard for the civil rights of persons with disabilities.”

FDR, who began using a wheelchair after acquiring polio, helped advance polio research and treatment, and as the 32nd President of the United States, became a prominent icon for wheelchair users. Plaintiffs argue that the park’s lack of accessibility tarnishes his legacy, and violates the same rights he championed.

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By Tiffany Carlson

**“Look at challenges you have as opportunities to help others.”**



### Inventions Inspired by Challenges

If Bruce Roberts, 63, passed you by on the street, chances are you probably wouldn't notice him. A C5 quad from an injury eight years ago, he walks. But this doesn't mean his incomplete injury was any less profound. As a lifelong inventor and engineer living in Silicon Valley, this was not what he expected for his life at age 55. "I knew right away something was wrong. I prayed like I've never prayed before."

Within two months of his injury, he began to get return in his legs, which spurred him to push himself in rehab. After four years, he was finally back on his feet, using forearm crutches. "It's been eight years since my accident. Am I back to normal? No. One of my friends asked me, 'Are you ever going to be 100 percent?' I said, 'Yes I will. But a different 100 percent.'"

During rehab, Roberts needed to keep his mind busy, so he invented the Horizontal Computing System — a laptop stand for bed use. "It's fully

clamped and secured to the hospital bedside table so the laptop doesn't touch the body."

Since his injury he has invented more products, including the CrutchPal, which snaps crutches together; Trash-At-A-Glance, which allows curbside trash bins to visually alert owners when their trash has been picked up; and the Heads-Up Lock, which allows you to see if the accessible restroom is in use before making the trip.

His advice to SCI folks looking to invent? "Write down everything that is hard for you to do. Make sketches. Look at challenges you have as opportunities to help others, then contact a company's chief product developer, the VP of engineering, marketing manager, etc. Most manufacturers always welcome new ways to improve their products."

See Roberts' products here: [www.crutchpal.com](http://www.crutchpal.com); [www.trashataglance.com](http://www.trashataglance.com); [www.headsuplock.com](http://www.headsuplock.com).

### Electric King of the Mountain

All-terrain mountain biking has never been more enticing — thanks to electricity. Dubbed the Horizon, this battery and hand-powered adapted on-road/off-road mountain trike is made by Outrider USA, a company started by college students in North Carolina.

At \$13,985, it's one of the most expensive modified units out there, but it's also the ultimate dream toy for anyone wanting to explore mountain trails. The base model comes with a battery range of 15 to 35 miles and has a top speed of 20 mph. And it's modular, allowing you to create a customized configuration — with your choice of two wheels in the front or the back.

There are plenty of electric all-terrain wheelchairs, but this vehicle, a trike with a drive train and wheels fit for rugged terrain, is based on a mountain-bike design that opens up some serious territory. It was field-tested by C7 quad Justin Falls as well as wheelchair racer Michael Mills.

For more information, and to see the Horizon in action, visit its official site: [outriderusa.com/products/horizon](http://outriderusa.com/products/horizon).



### Swedish Take on SCI Parenting

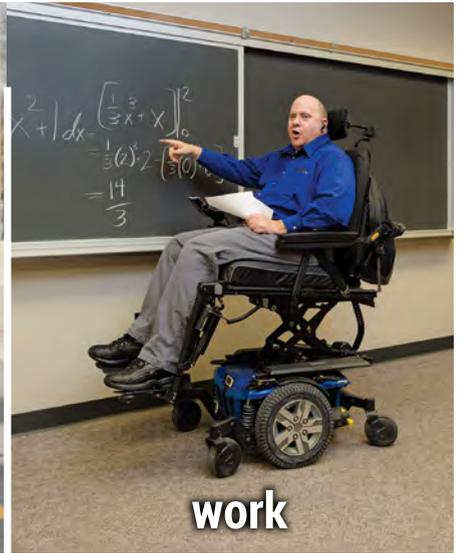
The Spinalis Foundation, one of the most well-known SCI foundations in northern Europe, has launched a new website called SCI Parenting. It features advice on fertility, childbirth, pregnancy and has tips and tricks for parents. It also has a blog by Swedish parents with SCI (the entries are translated). Check it out at [sciparenting.com](http://sciparenting.com).



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# HOW WE ROLL

## WELLNESS SPECIALIST **Harsh Thakkar**



A gunshot left Harsh Thakkar paralyzed and changed the course of his life. Wheelchair basketball helped him get back on track. Now he works at National Rehab Hospital in Washington, D.C., trying to help others do the same.



## Rebuilding Identity

**A**s the Spinal Cord Injury Peer Wellness Specialist for the National Rehab Hospital in Washington, D.C., Harsh Thakkar spends a lot of his time planning and running adaptive fitness programs for thousands of people with disabilities in the D.C. Metro Area. For Thakkar, 31, seeing people discover and rediscover themselves through sports and fitness is more than a job, it's personal.

Thakkar, who lives in Alexandria, Virginia, had just started classes at the University of Maryland, Baltimore, in 2005 when he was robbed and shot, leaving him paralyzed at T12-L1. A strong athlete in high school, Thakkar's injury changed everything. "I had identified myself as an athlete all my life," he says. "And then, for nine months, I was completely stripped away from that identity."

Thakkar eventually rediscovered his athletic identity through adaptive sports. While going back to finish his degree he learned about wheelchair basketball and ended up getting a scholarship to play at Edinboro University in Pennsylvania. He currently plays

for the NRH Punishers, and he was recently named team manager. When he is not hooping it up, Thakkar also plays on a wheelchair lacrosse team and enjoys adaptive skiing – both snow and water.

Almost 12 years after his injury, Thakkar is dedicated to helping others rediscover their identities, regardless of their athletic background. "I have a lot of people that I encounter that say, 'I was never an athlete before, why would I be one now?'" My response to them is you don't have to be one now, but knowing that the outlet is there for you to try it, why would you not want to try it?"

He preaches that there is value beyond the physical exertion and exercise. "When I first started playing, I met people who completely changed my views on what disability means. Not just in terms of playing sports, but that was the first time I saw somebody driving a car. That was the first time I saw somebody breaking down their own chair, getting in and out of a car. That was the first time I saw somebody roll into the gym with kids. That



### IF I COULD CHANGE ONE DISABILITY-RELATED LAW:

I would tighten up enforcement of disabled parking spots and add some degrees to it. Too many people take advantage and one size doesn't fit all.

**SAGE ADVICE:** Keeping a daily log of my pain helps me analyze different aspects of my pain and makes me aware of different triggers and strategies that can help lessen it.





was the first time somebody told me that there are colleges that have wheelchair basketball teams. The first time somebody told me that I can get a job. It was a lot of firsts. On top of that, I got to learn from other people's mistakes. I learned how and when to ask for help from them. Obviously, the sport helped because it's something that I liked in the beginning, but it was the people more than it was the sport itself."

Now, 12 years later, Thakkar often finds himself in the mentoring role. He tries to help people new to SCI/D understand the situation facing them. "This is something that isn't going away. This is your new reality," he says. "Even if there is a cure or your paralysis improves, you're not gonna go back to exactly who you were. I've seen many people recover. I've seen a lot of people recover to the point where nobody thought they would get to that point, including themselves. Yet, they are not like they used to be — not in a good or bad way, just different."

**CAN'T LIVE WITHOUT:** I use my KAFO leg braces two to three times a week, and besides the health advantages of standing, they're great for getting stuff like laundry and cleaning done.



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“ I'd completely forgotten about my National Parks Access Pass when I rolled up to Muir Woods. When the attendant reminded me everyone with a permanent disability gets in free to national parks, I looked in my wallet and there it was.



After three straight vacations at the beach — Jamaica, Bahamas and Cancun — I told my parents and my brother I was getting tired of beaches. I'm a big fan of national parks and I'd always wanted to see Yosemite. Scheduling a trip around a longer stay in San Francisco allowed us to see Yosemite, Muir Woods, Napa Valley and Lake Tahoe — everything is so close. The whole trip was great, but Yosemite was definitely the highlight. Other than a few hills here and there, everything was pretty accessible. I could access all the viewpoints on my own and I didn't feel like a burden having to ask my brother to push me in certain places. I even snapped a nice little video of me rolling through the accessible entrance to Half Dome over and over again. Rolling through the giant redwoods in Muir Woods was also surprisingly accessible and fun. And, of course, rolling across the Golden Gate Bridge was awesome. ”



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# COOL NEW PRODUCTS UNVEILED AT ISS

BY BOB VOGEL

The 33rd annual International Seating Symposium, hosted by the University of Pittsburgh's Department of Rehabilitation Science and Technology's Continuing Education Program, returned to the Gaylord Opryland Hotel and Convention Center in Nashville, Tennessee, March 1-4. ISS is the leading educational and scientific conference for wheelchair seating, mobility and related technologies. For rehabilitation professionals, ISS is considered the must-attend event of the year.

This year more than 2,400 rehab professionals from over 30 different countries traveled to Nashville, where over 100 educational sessions and workshops covering all aspects of mobility-related disability were offered. The focus of the sessions was maximizing health, mobility and functionality for wheelchair users.

A major feature of every ISS is the 70,000-square-foot exhibit hall, which is a vital staple for mobility and rehab

manufacturers to showcase their latest innovations and products. This year over 100 exhibitors filled the hall, giving attendees the opportunity to see and evaluate the latest in adaptive equipment — featuring new technology, manual and power chairs, cushions, accessories, adaptive sports equipment and more.

Here are some of the cool mobility-enhancing products that were featured at this year's ISS exhibit hall. Where Medicare coverage is indicated, the reader can assume that private insurance is also possible. Medicaid coverage is less certain, as it is determined by individual states and is often restricted by tight budgets.

**APEX Carbon:** Manufactured by Motion Composites of Canada, the APEX Carbon is a rigid wheelchair made of carbon fiber that is fully adjustable. The entire chair weighs a mere 15.5 pounds, and the weight of the frame is just 9.2 pounds, making it the lightest chair in its class.

In addition to being one of the lightest, strongest materials on earth, carbon fiber provides vibration-dampening properties, thus the APEX Carbon combines high performance response with a smooth ride. Integrated into the frame are impact guards made with Top Grip, which provides extra grip for transfers and protects high-wear areas of the frame.

Additional features include a carbon fiber camber tube, laser-etched markings and built-in "bubble-level" gauges for precise adjustments and exact positioning. MSRP: \$2,595 for APEX AI (aluminum frame) covered by Medicare. APEX Carbon is \$4,295, a \$1,700 upcharge, generally covered by the consumer.

**ROHO AGILITY CARBON:** The AGILITY CARBON back, by Permobil ROHO Seating and Positioning, is a rigid backrest made out of 12K flat-weave carbon fiber — thinner layers of carbon fiber that are closer together and compression-molded, resulting in a higher-strength and lighter material than standard carbon fiber. In addition, the tread is woven in a cool diamond-style pattern that matches the carbon components available on TiLite chairs. The back features a single clamp on each side that has



APEX Carbon

angular adjustment disks that enable 15 degrees of angle adjustment, and the disks are precision notched to lock into place when tightened.

AGILITY CARBON backs are available in Minimum Contour and Mid-Contour (additional side trunk support) and heights of 10, 13 and 16 inches. MSRP for the Minimum Contour Back System is \$985; the Mid-Contour System is \$995. Covered by Medicare.

**GlideWear:** GlideWear products are designed by Tamarack Habilitation Technologies to help protect skin from pressure ulcers by reducing three significant damaging factors: moisture, heat, and friction (shear). GlideWear does this by incorporating a patented silk-like breathable fabric that helps keep skin cool and dry, and uses two-ply technology with a low coefficient of friction in their designs. The two-ply fabric protects vulnerable areas from sheer by easily sliding against itself.

GlideWear products include cushion and headrest covers, socks and undershorts. MSRP for men's undershorts is \$54.99. GlideWear was expected to introduce women's undershorts shortly after press time.



GlideWear's shorts for men use two-ply fabric to reduce shear.

**SmartDriveMX2+ PushTracker:** The addition of the MX2+ PushTracker takes the popular SmartDrive power assist by Max Mobility to a new level of performance. The electronics are based around the PushTracker, a wrist-mounted Bluetooth control unit that combines SmartDrive control with an activity monitor.

To engage power to the MX2+ now requires a simple, double-tap of the wrist on which the PushTracker is being worn. This engages power, starting slow and steadily increasing in speed. A single tap of the wrist holds the desired speed, and another double-tap of the wrist disengages the power assist. PushTracker



SmartDriveMX2+ with PushTracker

performance characteristics including tap sensitivity and swiftness of acceleration, and top speed can be programmed via Bluetooth from a Smartphone App.

The PushTracker display has a scroll that shows current time, number of pushes, battery level, coast time, and distance covered. Additional in-depth performance and distance information can be viewed on the SmartPhone App.

MSRP: \$6,655. Covered by Medicare.

MX2 owners can upgrade, including the PushTracker, for \$425.

**RideWorks and Ride Custom Cushion 2:** RideWorks by Ride Designs is a fast, easy and extremely accurate way to capture shapes for Ride Custom cushions and backs. Rather than having to take an impression by sitting in a foam or plaster simulator, RideWorks captures a wheelchair user's shape by sitting on a bead-back and vacuum system coupled with RideWorks patent-pending Shape Capture Base. This is scanned with an Apple mobile device, like an iPad, and sent via internet to Ride Designs, where technicians utilize CAD procedures to create



RideWorks captures your shape with a bead-back and vacuum system.

a perfect custom cushion and/or back. At press time Ride Designs was in the process of setting up certified Ride providers (usually a local DME supplier) around the country.

The Ride Designs Custom Cushion 2 is the new version of the Ride Custom Cushion. It offers all of the skin and postural support as the original but is made with a softer, lighter weight material. A 16 by 16-inch Custom Cushion 2 weighs 1.8 pounds, with adjustment options including CAM wedges that can accommodate weight change, tissue atrophy, and postural change. Also, contours and spacer mesh fabric promote airflow and help keep skin dry. The cushion can be grown in width and length, and the scanned shape is kept on file for future cushion needs.

MSRP is \$1,590. Medicare approval pending at press time.



Ride Designs Custom Cushion 2 is made with a softer, lighter material.

**Küschall Advance:** Although popular in Europe, Küschall wheelchair sales have been absent in the United States since the mid-2000s. Now Invacare has brought Küschall back to the U.S. market, introducing three rigid chair models, the Attract, the

Champion and the Advance.

The Küschall Advance is especially eye-catching due to a unique carbon seat plate that provides rigidity to the chair. The front of the seat plate is solid, and the back blends into small carbon strips that can be adjusted via a Velcro strap for comfort and pressure distribution. Also unique to the Advance is the option of a quick-release removable front end that separates in front of the seat pan, enabling the chair frame to fit in extremely tight places, including small car trunks and/or in overhead bins of many airliners.

MSRP is \$3,375. Medicare coverage pending at press time.

**Twion power assist wheels:**

Twion power assist wheels by Alber USA have quick-release axles, fit on almost all active wheelchairs and weigh 13 pounds per wheel — about the same weight as a wheelchair frame. Built-in lithium ion batteries provide a range of up to 12 miles on a charge. Top speed of standard (Basic Twion) wheels is 4 mph, and top speed of the upgrade wheels (Active) is 6 mph, making them the fastest and lightest power assist wheels available.

Control input comes from the push rims. The faster you push, the faster the power assist. Steering and braking is the

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Twion Power Assist Wheels

same as a manual push rim, and Twion wheels assist in braking on ramps and going down hills. The wheels can also communicate with smartphones, enabling the user to custom tune performance characteristics, including acceleration and top speed, as well as read-out of parameters, including battery status, current speed, average speed, odometer and altimeter.

MSRP for Basic: \$5,895; for Active: \$6,396. Covered by Medicare.

**Q-Logic 3:** The Q-Logic 3 is an advanced drive control system from Quantum Rehab. In addition to controlling the functions on the powerchair, the Q-Logic 3 can also operate a wide range of devices that use infrared remote controls, such as televisions, and serves as a Bluetooth computer mouse emulator. The Q-Logic 3 can be set up to run up to eight devices and has four programmable push button options for customized seating access.

Currently the Q-Logic 3 is only available on the Q6 Edge 2.0, which is usually equipped with iLevel seat elevation. Over the coming months it will be phased in on other Quantum chairs.

MSRP upcharge on the chair is \$695 plus \$425 for the controller harness; however, it is covered by Medicare, so it should be wrapped in to the cost of the chair.



Q-Logic 3

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**Jay J3 HV back:** The HV back, by Sunrise Medical, is the cushion part of Jay J3 backs that has a unique feature — it helps warm you up when it is cold (as well as providing soothing warmth for a sore back) and helps cool you down when it is hot.

The HV back does this using a lithium ion battery that can be re-charged overnight to provide up to eight hours of continuous heat (the heating unit is tested to medical standards) and 12 hours of continuous cooling — via forced air ventilation through the cushion.

The HV back is only available on the Jay J3 backrest in Posterior (PA), Posterior Lateral (PL), and Posterior Deep (PD) models in mid-thoracic (15 inches), upper thoracic and shoulder-height backs.

At press time the HV back was not yet available for sale. Launch is scheduled for Spring 2017.

MSRP for the HV portion of the back is \$795, and the J3 back MSRP ranges from \$535-\$795 depending on size and contour. Currently the HV back doesn't have a Medicare code, but the company says it will be working on addressing this in the future.



Jay J3 HV back cools you when you're hot and heats you when you're cold.

These products represent a small sampling of the several hundreds of seating and mobility products featured at the ISS this year. For a complete listing of exhibitors, visit the ISS website (see resources).

## RESOURCES

- International Seating Symposium, [www.iss.pitt.edu](http://www.iss.pitt.edu)
- Apex Carbon, [www.motioncomposites.com](http://www.motioncomposites.com)
- Ride Designs, [www.ridedesigns.com](http://www.ridedesigns.com)
- GlideWear, [glidewear.com/shop](http://glidewear.com/shop)
- Jay J3 HV back, [www.sunrisemedical.com](http://www.sunrisemedical.com)
- Kuschall, [www.kuschallusa.com](http://www.kuschallusa.com)
- ROHO Agility Carbon, [permobilus.com/products/seating-and-positioning-by-roho/back-system-products/agility-carbon-series](http://permobilus.com/products/seating-and-positioning-by-roho/back-system-products/agility-carbon-series)
- SmartDrive MX2+ PushTracker, [www.max-mobility.com](http://www.max-mobility.com)
- Twion Power Assist Wheels, [www.alber-usa.com](http://www.alber-usa.com)
- Q-Logic 3 Controller, [www.quantumrehab.com](http://www.quantumrehab.com)

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# The Accessible AMUSEMENT PARK in Your Own Backyard

BY JOSIE BYZEK

Be it California's Six Flags, Ohio's King's Island or Florida's Sea World, every region has its amusement parks, and many of these are accessible enough to make a nice day of it. Better yet, although the admission price may initially make you gasp for air, compared to plane fare and hotel stays, they're doable, making them good options for families on a budget looking for affordable recreation options.

We caught up with four wheelers who share their favorite parks with us, as well as some insider tips.

## It's Right in Our Backyard

Kara and Adam Ayers' family has grown since they spoke with *NEW MOBILITY* about their first child, Hannah, 6, in February 2011's "Anything for Baby." The family adopted Eli, 9, who has a form of dwarfism, from China in 2014, and in March of this year, Kara gave birth to a baby girl named Riley.

Like any family with young children, they are always looking for ways to keep the kids entertained and busy — and since both Kara and Adam have osteogenesis imperfecta and use manual wheelchairs, anywhere they take the kids has to be accessible. Enter King's Island, located in Mason, Ohio.

"It's right in our backyard and takes 10 minutes to get to the gate. We can hear their fireworks in the summer, so it's really close to us, which has to do with how frequently we go," says Kara, 37, the advocacy coordinator at Cincinnati Chil-



dren Hospital's Medical Center. "And we get annual passes."

Admission isn't cheap, with renewing season passes usually coming in around \$100 per person, but Kara says it depends on what you compare the passes to. "I watch those videos about the Caribbean and cruise travel and all that's cool, but they're not affordable," she says. "And I do know amusement parks aren't perfect. But we get our money's worth with all the seasonal stuff. Like, they do a Halloween thing and this year they're bringing back their Christmas program — they freeze their big fountain and have ice skating, so we'll be able to go Christmas Eve and watch ice skating."

When you get to King's Island, you'll see there are plenty of accessible parking spots. "Rows and rows, and they're up front," she says.

"You park and roll right in, no tram." Next, stop at guest services. "It's right there — you don't have to search for it, like you do in many other parks." This is where you pick up your ride admission slip, which lets you use the accessible entrances and is printed on old-fashioned paper — as the park has not yet gone electronic. "We keep the papers from previous trips so we don't have to explain to a 16-year-old kid every time what we can do."

Guest services also estimates wait times for the more popular rides and gives paper passes with the times the Ayers can show up at the accessible entrance. "This doesn't always help with the line, as it's an estimate, but we don't have the option to not do it because there are several rides we enter through the exit.





Above: There is plenty for a young family to do at King's Island. Right: Adam and Hannah Ayers head off to a roller coaster. Left, opposite page: Sometimes Kara and Adam Ayers sneak off to the park without their kids and ride together.



So we build this process into our system, and our kids probably think this is what everybody does. The passes can be a headache, but we've got a good routine."

Built into their routine is who rides which ride with which child. "Hannah and Adam ride roller coasters. Eli will never meet the height requirement, but doesn't want to ride them anyway, so it works out." And once in a while the couple will be able to go to the park without the kids and ride the rollercoasters together.

Overall accessibility is decent. "You can transfer on the platform for the coasters and the car is right beside it, so there are no steps up and down," says Kara. "I have a strict rule of no loops, but Adam does more than I do, and there aren't any steps to and from the cars. Also, the park is not hilly."

"Another thing that makes it affordable for families is they update things frequently enough that there's something new to look forward to each year," adds Ayers. "Like one year there were animatronic dinosaurs, but usually it's a new ride, like a roller coaster."

• [King's Island, www.visitkingsisland.com](http://www.visitkingsisland.com), [www.visitkingsisland.com/plan-a-visit/guests-with-disabilities](http://www.visitkingsisland.com/plan-a-visit/guests-with-disabilities). Daily ticket price is \$44.99 and season pass package pricing ranges from \$114 for regular, \$129 for gold and \$210 for platinum.

## California Coasting

Professional surfer and chairskater Christiaan "Otter" Bailey spends much of his time traveling on tour as an adaptive surfer or — his other great love — chair-

skating with Team Box WCMX. Since he also enjoys amusement parks, his travels have given him the chance to experience roller coasters all over the world.

"I went to Tokyo Dome City. That was pretty amazing, especially the Thunder Dolphin roller coaster. The Japanese embrace a lot of cool themes and their parks are pretty amazing, and their rides are crazy," says Bailey, director of the nonprofit Ocean Healing Group and an L3-S3 para. "And Disneyland Paris was a lot of fun."

That's really cool, but how about parks closer to home?

"Great America in San Jose is really, really big," says Bailey, who lives in Santa Cruz. "It's awesome because they have everything under the sun as far as amusement parks go. They are a lot more accessible than a lot of other places I've been and are phenomenal in getting you to the front of the line."

If you think that's not necessary, Bailey says to reconsider. "Typically a line to a roller coaster is on a gradual plane. So if you're in a wheelchair and go halfway up a ramp and hold that position, then spend 30 minutes to an hour going incremental inches ... it's torture in a manual wheelchair."

Bailey also enjoys Six Flags Magic Mountain, which he says is, "awesome in terms of being accommodating to people with disabilities." His favorite part? "Six Flags has old-school wooden roller coasters. There's sentimentality when you ride





Christiaan “Otter” Bailey (left) and fellow chairskater Aaron Fotheringham goof off with young wheelers at a WCMX workshop.

them — you just can’t help but love them. You only have one of those little lap bars and gravity keeping you in, and they’re so rickety. As you come across these massive valleys, you hear the wood creaking ... it’s pretty gnarly.” The park boasts 19 wooden roller coasters, the most in the nation and possibly anywhere.

But the park he visits the most is the one closest to home: The Santa Cruz Beach Boardwalk.

“The Boardwalk is one of the oldest amusement parks in California, built in 1907, and still retains much of its charm. I always bring my friends there when they come to town and want a quintessential Santa Cruz experience,” says Bailey.

What does he ride the most? “It depends who I go with. If it’s a little kid in a wheelchair, I won’t do some rides, although most kids in chairs are pretty adaptable, especially the kids I work with through Ocean Healing Group. They’re WCMXers and have already broken down those social barriers. If I’m coming, they want to come, too. We have a great time.”

• *California’s Great America, [www.cagreatamerica.com](http://www.cagreatamerica.com), [www.cagreatamerica.com/help/accessibility](http://www.cagreatamerica.com/help/accessibility). Daily tickets start at \$39.99 for same-day admission and season passes start at \$69.*

*but daily ride passes range from \$36.95 to \$48.95, and season passes are \$81.95.*

• *Six Flags Magic Mountain, [www.sixflags.com](http://www.sixflags.com), [www.sixflags.com/magic-mountain/plan-your-visit/guests-with-disabilities](http://www.sixflags.com/magic-mountain/plan-your-visit/guests-with-disabilities). Daily tickets cost \$79.99 at the park and \$54.99 if purchased online. Season passes start at \$97.*

## Theme Parks and Family Time

Vance and Casey Taylor have two daughters — Isabelle, 11, and Samantha, 10. Like many young families, they’re on the lookout for affordable activities to do together, and often that means theme parks.

“Disney World, for example,” says

Vance, 39, who has muscular dystrophy and uses a power chair. “They put on a lot of shows, so it’s really great. You go, the kids are into it, and they do a Lion King show and it’s very accessible, very accommodating, with climate control. We have a lot of fun doing that.”

There are some rides the whole family can enjoy together, but sometimes Dad gets left out. “You can go on It’s a Small World After All and Finding Nemo with your wheelchair and that’s great,” says Vance, who is the chief of the Office of Access and Functional Needs at California Governor’s Office of Emergency Services. “They’ve got a fair number of rides you can transfer on to, but I don’t transfer onto rides.”

Before the system was wrecked by people who took advantage of it, Taylor’s whole family could go to the front of the line. “And then you get them on the ride and you’re done. Now they could wait in line for an hour and a half, and they’re together in the line, but where am I? When

## Tips for a Successful Trip

The number one tip for a successful trip to a theme park according to Sylvia Curbelo Longmire is “do your research.” Fortunately most major theme parks have a complete part of their site dedicated to listing their disability policy and how accessible they are. If the theme park’s website does not have a tab for accessibility, look for one that says something like “Park Info.” Click on that, and usually you’ll see an option for “disability services.” In addition to park websites, try Googling the name of the park along with the word “accessibility” or “wheelchair,” and you may find blogs or posts on forums by people with disabilities similar to yours.

Remember, there is no such thing as too much research when it comes to planning a trip, even if it’s just to your local amusement park. “You have to know what to expect before going,” says Vance Taylor. “Plan accordingly, know you’ll be bored a little bit, and it all goes into the whole ‘family trip memory bank’ anyway.”

that happens, I feel like I pay a lot of money to sit by myself, and they still get to go on rides.” [See “Disney Universe: Changing but Still Magical,” NM, March, 2015.]

Still, the Taylors find lots to do together at the park. “Not being able to ride a lot of rides is offset by the shows, eating together, watching fireworks and parades together.”

The Taylors, who live outside of Sacramento, California, flew to Orlando, Florida, for their Disney vacation. “I liked doing that because since we were staying in their hotel, I could go to the park, go back to my room and take a nap,” says Taylor. “Disney picks you up at the airport in an accessible bus and takes your bag up to the room before you even get there. Any buses to or from the park to the hotel are all fully accessible. Once you’re there, you’re good to go. Again, with the understanding that I might spend a lot of time by myself — if I don’t plan right.”

Besides Disney World, Taylor says Pennsylvania’s Hershey Park made an impression on him. “It was very accessible in terms of terrain,” he says, although there are a few hills. “And most of the rides were good about letting our family in the front of the line, so I didn’t have to wait by myself. I don’t think that’s an official policy, they were just being nice.



Vance and Casey Taylor enjoy taking their daughters, Isabelle and Samantha, to theme parks.



Sylvia Curbelo Longmire enjoys taking her kids to parks that have a lot of shows, like Sea World.

When they did wait in line, we could still see each other, so that was a plus. And there are a lot of cool things to do there, which is great. It’s not like the only thing to do is ride.”

Hershey Park’s zoo and water park are included in the admission fee. Chocolate World, located near the park’s entrance, is free and features a popular ride through a stylized candy factory that is only accessible for manual wheelchair users. The gift shop is accessible, though, and is a good place to mooch free Hershey samples.

“We had a great time at Hershey Park,” says Taylor. “Like everything, it’s not going to be perfect, but there are enough good things to do that you can have a great time as a family.”

- *Walt Disney World, [www.disney.com](http://www.disney.com), [disneyworld.disney.go.com/guest-services/guests-with-disabilities/](http://disneyworld.disney.go.com/guest-services/guests-with-disabilities/). Prices for Disney theme parks vary depending on how many days you wish to visit. The range is between \$44.50 per day for 10 days and \$99.50 per day for two. Same-day price varies park to park.*

- *Hershey Park, [www.hersheypark.com](http://www.hersheypark.com), [www.hersheypark.com/park-info/accessibility.php](http://www.hersheypark.com/park-info/accessibility.php). A one-day ticket costs \$64.95 and season passes start at \$170.*

## It’s Worth the Expense

Amusement parks were more fun before her MS transitioned from relapsing-remitting to secondary-progressive, says Sylvia Curbelo Longmire. “I live in Orlando, Florida, so I have a million parks to choose from, but I was also able to walk and go on all of the rides five years ago,” she says.

Longmire splits custody with her ex-



husband for their two sons, ages 6 and 9. “They primarily live with their dad — with my MS we agreed it’s better for them. Their dad takes them to Disney World, and I take them to places like Sea World, museums, and the zoo all the time.”

Not counting Disney, what is the most accessible park in Orlando that Longmire’s visited? Probably Sea World. “It’s a mixed bag because like a lot of people I have ethical issues with the park. You want to take your kids to see the animals in an environment where they can be studied and learned about, but they’re in captivity,” she says. “But that said, since I can’t go on most rides anymore and usually wait for everybody who does, I like Sea World because it’s heavy on shows. Just being able to go to the dolphin show, the whale show ... it’s easier to feel I am being entertained.”

If you can’t go on rides anymore, is it worth the expense? “If I was going with other adults at this point in my life, I’d say no, because I’m missing out on half the stuff,” says Longmire. “However, taking my kids, absolutely. It’s a totally different experience when you take your kids and see the experience they’re having. It’s totally worth it to be able to go with them.”

- *Sea World Orlando, [seaworldparks.com/en/seaworld-orlando/](http://seaworldparks.com/en/seaworld-orlando/), [seaworldparks.com/en/seaworld-orlando/park-info/accessibility-guide](http://seaworldparks.com/en/seaworld-orlando/park-info/accessibility-guide). Single-day tickets start at \$79 and season passes start at \$99.99.*

# RORY COOPER: THE MAN

BY IAN RUDER

Rory Cooper couldn't have known what to expect as he and his team from the Human Engineering Research Laboratories at the University of Pittsburgh prepared to test their state-of-the-art power chair at October's inaugural Cybathlon in Kloten, Switzerland.

The Cybathlon was conceived as a chance for the world's leading assistive technology researchers to show off their latest and greatest innovations in several different events: a virtual race using brain control interface, a bicycle race using FES, obstacle courses for people with arm and leg prostheses, an obstacle course for robotic exoskeletons, and the event Cooper was competing in, an extreme obstacle course for power wheelchairs.

That might sound like fun to someone like Cooper, HERL's founder and director and one of the preeminent researchers and engineers when it comes to assistive technology, but no one knew if people would fill up the hockey arena where the competition was being held — or if the general public even cared.

When Cooper strapped on his helmet and rolled into the arena, the response caught him off guard. "The size of the turnout was amazing," he recalls. Not only was the arena mostly filled with raucous fans, but a large media contingent was on hand to broadcast the event live across Europe and the internet. "I've competed in a lot of athletic competitions — I was a Paralympian in 1988 and I've been a coach a number of times — but rolling out there, it felt almost like I was a gladiator."

In many ways, Cooper is a gladiator for those who rely on assistive technology. Ever since he was paralyzed in 1980, Cooper has devoted himself to pushing assistive technology forward by inventing and improving the products people with disabilities rely on and fighting to raise the public's awareness of their needs. If you use a wheelchair or any other sort of assistive technology, the chances are extremely high that he has had some direct

## Products Galore

Over the course of 23 years, HERL's research has led to numerous products and advancements that have impacted hundreds of thousands of wheelchair users and clinicians. From power assist to ergonomic push rims to the seemingly obvious mechanisms behind folding chairs, if an innovation has moved the field forward and helped people, there is a good chance it came through HERL or someone connected with it. Here are a few notable products:

**SmartWheel** – An instrumented handrim used by clinicians to better understand the physical demands of pushing a wheelchair and the causes of repetitive stress.

**Natural-Fit Pushrim** – An ergonomic pushrim designed to relieve stress on the pusher's upper body.

**Pathlock** – A system to help wheelchair users drive on a slope more easily by biasing the casters (came to market as the Glide Suspension Fork from TiLite in 2014).

**PerMMA** – The Personal Mobility and Manipulation Appliance was the first wheelchair with two coordinated, fully robotic arms that could be controlled by the user.

**Strong Arm** – A wheelchair attachment to help wheelchair users transfer in and out of their chair with less caregiver assistance.

**Virtual Seating Coach** – An app and web-based tool that helps users and clinicians find the proper seating position (marketed by Permobil).

**E-Scale** – Hockey puck-like disks that can be placed under a user's bed to provide easy, accurate weights (being developed by Nexaware).

**PneuMobility** – A project using compressed air as an alternative to batteries to power assistive devices like the PneuChair and PneuScooter.

or indirect influence on its design.

With a list of awards, accomplishments and honors almost as long as the list of patents he has secured, Cooper didn't need the adulation of the Cybathlon crowd, but its significance was not lost on him. "Hopefully the enthusiasm that was there will drive more people to study science and engineering and help continue the progress that we've made," he says. "If I want anything, I want to grow the positive impact that we can have on people with disabilities."

## Building the Wheelchair Capital

Cooper's quest to elevate assistive technology began July 23, 1980, when he was paralyzed in a biking accident while stationed in Germany with the U.S. Army. He eventually made it home to California where he completed his rehab and mar-



ried the German woman he had fallen in love with. As he studied electrical engineering at California Polytechnic State University, San Luis Obispo, he grew increasingly aware of the obstacles facing people with disabilities and his knack for solving them. He was particularly inter-

# BEHIND THE TECHNOLOGY

Rory Cooper demonstrates how the MEBot he and his team developed handles obstacles.



Photo by Joe Appel

Photo courtesy of University of Pittsburgh

ested in the repetitive stress injuries many people suffered from pushing wheelchairs. He earned his bachelor's, master's and got a Ph.D. in electrical and computer engineering. He completed a fellowship in rehabilitation engineering and science and then taught at California State University in Sacramento. In 1990 he was appointed director of the school's Human Engineering Laboratory and coordinator of the Rehabilitation Engineering Program. The University of Pittsburgh hired him away in 1994 and soon after he founded HERL.

"It started in my living room and dining room at home with me and two graduate students. My wife kicked us out and

the VA gave us an old locker room," he says. "Literally one of my students got an award last week, and he mentioned that there was a sign over his desk that said 'Please flush after using.' I reminded him that my office was the towel cage."

Even Cooper has trouble reconciling those humble beginnings with the program's current setup. Six years ago HERL moved into a custom-built space in a swanky Pittsburgh research park alongside Google, Ford and other industry giants. The space is big enough to accommodate the 70 to 100 students, faculty and interns that regularly pass through, and it holds all the design and manufacturing equipment for researchers to see their projects

through from inception to completion.

"It is kind of unique in that everything's housed at one place," says Jonathan Duvall, a C6 quad completing his Ph.D. at HERL. "You can design something using 3-D CAD software and as soon as you're done designing it, you go down to the basement to the machine shop and actually build it yourself. We don't outsource any of our production. We have all the machines there to do it ourselves. So we go from concept and idea to prototyping to testing in the field — and even doing human subject testing to see how people feel about the technology that we develop and how effective it is."

That unique setup, combined with

# The E-Scale: The Wait for Your Weight May Be Over

As a C6 quad, Jonathan Duvall is all too aware of how difficult it can be for a wheelchair user to find an accessible scale. “The only way to know really whether you’re gaining weight or losing weight is if your pants start feeling tight or start feeling loose,” he says.

That may soon change thanks to the E-Scale, a new device developed by Duvall and other HERL researchers that takes the hassle out of weighing. “It’s four little hockey puck-like devices that would go under the legs of a bed, and wirelessly measure the change in weight every time somebody gets in or out of the bed,” explains Duvall, who is developing the E-scale as part of his Ph.D. dissertation. “So it allows wheelchair users to not have to buy a roll-on scale or a lift scale and to monitor their weights via an app on their phone.”

Jonathan Pearlman, HERL’s associate director for product innovation and translation, got the idea watching his paraplegic stepfather struggle with gaining weight as he ages. “If you dig deeper into the research, what you find is that there’s a lot of evidence that weight feedback helps people maintain weight. I think that should be no surprise, but from a research standpoint there’s also strong evidence that says if you have weight feedback, it helps facilitate weight loss. And there’s just virtually no way for wheelchair users to get their weight on a regular basis,” he says. “We see the E-Scale as something that could potentially have a really large scale impact for wheelchair users, but it also has applicability for the general population.”

Fellow researchers and entrepreneurs seem to agree. The project has received numerous grants and was optioned to Nexaware, a Richmond, Virginia-based startup for commercialization. Gerard Eldering, the manager for Nexaware, says the company has raised over \$250,000 from investors and hopes to have beta units in the hands of testers this summer.

a dedicated team of researchers and medical professionals, has helped make HERL into the “wheelchair capital” for researchers, according to Jonathan Pearlman, the associate director for product innovation and translation. “I don’t think I’ve ever seen a shop like we have,” he says. “Even our engineering schools here at Pitt — their jaws just drop when they see the resources we have. ... Our setup helps create the kinds of synergies that happen less frequently elsewhere.”

The 70 or so projects going on at any one time run the gamut. Beyond wheelchairs and orthoses, you might catch a glimpse of robots preparing meals, researchers testing home environmental control units or something else you’ve never seen before.

“You really never know what’s going to be talked about the next day,” says Brandon Daveler, a C4-5 quad who completed his master’s at HERL and is now working on his Ph.D.

Daveler and Duvall are two of the many wheelchair users and veterans to call HERL home. From the beginning, Cooper has made it a priority to have the people who actually depend on rehab technology be the ones working to design it. “Dr. Cooper’s always willing to try anything or get any other piece of adaptive equipment that we need,” says

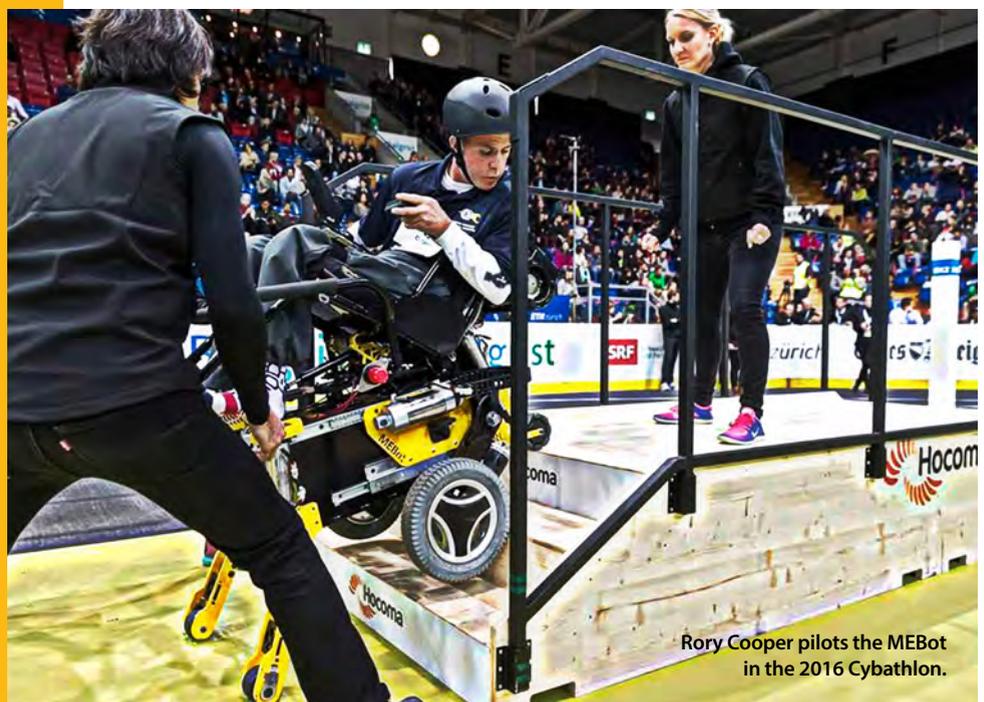
Daveler. As an example, he shared how Cooper went out of his way to get a grant for a 3-D laser measurement system to help Daveler and others work more efficiently. “Now I can do it individually, independently, by myself. And it will be more accurate and faster, too. That’s the kind of individual that he is. Always trying to make people more independent.”

Cooper’s commitment to inclusion goes beyond physical access. “Rory certainly serves as a role model, but more than that, he really sets an expectation that students go and travel to conferences and have the support that they need. That is in some cases very transformative for the student with a disability,” says Pearlman. “He is 1,000 percent committed to the lab and to providing opportunities to people with disability to move into research and to developing the best, most advanced assisted technology.”

## A Natural Leader

If you could craft a perfect person to lead a facility like HERL, you’d be hard pressed to come up with a better model than Cooper. “I heard somebody say that the ideal CEO is somebody with their head in the clouds and their feet planted on the ground,” says Duvall. “As our CEO, the director of our lab, he is a good mix of both of those.”

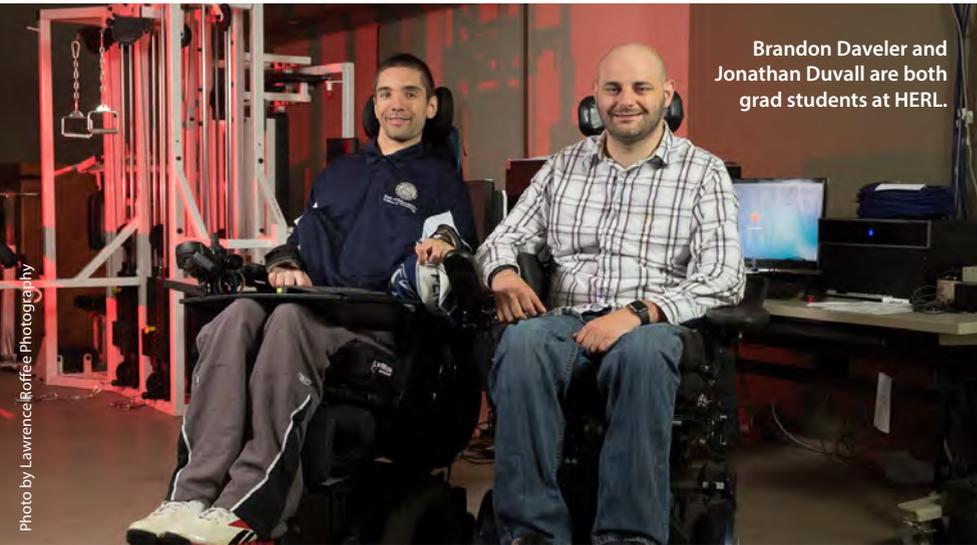
Being a wheelchair user helps but is just



Rory Cooper pilots the MEBot in the 2016 Cybathlon.

Photo courtesy of HERL

Photo by Lawrence R. Coffey Photography



Brandon Daveler and Jonathan Duvall are both grad students at HERL.

a small piece of a bigger puzzle. His knowledge, skill set and passion, combined with his dedication to solving clinical and real life issues using a scientific approach, are singularly suited to his profession.

“I’ve never worked with somebody who understands both the theoretical side of engineering as well as the practical aspects of just designing something like a good hand rim,” says Pearlman. “That’s a very unique person who can both speak about the very high level, complex mathematical aspects of engineering but also just talk about things in very practical terms.”

Pearlman has worked with Cooper since he came to HERL in 2003 for his Ph.D. and is still impressed by his boss’s passion. “He really enjoys what he does, and it comes naturally to him to come up with ideas, get down in the shop, work with engineers and design and build things.”

“There used to be a time where we would joke that Rory had a sixth sense because when somebody was going to weld something he would come down and suddenly be there and be the guy that wanted to weld up the frame of the wheelchair or show you how to weld.”

That passion extends to helping students and faculty around him hone the way they think about design and manufacturing. “If I come up with an idea for a product or a technology, he’ll skip meetings and sit there and brainstorm about what he thinks about it. He’s never going to brush you off or say he’s got to get to a meeting,” adds Pearlman.

Daveler credits Cooper’s rigorous evaluations and discussions with push-

ing him to create the best solutions possible. “I’ll get all excited and take a project to him and show him, and he’ll inevitably say, ‘It could be better,’ and ‘Why didn’t you do it this way?’ or ‘Why did you do it this way?’ He’s always trying to make you a better student or advocate or individual or designer or whatever it may be. And that’s just the type of person he is.”

Cooper says his goal is to push the field forward while actually meeting the users’ needs. While that may sound simple coming from him, finding the passion and drive to keep innovating is not easy. “I don’t know how he continually comes up with ideas,” says Daveler. “For example, using air to power a wheelchair. How do you come up with that idea just out of the blue? It’s kind of mind blowing — he takes it that next extra step to figure out a way to address issues that he encounters or other people encounter, and then takes the initiative to come up with the idea for that, to fix it. It’s inspiring, like, ‘What the heck? Why didn’t I think of that?’”

### From Prototype to Product

There are so many assistive technology patents and products to have come out of HERL that Cooper often runs into strangers out in public who are using them. “It’s always cool to see,” he says. “If I get a chance to, I try to go up to people and ask them what they think and not tell them who I am. It’s really cool when they say, ‘Oh man, it’s wonderful and it changed my life, I don’t have any pain anymore!’ or ‘Oh, I can go anywhere I want to now!’ I usually say, ‘Thank you for contributing

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# PneuMobility: Riding on Air, Literally

An air-powered wheelchair that can function in the water? It may sound like James Bond's latest gadget or something from a Jetsons-eque future world, but thanks to the HERL researchers, it is already a reality. The PneuChair air-powered chair made its debut Apr. 7 at Morgan's Inspiration Island, the accessible theme park in San Antonio, Texas.

"I'm pretty excited about it because now a power chair user could drive into a pool that has a ramp, or you could go to the beach and drive into the water or play along the water, or you could now go to a water park and drive through the fountains," says Rory Cooper, HERL's director. "Just think if you've got a kid, how many of those water fountains or water features do little kids play in? Now in a power chair you can be out there with them."

Brandon Daveler, a C4-5 quad and the lead mechanical design engineer on the PneuMobility (not affiliated with this magazine) project of which the PneuChair is a product, says he doesn't envision the air-powered chair as a replacement for complex power chairs or scooters — there is also a scooter, the PneuScooter — at this stage. With a range of 2-3 miles on smooth flat surface, Daveler suggests air power could be an alternative for places like nursing homes, veterans homes, airports or grocery stores. Despite the limited range, air offers a number of advantages. First, the high-pressure air canisters are easier to replace and faster to recharge than batteries. Second, without any electronics, maintenance decreases, and it's easier to perform maintenance on the chair because many of the components are available at normal hardware stores.

Initially, 10 PneuChairs produced by Stealth Technologies of Burnet, Texas, a division of Pride Mobility, will be available for use at Morgan's Inspiration Island.

towards my retirement."

Developing a useful product and then actually getting it to market is not an easy thing. But again, Cooper has positioned HERL for success. For instance, Gerard Eldering, owner of a venture creation company that has been scouting research universities for promising products for almost 10 years, has helped create a new company, Nexaware, to bring one of HERL's current projects — the E-scale — to market (see sidebar, page 26). He calls HERL "one of the coolest facilities" he has worked with and attributes much of the program's success to Cooper's approach and the people he has surrounded himself with. "There a lot of things that we look and listen for when we go in some-

where, but certainly one is the credibility and the standing of the research team. And not just their standing, but are these guys really involved in this particular industry and likely to be on the edge of the innovative thinking. That's definitely what I saw with this group."

Being on that edge is critical, but so is the ability to make sure that the research and products are developed with users in mind. Kara Kopplin, senior research manager for research and innovation within the Permobil Group, has gotten a firsthand look at how Cooper's team emphasizes a user-based approach while collaborating on the Virtual Seating Coach, an app and web-based tool that helps users and clinicians find the proper seating position. "Throughout the (development) process they are getting user feedback and doing qualitative studies and understanding how to refine as they're doing research and starting to develop solutions," she says. "I think having that perspective and that engagement with the actual environment and people that would be using these solutions is what's made them so successful in the past and what has made them really good partners for us with our development efforts, too."



Photo courtesy of HERL

Look for HERL's air-powered chairs at Morgan's Wonderland theme park.

Brandon Daveler is the lead engineer on the PneuMobility air-powered wheelchair.



Photo by Lawrence Roffee Photography

## The MEBot

The Mobility Enhancement Robotic Wheelchair (MEBot), the power chair Cooper and his team showed off in the Cybathlon, is a perfect example of how user feedback can drive the HERL team's research and design efforts. As Cooper tells it, the MEBot's origins lie in a conversation he had with wounded Marines who were unable to tour the

battlegrounds at Gettysburg because of their wheelchairs. “They were like, ‘Hey, Dr. Cooper, you should be able to solve that problem,’” he says. “It got me to thinking that we need a chair that can be used indoors and be practical but also go outdoors and be practical.”

Cooper addressed some of the same issues early in his career when he worked on the original iBOT, the famed “stair climbing chair” invented by Dean Kamen. But the iBOT’s high price tag and user requirements kept it from getting Medicare approval and restricted who could actually use it. Creating a chair that would allow higher level quads and more demanding users to enjoy the same freedoms, and doing so in a way insurances would pay for, were critical to Cooper’s vision.

With large, center-drive wheels that can reposition themselves to simulate front-, mid-, or rear-wheel drive, and four smaller casters that can move up and down, the MEBot allows users to navigate curbs, steps and rough terrain regardless of their upper body strength. Cooper and HERL have been working on the MEBot for four years, custom designing and building everything from the frame to the electronics on site.

Currently, Cooper and crew are working to incorporate sensors, gyroscopes, cameras and more to make what could truly be considered a smart chair. “It will be able to detect obstacles and do the path planning for you. It’ll tell you whether you can actually climb that obstacle or descend it safely and improve the self-leveling so it’s smoother and more intuitive,” he says. While the team works on reliability, Cooper focuses on key questions. “How do you interface with a chair like this? How would you want to control something this complex? How much do you want to do yourself, and how much do you want to be automated?”

Building such a complex chair with so many high-tech components might seem counterintuitive to the stated goal of building something insurance would pay for, but Cooper insists that is not the case. Over two decades after the iBOT, 3-D printing makes prototyping much easier and cheaper, and the cost of sensors and computing power has dramatically decreased. “The iBOT used four

386 computers,” he says. “I mean, you can almost get that much power on a holiday card now.”

Despite a strong showing, the MEBot did not end up winning the power chair obstacle race at last year’s Cybathlon. Cooper got hung up ascending a set of stairs and ended up losing to a chair that had been specifically designed for the course. He noted that the winning chair would be of little real-world benefit to most users and was happy to point out that the ME-

Bot traversed all the obstacles leading to the stairs with the greatest speed and ease of the finalists. “We tried to design a chair that you or I would buy,” he says. “If I had another month to work on the stairs, we would have had no problem.”

Cooper joked that the MEBot was “redeemed” soon after its defeat when it won the 2016 Blackwood Design Award for “Best New Concept.” The annual awards are run by a Scottish care company and focus on products designed to help people

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with disabilities and special needs. The judges praised the design “because it was very clear that it was designed by wheelchair users, for wheelchair users, and with very full inclusion from the outset.”

Daveler says that approach is a big part of why he enjoys working on the MEBot and at HERL in general. “I know what it’s like to encounter a single step when you go to a house or a bar or a restaurant or something and you can’t get in, and knowing that feeling, like, ‘Oh, this sucks, I can’t go in here.’ The feeling that one day that barrier is not going to be there because you designed a chair that can go up and over, or around that, is what drives me to make that project and projects like MEBot work.”

### Still Going Strong

Nearly 37 years after being paralyzed, and 23 years after founding HERL, Cooper is showing no signs of slowing down. Unlike many people who have been doing something for a long time, he is still on the cutting edge and thrilled to be there. He’s got ideas about robotics and

intelligent machines. He’s excited about wearable technology. He wants to make sure people with disabilities can take full advantage of the self-driving car revolution. And of course he wants to keep honing MEBot. He won’t rule out a return to the next Cybathlon. “I think MEBot has a chance to win,” he says. “It’s just getting the algorithms and sensing down better.” In classic Cooper fashion, he added, “But if not, yeah, I’ve got some other ideas that I’m not quite ready to disclose yet.”

“He’s certainly still the same Rory,” says Pearlman. “He is still writing a lot of grants, getting a lot of grants, advising students, and I haven’t seen any change in the day-to-day activities of what his goals are related to his own research.”

Still, as his stature in the community has grown, Cooper has embraced the spotlight to extend his advocacy efforts. Cooper is just as knowledgeable about the inequities of Medicare and Medicaid and more than happy to use his connections to get the ears of key policy makers.

“As a leader he has grown and diversified,” says Pearlman. “He has started to get

involved in other types of technology and broader initiatives with the Department of Defense. He understands that his influence can be broader and that just as his career has moved forward and his connections have grown, that he can be involved in committees at higher levels and start to focus on more policy initiatives.”

Despite all of this, Cooper continues to amaze all those who know him with his humble approach.

“He’s known all around the world, but he still takes time to talk with his students one-on-one and to write letters of recommendation,” says Duvall. “He even takes time to make networking connections to help his students get jobs in the government or in the industry or in some other school. For all he’s accomplished, he’s still an individual friend and mentor. He takes the time to help his students and the other investigators in the lab succeed.”

Cooper sees no reason why any of that should change. “My philosophy is, as long as I’m still having fun, if people are willing to help give us grants, and I’ve got new ideas, I’m not planning to go anywhere.” ■

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# ROLL ON CAPITOL HILL: *Six Years Old and Counting*

BY ALEX BENNEWITH,  
UNITED SPINAL VICE PRESIDENT, GOVERNMENT RELATIONS

**A**s some of you may have guessed, this year the Roll on Capitol Hill will be different for United Spinal Association, as we are facing both new challenges and new opportunities on a whole range of policy issues with a new presidential administration. More than ever, it is important that we remain vigilant to ensure that our rights, access and independence are not rolled back. As we have proved in previous years — and as we did at the end of 2016 with the 21st Century Cures Act — when we all work together, we can be successful.

The 21st Century Cures Act passed both chambers of Congress and was signed by President Obama at a signing ceremony in Washington, D.C., on December 13. It was the largest bill to pass since the Affordable Care Act in 2010, and it ensured many of the causes we advocated for at last year's Roll on Capitol Hill, including: protecting CRT; improving medical rehabilitation and neurological research; and ensuring approved prescription drugs and devices are brought to market more quickly. It also provides:

- \$4.8 billion to National Institutes of Health;
- \$1.8 billion for Cancer Moonshot to speed cancer research;
- \$1.5 billion for the BRAIN initiative to improve our understanding of diseases like Alzheimer's and speed diagnosis and treatment;



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- \$1.5 billion for the president's Precision Medicine Initiative to drive research into the genetic, lifestyle and environmental variations of disease;
- \$1 billion in grants to states to address the opioid crisis;
- \$500 million to the Food and Drug Administration.



**At this year's ROCH, vets will join other United Spinal members to meet with their legislators.**

## VETSFIRST ROLLS SIDE-BY-SIDE WITH UNITED

VetsFirst, a program of United Spinal Association, is excited to offer veterans an opportunity to join us in Washington, D.C., for our 6th annual Roll on Capitol Hill. We will have sessions at the Roll on Capitol Hill discussing legislation to improve employment services for veterans and improve the Department of Veterans Affairs' accountability to manage workforce issues effectively to improve veterans' access to health care.

VetsFirst is focused more than ever on ensuring Congress addresses the critical policies affecting our veteran community. From improving VA health care and benefits to strengthening access to employment and housing, VetsFirst continues to fight for all generations of veterans, including individuals living with post-traumatic stress disorder and traumatic brain injuries. Visit us at [www.vetsfirst.org](http://www.vetsfirst.org).

This June 11-14, we are celebrating the sixth year of the Roll on Capitol Hill. We'll kick things off with a fun reception Sunday night and then dive into a full day of speaker presentations and issue education on Monday. New this year, for those who have never attended the Roll before or would just like a refresher, we will be doing a new attendee orientation to prepare for your meetings on the Hill. Also new this year, we will be capturing you on video throughout the event and interviewing you after your Hill meetings for some up-to-the minute intel. That video will be shared with all attendees on Wednesday morning. Tuesday, advocates will spend most of the day on Capitol Hill meeting with their legislators, making sure that our voices are heard.

We'll take care of scheduling the meetings and leave the fun part, the actual meetings, to you. After all those Hill meetings, there will be an awards reception on Capitol Hill where we thank you, as well as our congressional champions, for all the support and leadership over the past year.

Forecasting the political climate in the capital is more difficult this year than ever before. This has not been a conventional year so far, by any means. From the end of last year through the end of March, disability advocacy groups across the coun-



Spinalpedia's Josh Basile and Backbones' Reveca Torres greet each other at last year's ROCH.

try have been on the front lines pushing back against efforts to cut Medicaid and to remove consumer protections in the Affordable Care Act such as the assurance of continued coverage for individuals with pre-existing conditions. And at the end of March, all of us were successful in that fight when Speaker Paul Ryan (R-Wisc.), pulled the American Health Care Act from the floor of the U.S. House of Representatives.

United Spinal opposed the bill because of the removal of the mandatory essential health benefits package in Medicaid. That includes crucial services to people with disabilities such as rehabilitation and habilitation benefits and chronic disease

management benefits, prescription drug benefits and maternity and newborn care services. United Spinal also opposed the bill's elimination of funding for the Community First Choice option. That option allows individuals with disabilities to receive needed supports and services in their communities and provides funds to Medicaid to cover those services.

Both sides of the aisle are still looking at ways to improve health care for everyone, and United Spinal will always be on the front lines with all of you. This year was no different. United Spinal saw a threat to our health care benefits and

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community supports and services with the efforts to repeal the Affordable Care Act. We worked together to push back those efforts with lots of calls, emails and Hill meetings — and that resulted in a win for us.

## The Coming Battle

This year's Roll on Capitol Hill will continue the fight for policies that improve the quality of life for our members and people nationwide. We must protect our right to assistive technology, including complex rehabilitation technology — also known as individually-configured wheelchairs and accessories — medical equipment, medical supplies, prescription drugs and other health benefits and services. Our non-medical issues are: safeguarding the provision of home and community-based services and supports so that individuals can live and participate in their communities; ensuring robust funding for the benefits and services our community depends on; and making sure that people with disabilities are not barred from entering public accommodations at the federal and state levels. If you know about these issues, great! If not, don't worry. We will cover them thoroughly in our Monday sessions so you feel well-prepared for Tuesday's meetings. Here are a few of the specific policies we will focus on:

- Protecting health care benefits and services for the SCI/D community, such as pushing back against all efforts to remove our community's consumer protections for health care coverage.
- Advocating for improved access to complex rehab technology: Ensuring Access to Quality Complex Rehabilitation

Technology Act of 2017 — H.R. 750; and H.R. 1361/S. 486 — Protecting Beneficiary Access to Complex Rehab Technology Act of 2017.

- Ensuring robust funding for agencies from the U.S. Department of Health and Human Services to the Department of Labor, etc., so that our community's benefits and services are maintained.

- Strengthening community supports and services: the Disability Integration Act states that our community has the right to receive supports and services in our communities that mirror what we receive in institutional facilities matching our choice of where we would like to live. We advocated for this bill last year and the bill should be re-introduced soon for 2017.

For those of you who want to know more about all the bills we will be addressing at Roll on Capitol Hill, visit United Spinal's Roll on Capitol Hill page at [www.unitedspinal.org/events/roll-on-capitol-hill](http://www.unitedspinal.org/events/roll-on-capitol-hill) or take action now: [www.unitedspinal.org/action-center](http://www.unitedspinal.org/action-center).

Come join us this summer on Capitol Hill to network with friends and colleagues and, of course, to make sure policymakers hear about what matters to you. We had great representation at the Roll last year with close to 35 states, including Hawaii, plus Puerto Rico and the District of Columbia. We would love to have even greater representation this year. Don't miss this valuable opportunity to join us at the Roll on Capitol Hill. Together, we can make a difference. I look forward to seeing you all again in D.C. Let's roll!

MI

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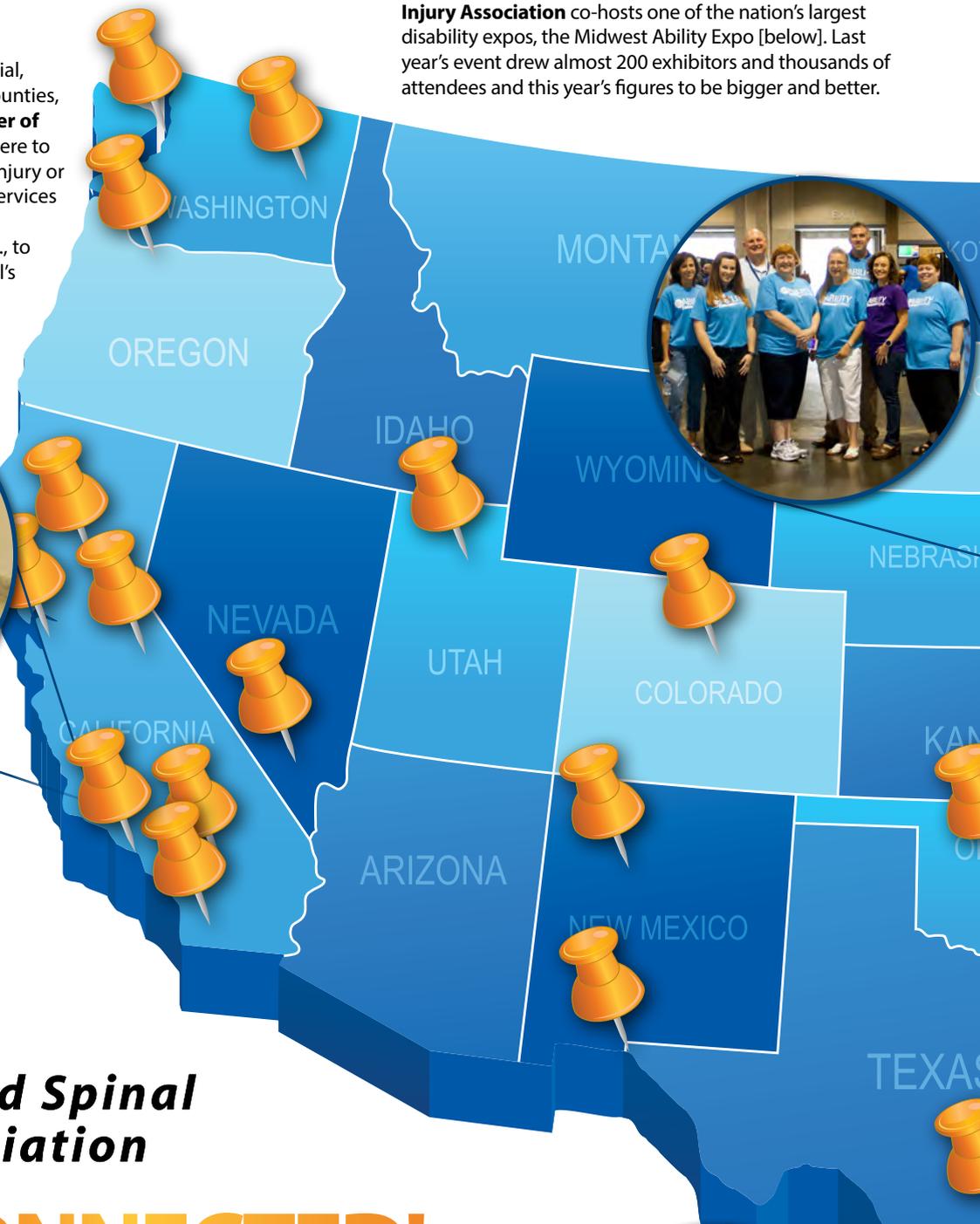
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Serving scenic San Diego, Imperial, Riverside and San Bernardino counties, the **Southern California Chapter of United Spinal Association** is there to help anyone with a spinal cord injury or disease find the resources and services they need. Like many chapters, members fly to Washington, D.C., to advocate for SCI at United Spinal's Roll on Capitol Hill [below].



In addition to offering multiple peer support options and regular events, the **Greater Kansas City Spinal Cord Injury Association** co-hosts one of the nation's largest disability expos, the Midwest Ability Expo [below]. Last year's event drew almost 200 exhibitors and thousands of attendees and this year's figures to be bigger and better.



## GET CONNECTED!

United Spinal has more than 50 local chapters nationwide, connecting people with SCI/D to their peers and fostering an expansive grassroots network that enriches lives.

To find a chapter near you, or to find out how you can start one where you live, go to

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# Fascia

## the Skin Under Your Skin

BY LILLY LONGSHORE

For years after my spinal cord injury, I lived with a constant, painful pinch on the inside of my left upper thigh where my leg joins my pelvis. All the muscle relaxers and pain meds wouldn't make it go away. I tried repeatedly stretching in hot tubs and utilizing personal trainers and yoga instructors, years of deep tissue massage — nothing I did worked.

Then one day I was referred to Ike Anunciado, the owner of 360 Physical Therapy in Vancouver, Washington, for a frozen shoulder. He introduced me to the world of fascia release and a technique called strain counterstrain. From that day on, I have used fascia release and strain counterstrain therapies to reduce my pain all over my body and to maximize what movement I have.

What is fascia? We are all familiar with that sinewy, clear membrane on raw chicken that seems to stretch forever. We have hundreds of yards of that stuff, known as fascia, wrapping each of our 650-plus muscles and every muscle fiber, blood vessel, lymph duct, organ and nerve — from our heads to our toes. Once thought to be solely support tissue, research now shows that fascia is much more complex.

"Fascia surrounds everything," says Anunciado, who holds a master's in physical therapy. "It is a neural highway with many branches and connections — it flows." Research has revealed that fascia not only supports our many organs and body structures, but it also contains the

same contractile fiber as smooth muscle, as well as pain receptors and neurotransmitters. In response to trauma, fascia can contract and clamp down on muscles, vessels and organs, restricting blood flow, preventing proper function and inhibiting drainage. This causes pain.

Debbie Boe, licensed massage therapist and owner of Head2Heal Massage Therapy in Vancouver, Washington, discovered the value of fascia release through personal experience. "I was in a horrible accident," says Boe. "Fascia work had the most profound effect for my personal healing." She has since taken numerous courses beyond standard massage therapy requirements to hone her skills in fascia release.

"I tell people to picture themselves in a long-sleeve, long-leg, one-piece leotard," Boe says, describing the continuity of fascia and its constrictions. "I take the tummy of the leotard, grab it in my hands and I wad it up ... a couple of times. You can visualize that leotard no longer fits right going up in the shoulders, around the waist, down into the legs. I've changed the fit of it and I've increased tension. That leotard is one-dimensional, it is just on the surface of your body. Fascia is a more intricate 3-D web than you can wrap your head around."

For me as a client, I have noticed that as Boe works on my left ankle, for example, using a subtle, stretching motion, I might feel a distinct pinching way up in my ribs on the same side. Sometimes as she works on my right shoulder, I might

feel pulling in my left hip. My fascia feels like a continuous sheath that crisscrosses my whole body.

### No Magic Pill

There is no magic pill that releases fascia. It must be worked and released using physical means. An extreme example of fascia release is a "fasciectomy." Fascia's compressive strength is significant. With severe muscle swelling from significant trauma or something like a snake bite, fascia can constrict the swollen muscle to the point of causing necrosis or tissue death. A fasciectomy, or slicing through the fascial tissue, can be performed to relieve pressure and save the limb.

However, the medical professionals I see use very gentle, pain-free methods to release fascia and the associated tight muscles and kinked vessels.

Anunciado has mastered strain counterstrain for muscle and fascia release. He learned the counterstrain techniques by taking many courses provided by the Jones Institute of Carlsbad, California, and from years of hands-on practice in his clinic. "[Before owning my own practice,] I worked in a multi-disciplinary chronic pain center ... where we addressed pain from all different sides ... using direct technique," explains Anunciado. "[Using traditional] physical therapies, I noticed there was a gap — people still hurt." This observation caused Anunciado to further pursue strain counterstrain, which he was introduced to during his first year of physical therapy school in 1990.

“The basic concept of strain counterstrain,” he says, “is to find a dysfunctional tissue ... shorten the fascia through that offending system, then that tissue will relax and pain will come down.” The concept of shortening muscle fiber to its shortest position, then allowing it to relax essentially allows the muscle fiber to “reset” itself. The concept works for fascia, too, but through different receptors. Fascia resets via nociceptors (pain receptors), whereas muscle resets through stretch receptors. Recognizing the value of strain counterstrain for clients, Anunciado now teaches this technique in his own clinic, as well as in seminars worldwide.

Sue Martin of Progressive Therapy, in Dadeville, Missouri, initially studied massage therapy to help her husband with his headaches. Seventeen years and thousands of course hours later, she makes her living helping many people with pain. “I learned about neuromuscular therapy, then [later] learned the fascial system and how it wraps around tender trigger points,” Martin explains. “When I put those two together, it seemed very effective and worked for the

vast majority of people.”

It worked for me, for one. From my personal experience with Martin, I gained significant, long-lasting pain relief and better joint and muscle movement. Her technique of gently moving

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**“As years go by, they are finding how fascia is integral in the health of our bodies.”**

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fascia and following it as it relaxes is very effective. And that pinch in my left leg? It has disappeared.

The mysteries of fascia are still being unraveled. Every two to three years, a worldwide group of medical professionals get together to discuss and present the latest research findings on fascia at the International Fascia Research Congress, the next of which is scheduled for November 2018 in Berlin. “As years go by, they are finding how fascia is integral in the health of our bodies,” says Anunciado. Some professionals are even calling

fascia a new organ. Anunciado is excited about the ongoing research. “I’ve done a lot of different types of therapy ... [Fascia] counterstrain is really an amazing tool for reducing pain.”

Knowledge of fascia and fascia work has been around for decades, yet it is not nearly as ubiquitous in practices as traditional, exercise-based physical therapy. As it is an essential tool that is often overlooked even though its efficacy is proven [see sidebar], it is well worth requesting it from your doctor. Professionals in your area who have completed training on strain counterstrain at the Jones Institute can be found at [www.jiscs.com](http://www.jiscs.com). **MM**

## Resources

- Jones Institute and certified practitioner list, [www.jiscs.com](http://www.jiscs.com)
- Fascia Research, [www.TuckeyPT.com](http://www.TuckeyPT.com)
- Fascia World Congress, [www.fasciacongress.org](http://www.fasciacongress.org)
- Clinical Trials Evaluation, “Myofascial Release as a Treatment for Orthopaedic Conditions: A Systematic Review” (*Journal of Athletic Training*, July-August, 2013)

# Fascia Release Clinical Trials Reviewed

BY TIM GILMER

The authors of a review of 88 clinical trials on fascia release [“Myofascial Release as a Treatment for Orthopaedic Conditions: A Systematic Review, *Journal of Athletic Training*, July-August, 2013] concluded the following: “Anecdotal evidence shows great promise for MFR as a treatment for orthopedic conditions. However, evidence-based research to support the anecdotal evidence is lacking.”

It is important to understand that fascia release (synonymous with MFR) is not inherently an evidence-based medical technique because it involves one practitioner using his or her unique skills and knowledge on one person with a specific complaint, and there are different techniques. In other words, by its nature, it lacks objectivity. Brent Bauer, M.D., observes in his analysis for the Mayo Clinic on fascia release and back pain [[www.mayoclinic.org/diseases-conditions/back-pain/expert-answers/myofascial-release/faq-20058136](http://www.mayoclinic.org/diseases-conditions/back-pain/expert-answers/myofascial-release/faq-20058136)]: “Many studies have found that massage, chiropractic manipulation and similar manual therapies work as well as other treatments for back

pain. Few studies, however, have tested myofascial release therapy specifically, partly because the exact elements of myofascial release therapy vary from therapist to therapist.”

The *Journal of Athletic Training* review of studies concludes that “results of the studies were ... mixed, with some finding MFR to be effective for an orthopedic condition and others finding little to no effect. ... This wide array of results reveals the need for future research.”

The authors go on to suggest an appropriate design for future research: “Participants should be randomized, the design should be double blind, and the clinician performing the MFR should use it regularly in clinical practice. ... Because of the nature of the technique, the effectiveness of MFR can vary with the comfort level of the patient, so the patient and clinician should both feel at ease around one another. Only one medical condition should be studied at a time, and MFR should be used alone. Also, if possible, MFR should be compared with a control (no-treatment) group and with other proven treatments.”

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# OUTDOOR TRACKS

## Magical Day at the Beach



By Kary Wright



A single oyster.

As you've probably guessed by the name of this column, I love the outdoors. I love seeing new places, doing new things, getting lots of fresh air and sunshine and meeting new people. There are so many new experiences out there that we have no idea about, and how better to learn than to talk to people about their world? Luckily, we have Ginger, our golden retriever. She is the perfect ice-breaker.

My wife Terry and I have escaped the Canadian prairie winter to enjoy some outdoor time on the West Coast of British Columbia. It is so refreshing to take long walks along the shore with Ginger. We explore trails and observe seals and sea lions. Eagles soar overhead and watch us from trees. Inevitably we meet other dog owners and let the dogs run. One of Ginger's favorites is Rose, a chocolate lab that loves to play. The two run and jump and growl like they're real tough. It gives us time to get to know Dave, Rose's owner. We chat about hunting and fishing, and where the best seafood is found.

"Do you like oysters?" Dave asks me. "I do."

At one time I hated oysters, but I've acquired a taste for them gradually over several years of having one ... per year

... fried, at Christmas time. Maybe my tastes have changed, maybe my taste-buds are getting dull, or possibly with old age I'm less opinionated ... yeah, right. Now when we visit the coast, I have several feeds of oysters, and even pay for them in restaurants.

"You can pick them just down the beach from here," says Dave. "Drive down the highway, turn right at the hardware

store and park at the end, at low tide. You can get a license online." Sounds easy, doesn't it?

As soon as we're back at the cabin, I'm on the computer researching the rules of where, when, and how to pick them. Apparently you need a really low tide, and the area has to be open to shellfish harvesting. Anywhere near rivers is out of bounds due to contamination, as is near industrial outflows. Also there is the Red Tide to consider. This is a toxin that comes from an algae bloom. With all this to take in, I was busily cross-referencing several websites and Google Earth. Finally I had it organized and off we went with pail in hand to harvest a bounty of fresh seafood. Oh, how fun it will be. Think of the money we'll save by picking oysters ourselves!

We drive down to the aforementioned location and unload to the salty breeze of the Pacific. It really is incredible scenery, and we sit a moment to enjoy the waves lapping at the shore, gulls coasting overhead, and the mountains in the background. I wheel across the parking lot to access the beach.

It seems Mother Nature has neglected to follow accessibility code, and all wheelchair-friendly routes are blocked by immense logs. Even if I miraculously get



past, the beach is covered in boulders. Hmm ... Murphy scores one big point.

"How about the dog and I go get 'em," says Terry.

"OK," says I, licking my chops, thinking about the feast we'll have.

I lean back my chair to enjoy the scenery in style. I love the tilt/recline feature of this chair. Terry and Ginger disappear down the shore. The waves are gently splashing on the rocks, eagles soaring overhead looking for the next meal. A sea lion barks in the distance. There is something magical about being at the ocean ...

\* \* \*

"Nothing, not one oyster!" — My day-dreaming is interrupted.

"None?"

"None."

"Really?"

"Really."

I look at the shore. The tide is only halfway out. Apparently waiting until the tide is all the way out wasn't merely a suggestion. We revamp the program. Back at the computer we re-examine the plethora of websites that you must know inside and out in order to safely and legally harvest an oyster. Away we go with new enthusiasm and full coffee cups, back out to hit low tide.

We drive farther up the coast to another supposed hot spot noted on the map, and head down a secluded road that ends at the ocean. We unload from the van, surveying the area.

"Can we pick here?" asks Terry.

"Yep," I reply, recalling website number 15 that showed open areas.

"Are they safe, any red tide?"

"Safe," I say, trying to recall that page.

We wheel onto the beach, and sure enough there they are, live oysters!

"Which ones do we take?"

"Bigger than 2 inches guarantees that they're not a protected species." I'm getting good at regurgitating newfound knowledge. We take enough for a modest feed.

When sampling new-to-my-body food, I'm very careful not to be a glutton — I'm sure every wheelchair-user would agree. Later at the cabin we steam them in a frying pan with a little water, then bathe them in garlic butter once they are open.

"Here ya go, enjoy ..." says Terry, sar-



castic tone barely detectable.

"You gonna try them?" I reply.

"One," says she, grabbing the smallest one gingerly.

"OK, it's good," she begrudgingly admits.

"Want another?" I grin.

"I'll pass."

"I was there once," I say. "In 10 years or so you'll love them."

They were absolutely delicious! A rich but not overpowering seafood flavor, not unlike scallops. They are much better fresh like this than store-bought. It was fun to experience researching, finding, harvesting and cooking a local specialty.

## Questions Worth Asking

1. Were they good? Yes. Although oysters are an acquired taste for some, these were not overpowering, just very pleasant.
2. Were they easy to find? Well ... sort of. You need to know where to find them, and to search at the lowest tides. A tide chart is a must.
3. Did you save any money? (Place laugh track here). Oysters cost about \$6 per pint at the store. I figure that if we add up the license cost, fuel cost, allow \$15 per hour labor cost for research and beachcombing, and divide it amongst the six oysters harvested, we paid about \$43 per ounce.

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By Mike Ervin

I imagine the circus boss might have been tempted to replace the striking crippled freaks with robots, had such things existed back then.

## Demise of the Once-Mighty Crippled Circus Freaks

**T**hey were once a thriving species, roaming the earth in abundance. But today they are all but extinct.

I'm referring, of course, to crippled circus freaks. What catastrophic event led to their demise? Was it a plague? A famine? A sudden, unexpected glaciation? No one knows for sure. And whereas I am not an anthropologist, I do have my theories on what did in the crippled circus freaks.

Theory No.1: They tried to unionize. These things usually begin with outside agitators. Perhaps a disgruntled cripple was rejected by the freak show because he wasn't freakish enough. Maybe he only walked with a limp or something. So he sought to exact revenge on the circus boss by pumping up his prized freaks with a bunch of commie talk. And soon they formed the United Brotherhood of Crippled Circus Freaks.

Now normally a bunch of cripples threatening to go on strike would only make the bosses laugh. If you're a cripple assembling Barbie dolls in a sheltered workshop for 50 cents an hour, there are plenty of scab cripples ready and willing to replace you on the job. But if you're an albino with three noses who can juggle, you've got a lot more leverage.

So no doubt the boss responded to any disruption of business as usual such as this with brute force. They probably hired private security goons like the Pinkertons to mow down the

striking crippled freaks. I'm sure it was a real bloodbath.

I imagine the circus boss might have been tempted to replace the striking crippled freaks with robots, had such things existed back then. But that wouldn't have worked at the box office. An albino robot with three noses doesn't pack the same emotional punch as the flesh-and-bones version because there's no such thing as a planned freak. It's an oxymoron.

Theory No. 2: They were the victims of do-gooder protests. Maybe there was a party-pooper group called People for the Ethical Treatment of Differently-abled Circus Entertainers (PETDACE). And maybe they regularly picketed the circus, denouncing the degrading mistreatment of these noble beasts and demanding that the crippled freaks be released into the wild. This is the same strategy that was successfully employed in the 21st Century to free all the circus elephants. One could argue that the difference between cripples and elephants is the matter of consent. Crippled circus freaks join the circus of their own free will, which is true, I suppose, if you want to be super picky technical about it. But by that same logic, one could also hand a starving person a menu on which the only entrees are a moose turd sandwich or moose turd pie and then argue that the starving person is eating moose turd pie of their own free will.

Theory No. 3: The gimmick ran out of gas. With advances in technology, humans became more interconnected

and the novelty of crippled freaks wore off. No longer did people have to leave their homes or spend money to partake of a grotesque display of freaks that scare the hell out of you and make you feel exceedingly grateful that you're not one of them. Spectacles far more disturbing than a band of crippled circus freaks could be witnessed for free on television. If you don't believe me, watch the next Republican National Convention.

Well, whatever it was that wiped out the crippled circus freaks, it's probably a damn good thing that it happened. Otherwise by now there would be a cutthroat underground network of unscrupulous crippled circus freak traffickers. These despicable creatures would troll the darkest, most remote asylums, like talent scouts in search of the most uniquely deformed infants. The traffickers would take the orphans off the asylum keeper's hands in exchange for a small finder's fee, whereupon the infant would then be turned over to be raised by a foster family of clowns. Like the tigers of Siegfried and Roy, these crippled infants would be raised from the womb to be entertainers. They'd be riding unicycles by the age of 18 months. And soon they would be sold to the circus.

And if they were ever exposed and confronted by PETDACE, these traffickers would assert that their mission is humane. They would say being a crippled circus freak beats the hell out of assembling Barbie Dolls in a sheltered workshop.

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*Acknowledgements on our website, in New MOBILITY, in United Spinal e-news or any other United Spinal publication should not be considered as endorsements of any product or service.*

### CHAIRSKATER AARON FOTHERINGHAM'S BAD DAY AT WORK

"Houston, we have a problem," quipped famed WCMX athlete Aaron "Wheelz" Fotheringham about this photo he posted to his Facebook page on April 7.

"That's horribly hilarious! That had to hurt. Of all the times to lose a wheel," commented Samantha Carpenter.

"On the positive side, it provided an epic photo," replied Fotheringham.

"Well, I guess you're just *wheel* now," observed Rick Weed.



Photo by Darren Urquhart



### YEARS LATER, SHARE-A-SMILE BECKY'S INABILITY TO ACCESS THE DREAM HOUSE STILL STINGS

On April 10, *NEW MOBILITY*'s Bob Vogel shared this blurb on our Facebook page:

Mattel discontinued Barbie's friend Becky, a wheelchair user, because "Barbie's Dream House" is inaccessible. Rather than make some changes to the Dream House based on universal design, they got rid of Becky. A blogger in the article says Becky's story speaks volumes: "A lot of the ways we think about disabilities, we talk about 'fixing disability,' instead of focusing on 'fixing society.'"

"Dear God," commented Pauline Vetuna on our FB page. "The story of Becky mirrors real life cultural ableism exactly."

"A reflection of life for wheelchair users. "We'd love to help, but it's too expensive," wrote Phil Bates.

"Art imitates life," said Cheryl Butler. "Get rid of the doll rather than fix the house."

"Becky #resist," commented Theda Zawaiza.

To say this story hit a nerve is a gross understatement. From our page, that blurb and accompanying link reached almost 120,000 people and was shared almost 1,000 times.

Read PRI's article here: [www.pri.org/stories/2017-04-09/becky-barbies-wheelchair-bound-friend-was-discontinued-heres-why](http://www.pri.org/stories/2017-04-09/becky-barbies-wheelchair-bound-friend-was-discontinued-heres-why)

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