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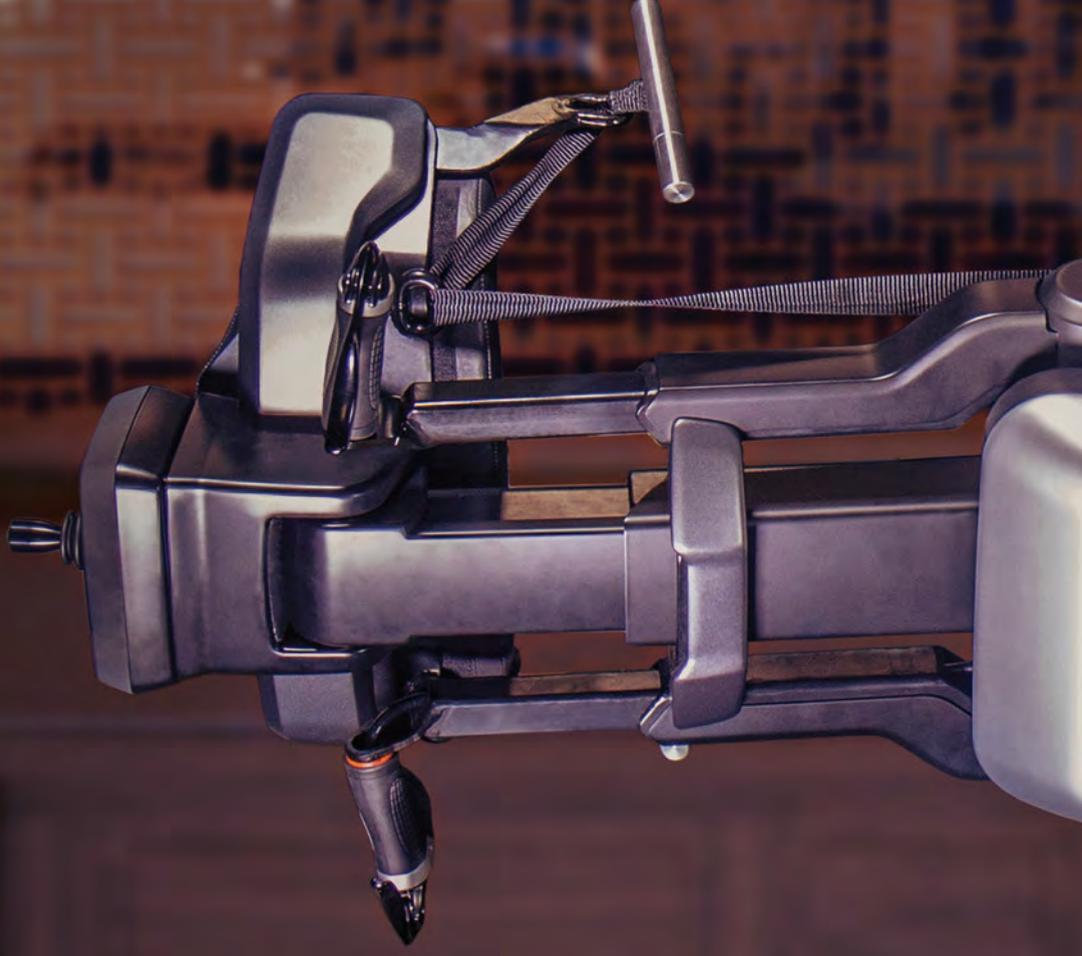
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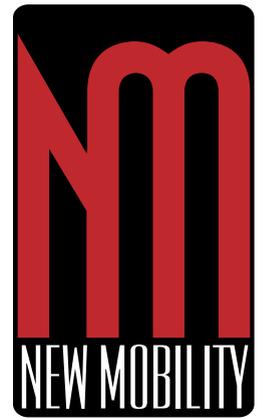
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FEATURES

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19 CHINA SCI TRIALS EXCEED EXPECTATIONS Wise Young has been seeking ways to overcome paralysis for decades. IAN RUDER interviews him about his latest results.

37 LEARNING TO SAY YES Transitioning from life-altering injury is difficult, but finding a pathway to growth can lead to success. BY STEVE DALTON



CANNABIS STEW: STIRRING THE POT 24

Twenty-five states now have some kind of medical marijuana program, four have legalized recreational marijuana, and tax revenue from pot products is certain to lure more states into recreational expansion. The old hippie vision of “if it feels good, do it” has taken America by the purse strings. But will medical use grow or wither from the competition? MARK BRAUNSTEIN AND IAN RUDER report.

Cover Photo by Matt Wong
Contents Photo by Monique Chevalier



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(BULLY PULPIT)



Your Right To Drive Is Under Attack

In May I reported on adaptive van dealerships no longer making rental vans available with hand controls. I called out the nation's largest wheelchair accessible van dealer, MobilityWorks (61 stores), as a major offender. When our right to drive is restricted by a company's policies, it is not only offensive, it may be illegal. However, according to MobilityWorks' director of store operations, Trevorr Jurgensen, his company is sympathetic to our needs — it is their insurance carrier that is calling the shots.

Jurgensen says that PSA Insurance and Financial Services, the leading insurer for adaptive van dealers across the nation, requires the prospective driver (renter) to provide an "updated prescription or certification from a certified driver rehab specialist" identifying the type of adaptive controls to be installed and proof that the driver is qualified to use this specific type. Jurgensen says that none of the MobilityWorks stores has wheelchair accessible rental vans available with hand controls installed. They do not even stock hand controls. If a driver presents the required documentation, the hand controls must be ordered, purchased, shipped and installed prior to renting. The process would take a minimum of one to two weeks.

As onerous as this policy is, a more restrictive requirement is engaging the services of a certified driver rehab specialist (CDR) in the first place. Six states do not even have CDRs within their borders. Fifteen states have three or fewer CDRs. Entire geographical regions are very poorly served. A few states are exceptions. California, for instance, lists 15 CDRs, but almost all of them are confined to Southern California or the Bay area.

Even if you succeed in engaging the services of a CDR, you must then pay out of your own pocket to become certified. Expect to pay at least \$500 to \$1,000 for a "current" cer-

tification. All of this in order to rent and drive a wheelchair accessible van with hand controls. Your driver's license or years of experience driving with hand controls are no longer sufficient to prove you are qualified.

How did we regress to this sorry state? Rampant consolidation and buy-outs. Local family-run businesses are being taken over by major national corporations whose policies are more about liability and less about service.

NEW MOBILITY readers Felix and Vicky Gutierrez used to rent vans with hand controls from a small company in northern California. When MobilityWorks bought them out, the Gutier-

Local family-run businesses are being taken over by major national corporations whose policies are more about liability and less about service.

rez family had to rent a car with hand controls from Hertz (no ramp or lift). In this month's letters they write: "One has to wonder why a commercial car rental company can provide hand controls, while a company that specializes in wheelchair accessible vehicles is so short-sighted and insures with a company that does not allow renters the independence they should be entitled to."

At the same dealer, Chuck McAvoy was not allowed to test drive a van he was considering buying since he had no CDR certification. Is driving with hand controls under attack? Is our right to drive our personal vehicles next? What can we do to protect that right? Post a comment or send an email to tgilmer@newmobility.com.

— TIM GILMER

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JULY 2016

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Mark Mathew Braunstein was welcomed into the ranks of SCI by way of a diving accident in 1990. Lucky him, his injury and recovery were made into a short TV documentary (youtu.be/96EhHzN6Rol). As a T12 paraplegic, he uses cannabis medicinally for below the waist (leg spasms) and recreationally above. He is the author of three books, including *Radical Vegetarianism*, and says he considers cannabis a radical vegetable. He frequently contributes to many holistic health magazines and to *NEW MOBILITY*. You can be outraged by his counterculture writings at www.MarkBraunstein.org.

A motorcycle accident in 2003 left Matthew Castelluccio with a T6 spinal cord injury. He credits the United Spinal Association with providing the resources and mentoring to help him become comfortable as a paraplegic, and Helen Hayes Hospital with exposing him to adapted sports. Following his rehab there, he joined the hospital as its adapted sports program coordinator/patient mentor in November 2007. He has not only facilitated the hospital's membership as a Paralympic Sports Club and a Disabled Sports USA chapter, but has spearheaded the establishment of the Hudson Valley Chapter of United Spinal, of which he is president.



Embracing living with a T4 spinal cord injury in 2002 with seeming ease, Steve Dalton wondered why this usually difficult transition went so well. Years later he learned about the science of post-traumatic growth and focused his senior thesis on the intersection between PTG and the humanities in completing his bachelor of arts. Since his injury he has been able to share his growth experience and scholarly interests in peer support groups, as well as lecturing in PT, OT and humanities classes. He lives in San Pablo, California with his wife, Sydney, and their new kitten, Camhi.

Steve Wright is an award-winning travel writer who has been a mainstay freelancer for *NEW MOBILITY* for two decades. His interests include universal design as well as travel. Whether on the road solo or with his wife Heidi Johnson-Wright — an ADA expert (and also a NM freelancer) who has used a wheelchair for 40 years — he searches out the perfect blend of local culture and barrier-free access. Steve and Heidi live in Miami. Read Steve's blog at urbantravelandaccessibility.blogspot.com



When Uber and Lyft started here, the taxi company decided to stop offering the [wheelchair accessible vehicle] service.



Ride Sharing Comes, Taxis Leave

In Corpus Christi the local taxi company had WAVs, but when Uber and Lyft started here, the taxi company decided to stop offering the service [“Uber: Does the Transportation Revolution Include Us?” May 2016]. They claimed that the competition from the ride sharing forced them to cut costs. After the city passed a law requiring a fingerprint check, the ride sharing companies left town. The city’s bus service for wheelchair users is unreliable. So now there is no transportation for wheelchair users. I am restricted to going only as far as I can in my power wheelchair, about one mile.

*John Ralph
via newmobility.com*

Cool OpenTaxi App

In Chicago, they have the OpenTaxi app, which allows you to arrange for a wheelchair accessible taxi through your iPhone and see the cab on a map as it approaches your location. Pretty cool.

*John Hauschildt
via newmobility.com*

Hand-Control Rentals Denied

Two years ago we attempted to rent an accessible van with hand controls from MobilityWorks, which had bought out Nor-Cal Mobility, where we had previously rented accessible vans on more than one occasion [“Where Have All the Rental Vans Gone?” Bully Pulpit, May 2016]. We were told that they did not have any rental vans with hand controls available. When we inquired further, they insisted that due to insurance regulations they can no longer rent vans with hand controls. We asked about this at the Abilities Expo later that year, and were fed the same line.

Being determined to rent an accessible

vehicle that we could both drive for our trip to southern California that year, we contacted a number of commercial car rental companies. Hertz was able to rent us a car with hand controls which they installed for us at no extra charge. This vehicle was not equipped with a wheelchair ramp, so we were limited to the push chair, which had to be loaded and unloaded from the trunk, but we were grateful for what we were able to get.

One has to wonder why a commercial car rental company can provide hand controls, while a company that specializes in wheelchair accessible vehicles is so short-sighted and insures with a company that does not allow renters the independence they should be entitled to.

*Felix and Vicky Gutierrez
Richmond, California*

Women and Quad Rugby

I played recreational quad rugby for three years and worked out with a team for almost a year [“Hitting Like Women,” May 2016], classified and participated in one tournament. Some male attitudes seem to be that if you aren’t getting injured, you aren’t giving 110 percent. Most women are not encouraged to participate, let alone play on a team. I still love the sport. But I’m too old and my arms can’t take the punishment now.

*Lois West
via newmobility.com*

Nowhere to Turn

I have a four-year-old chair that constantly needed tweaking. I was fortunate enough to have a friend who would help me when small repairs were needed [“Frustrated About Trying to Get Your Wheelchair Fixed? You Are Not Alone,” May 19 NM blog]. Finally, work needed to be done

that was beyond his ability, so I spent many hours trying to find a repair shop. Most wanted to sell me a new chair, not repair my present one. I was also told that the charges were my responsibility, as insurance or Medicare did not cover repairs. At last I found a shop that would “try” to help me out. They charged me \$313 to work on it but could not guarantee the work. Eight months later I am experiencing many of the same problems and don’t know where to turn. I have recently purchased a new chair as a backup, also at my expense. Sad state of affairs for immobile individuals, it seems.

*Trudy Decker Pratt
via newmobility.com*

My Chair Is My Legs

When my wheelchair broke down [I was told] it would be two weeks before it was repaired and they did not have a loaner, so I would have to use a manual chair. I said that was unacceptable because I needed to get to my son before he put a finger in the outlet or before he got the matches. People really do not understand! I so badly want to take everyone’s car away!

*Melissa Monser
via newmobility.com*

Had to Eat My Cost

My company had a United Healthcare contract for nine years. We had to cancel it because we disliked calling patients [customers] all the time to say, “I’m sorry, your insurance will not even cover the cost of the parts.” My cost, mind you. We’re not even talking about retail or even a reasonable margin. They wanted to pay me less than I had to pay to buy the parts for my customers!

*David Nix
Alabama Wheelchair Specialists*

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Outrage Against 'Me Before You'

Outrage against the movie *Me Before You* by people with disabilities began escalating prior to the movie's opening in theaters on June 3.

The movie, based on JoJo Moyes' book of the same name, bills itself as a positive, life-affirming romance — its Twitter hashtag is #LiveBoldly. But it ends with its young quadriplegic protagonist, Will Traynor, being euthanized in a Switzerland clinic, leaving his fortune to his caregiver/girlfriend so she could have financial freedom.

Pushback against the movie's message of "better dead than disabled" began on May 23, when disabled tweeters crashed #AskSam, hosted by Sam Claflin, the actor

playing Traynor. "#AskSam why don't you #LiveBoldly ever after with Louisa? That's what we would do," said one tweet by Second Thoughts' John Kelly, a quadriplegic from Boston, Massachusetts.

"The movie's tagline is: 'Live Boldly. Live Well. Just Live.' Yet, Will does quite the opposite," wrote Emily Ladau, who has Larsen syndrome, in Salon on May 24. "The entire premise rests on the belief that life with a disability is not worth living. In spite of each of the characters in Will's life trying to persuade him otherwise, the fact remains that Moyes imagines a world in which disability is synonymous with misery and assisted suicide is the only solution."

Then on May 25, members of Not Dead Yet-UK protested the film's posh London

premiere, which was attended by Moyes and cast members, including Game of Thrones' Emilia Clarke, who played Louisa. "This film is offensive to disabled people, the vast majority of whom want to live — not die," said Liz Carr, who led the protest. An actor with muscular dystrophy, Carr is well known in the United Kingdom for her role in the BBC's *Silent Witness*.

On June 8, Joni Eareckson Tada, founder of the longstanding Christian ministry, *Joni and Friends*, said in a press release: "In the movie, the quadriplegic says to his loved one, 'I don't want you to miss all the things someone else can give you.' Instead, he took away everything she wanted from him — his love and the essence of who he was — when he decided to end his life. Not

People in the News: Foster Andersen Helps Wheelers Hit the Waves

The waves will not be the only thing rolling onto the shore of Cowell's Beach on Saturday, July 16. Wheelchair users of all ages will gather upon the Santa Cruz, California, coastline for the 24th Annual Day on the Beach. The yearly event, the brainchild of Foster Andersen, brings together people with disabilities to take part in accessible beach activities such as kayaking, outrigger canoeing and scuba diving.

A Day on the Beach is one of the nonprofit Shared Adventures hallmark events and marks a bittersweet anniversary for Andersen. "I was injured on July 17 and I always wanted a positive celebration to commemorate the anniversary." Anderson, quadriplegic since his 1978 motorcycle accident, went on to say, "While in many ways I suffered a loss, I was able to survive and live again even if it was in a different way. A Day on the Beach has been a perfect way to celebrate what I and so many of us can still do after injury."

Andersen and his staff, along with

hundreds of volunteers, will transform the beach into a rolling seaside oasis filled with over 200 plywood planks so wheelchair users can move freely over sand. Beach wheelchairs will also be available. In addition to the many water activities, the event also features live music, rock climbing, massages and sand castle building.

Shared Adventures works tirelessly throughout the year to provide other recreational activities such as art and gardening classes, adaptive yoga classes, and a four day summer camp for children with disabilities. They also organize outings on local yachts, trips to the aquarium and picnic potlucks.

Andersen says Shared Adventures has given him a renewed sense of purpose. "Being disabled doesn't mean a death sentence," he says. "There is still so much we can do, and it's my passion to help those who want to be adventurous, who want to experience all that life has to offer."

For more information on Foster Andersen and Shared Adventures, visit: www.sharedadventures.org.



only does this movie glamorize assisted suicide; it conveys the distinct impression that marriage to someone with quadriplegia is too hard, too demanding and sorely lacks the joys of typical marriage." Tada, a quadriplegic who has been married for nearly 34 years, went on to say that she and her husband have a "deep and satisfying relationship" characterized by patience, self-sacrifice, endurance, respect and joy, all of which are related to her disability.

While the initial pushback no doubt galvanized the disability community, it apparently did not discourage moviegoers. According to a June 5 LA Times article, the film exceeded expectations for its weekend debut, grossing \$18.3 million. The article went on to say that "audiences gave it an A CinemaScore. Critics, however, were more split with only 55 percent of them on Rotten Tomatoes rating it favorably."

Pathway SCI Stem Cell Trials Shut Down Abruptly

Stem Cells, Inc. has shut down its promising Pathway SCI stem cell trials, saying

improvements from participants are "not big enough" for investors.

On May 31, in a press release that shocked the SCI and research communities, Stem Cells, Inc. announced it was shutting down its Pathway SCI research trials using adult neural stem cells. These were the same trials that participants reported seeing promising results from, such as increased hand function and better bladder control. ["Stem Cell Trials Show Improved Hand Function, Sensation and Bladder Awareness," June 2016].

Less than one month earlier, Stephen Huhn, the company's lead researcher and chief medical officer, had told <H>New Mobility<H> that he was optimistic about the trials, saying, "We will be enrolling more subjects in the ongoing trials at least through September." But the company's board of directors, after revisiting outcome data and "given the financial resources available to the company," decided to close down the trials.

Kim Anderson-Erisman, Ph.D, associate professor, department of neurological surgery, Miami Project to Cure Paralysis,

was surprised by the announcement. "It was a shock to us [and] ... we're one of the top sites in the study. The sad part is they did an interim analysis on a subset of the subjects enrolled in the randomized cohort and they saw improvement in the treatment group compared to the control group, but not a 'big enough' improvement for their investors to continue their funding. It's disappointing because even small improvements can have a significant impact on the lives of people living with SCI."

The trial results, according to Huhn, were still encouraging. "There are neurological and retinal disorders with unmet need that may be helped by cell transplant. Unfortunately," he added, "the company does not have the resources to implement changes in our development program to permit further investigation." The press release also stated that the board of directors had approved a plan to "wind down the company" and that "it is possible that there will be no liquidating distribution to stockholders."

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By Michael Collins

Perfume in my Workplace

Q. *I work for a company that made an accommodation for me and my wheelchair, which allows me to work on the first floor of our two-story building. Others in my department work upstairs, but our office building lacks an elevator. I now have a larger problem. Another employee on this floor wears a perfume or cologne that makes it difficult for me to breathe, gives me migraines, causes my heart to beat faster, makes me nauseous, my legs weak and causes them to spasm. It is impossible to focus on my work when that happens.*

When I confronted her about it, she laughed at me and said it was “a personal problem.” I brought up the issue with my manager, who had a talk with her, but it didn’t do much good. She wore the scent again the next day, knowing the impact it was having on me. In fact, I think she began wearing an even larger amount of the perfume after that.

This situation makes me nervous — I have heard that Ohio has a “no-fault” employment law that would allow an employee to be dismissed without being given an explanation. If that is true, I am afraid the company might just let me go instead of dealing with the problem I brought to their attention. Do I have any protection from such an action? I would appreciate some advice.

— *Nervous, and Sick, at Work*

First you should identify the cause of your physical problems and the extent of the potential harm. The next time symptoms occur, visit your physician or an allergist to document the cause and provide that information to your company. Your employer can then focus on whatever might make you ill or unable to work. While you may believe your co-worker is the root of your prob-

lems, environmental illnesses or chemical sensitivity can also be related to commonly used scented additives. Tests for allergic reactions can help you avoid such products. Sometimes the physical reaction to them can be debilitating or even life-threatening.

Environmental illnesses or allergic reactions can also be caused by products used in construction, or in furnishings, like carpets. For instance, formaldehyde, which for many years was used as a component of insulation. Those products are hidden from view but can have the same impact as other, more visible, causal factors.

In order to make the workplace safe for all, many companies and government agencies have, as a reasonable accommodation, established scent-free workplace policies. If that doesn’t improve your situation, your employer could relocate you (or any co-worker who refuses or is unable to comply with the policy) to an area that won’t put your health at risk. Options may include a private office, telecommuting or placing air purifiers or fans in your existing work space. Other potential solutions can be found online at the Job Accommodation Network.

Since the conversation with your manager did not resolve the situation, request a meeting with your human resources officer. That person will have responsibility for determining what accommodation may be necessary, and will also be responsible in case the company’s attempt at resolution is unsatisfactory and results in a formal complaint. Depending on whether you are working for a private or government employer, the Americans with Disabilities Act (Title I or Title II) may be applicable to your situation. The Equal Employment

Opportunity Commission or a similar state agency enforces the ADA and also any state civil rights laws relative to employment. Procedures for making complaints can be found online, and you can receive advice or representation regarding a complaint from your state’s Disability Rights organization.

The ADA Amendments Act of 2008 covers employment and situations like you are experiencing. Changes in the law that took effect Jan. 1, 2009, clarified what comprises a disability and expanded coverage of the law to include more conditions. Since you have a pre-existing mobility disability that causes you to need a wheelchair, your company provided the necessary accommodations to allow you to work there. Problems you face related to environmental causes (your co-worker’s fragrance) would require other courses of action on the part of an employer.

By establishing that your physical health makes you unable to work under certain circumstances and the reasons for that, then documenting that with your employer, you will receive the protections that the ADA and state civil rights laws grant. Retribution would be illegal and, unless you goof up otherwise at work, you would be protected from being penalized or fired due to your disability. That should get you started, and good luck.

Resources

- Department of Justice ADA homepage, www.ada.gov
- Equal Employment Opportunity Commission, www.EEOC.gov
- Job Accommodation Network, askjan.org/soar
- National Disability Rights Network, www.ndrn.org

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By Tiffany Carlson



“It all starts with not letting your injury limit your true self.”

Heidi McKenzie Wants to Alter Ur Ego

For Heidi McKenzie, fashion took a back seat after she suffered a spinal cord injury in 2007. After becoming a T4 paraplegic in a car accident, McKenzie resorted to the usual mode of “nothing will work in a wheelchair.” As a 21-year-old student studying fashion merchandising at Ohio State University, she didn’t see how she could still pursue a career in fashion.

“After my accident I attended Morehead State, and they didn’t have a fashion program, but even if they did, I don’t know that I would have studied fashion. I didn’t quite know how I would fit in the fashion industry as a girl in a wheelchair,” says McKenzie, now living in Saltlick, Kentucky. She instead graduated with a bachelor’s in small business management.

In 2012, she became Miss Wheelchair Kentucky, a title that gave her the courage she needed. “When I went on to compete in Ms. Wheelchair America as part

of my title, I was able to spend time with women wheelchair users from other states and realized we all struggled to find fashionable, functional clothing.” This knowledge gave Mackenzie the push to start her adaptive clothing line — Alter Ur Ego.

After a successful Kickstarter campaign, she was able to fund her fashion label, and in the fall of 2015 her company began production. Her jeans are created for wheelchair users on multiple levels — they have thigh pockets, a catheter hole, a tummy panel, a higher back, an elastic waistband and they’re made of a soft denim. Both men and women’s styles are available.

McKenzie, 30, firmly believes that fashion can change your entire mindset after an injury. “How you feel on the inside shows on the outside,” she says. “It all starts with not letting your injury limit your true self.”

See her creations at: alterurego.com

Pontooning Just Got Cooler

If you’re a big fan of the water and have always dreamed of an accessible watercraft, Klein Ponton Boat, a custom boat builder in Denmark, is an accessible manufacturer to watch. They’ve created a line of accessible pontoon-like boats called “disabled friendly leisure boats,” and they are something to behold.

They come with an adjustable ramp outfitted to your wheelchair dimensions, and each boat is designed and constructed for each purchaser from scratch. One of the cooler features of their boats is that they can be steered using a joystick control system, which is perfect for quadriplegics.

The boat deck, too, is accessible, featuring a skid-proof floor made of PVC that looks like teakwood. For the anglers with injuries out there, Klein has certainly set the standard high for accessible boats. Hopefully manufacturers in the United States will follow suit very soon.

Go to: klein-ponton-boat.dk/en/disabled-friendly-leisure-boats

Watch Out Bobby Flay

If you’re a fan of cooking shows, check out “Kickin’ It in the Kitchen,” a how-to cooking show hosted by David Robertson, a C6 quadriplegic from Arizona. He shows his techniques for everything from opening bags to flipping sandwiches, and he’s learning as he films his videos, which is great for newbies.

Watch: youtube.com/user/waylandhi





By Joanne Smith
and Kylie James, authors of
*Eat Well Live Well with SCI and
Other Neurological Conditions*,
eatwelllivewellwithsci.com

Eat Your Mosquito Repellant

Summer is great, just not the mosquitos that come with it. And if you have limited movement and dexterity, swatting those annoying blood suckers away can be a long lasting pain ... or itch.

Mosquitoes find their warm-blooded victims by smell. Their sensory organs lead them to chemicals such as carbon dioxide and lactic acid that we exhale. While the most popular and effective bug repellant is DEET (which masks the chemical signals that mosquitos use to find their food sources), it is toxic to fish and birds, and can cause skin irritation in humans. In Canada, where I live and mosquitos roam large in the summer, our government recommends limiting DEET concentrations to no more than 30 percent. So if you're looking for a more environmentally friendly and safer way to protect yourself from mosquitos, eat garlic — and lots of it! This herb contains powerful compounds, such as allicin — which is released in our breath — and sulfur that is emitted through our skin. Together these two natural elements can help repel these irritating mosquitos.

Several days before you take a trip into mosquito-filled territory, start eating one or two cloves of garlic a day. Also, this simple, easy to prepare garlic recipe I've included can be used as a chicken marinade or salad and quinoa dressing. Not only will this savory sauce keep mosquitos at bay, but you'll also get the added benefits of garlic's potent medicinal properties, such as supporting cardiovascular and immune function, reducing blood pressure, lowering cholesterol and enhancing liver detoxification.

If you are not a fan of the taste of garlic, but still looking for a healthier option to DEET, try making your own repellant spray. Yes, you may end up smelling like a pizza parlor, but better than being a buffet for mosquitos!

Mosquito Marinade/Dressing

½ cup extra virgin olive oil
2 tsp Dijon mustard
¼ cup fresh lemon juice
¼ cup apple cider vinegar
Pinch sea salt
2-4 cloves garlic
Combine everything in blender for 10 seconds.

Mosquito Spray

4-6 cloves garlic
¼ cup cooking oil (olive or vegetable)
2 cups water
1 tsp fresh lemon juice

Coarsely mince cloves of garlic and cover them in bowl with oil. Allow to sit and soak for 24 hours.

After they have finished soaking, remove the minced garlic chunks and mix the oil with 2 cups water and fresh lemon juice. Strain everything through a cheesecloth and add to a spray bottle. Spray away!



Accessing AMERICANA

3 uniquely American travel adventures

BY STEVE WRIGHT

Americana still exists all over our great nation. It comes in different forms, defined by deep-rooted local traditions embodied in sights, smells and sounds that spring only from iconic locations, such as: Cajun country — zydeco on stage, swampy bayous in the distance and boiled crawfish spread out on the lunch table; the Heartland — bluegrass radio, cool glacier-cut gorges dotting the landscape and homemade bed and breakfast fare on the table; and Out West — Native American chants bouncing off ethereal rock formations and a fine spread of Navajo fry bread and beef stew waiting at the dinner table after a day of exploring the beauty of the desert.

Wheelchair users and their families can explore Americana via access to these remote, historic areas with ramped entrances to restaurants and attractions, boardwalks and paved trails, and lodging with roll-in showers, accessible common areas and ground-floor rooms/large elevators to upper floors. It can also be accessible by car or van and should be reasonably priced, where a couple can stay three days and two nights, eat local fare and pay for attractions while keeping the total bill as close to \$500 as possible.

Here are the details that capture this trio of accessible, affordable examples of Americana:

Monument Valley/ Navajo Spiritual Encounters-

UTAH/ARIZONA

Desert solitude and silver screen-worthy rock formations — that's what drew legendary Western movie director John Ford to Monument Valley. The heavenly scenery and fresh air will draw you to the corner of southeastern Utah and northeastern Arizona. It is especially engaging in late October, when the mercury rarely exceeds 70 degrees — even in this arid des-

ert climate. Toward the end of a fall day, the light is forever painting and repainting the valley's rocky fortresses. Blues become light purples, then dark purple, then fiery red, then back to blackish blue.

Monument Valley is a 30,000-acre Navajo tribal park established in 1958 located on the border of Arizona and Utah within the 16 million-acre Navajo Reservation. The barrier-free visitor center has clean restrooms, an air-conditioned gift shop and excellent observation areas for breathtaking views of the iconic Mittens and Merrick Butte. The visitor center building has a small elevator that takes wheelers up to the second story observation deck.

A 17-mile loop road winds along the valley floor among the rock sentinels that tower 400 to 1,000 feet above. The road is raw and unpaved, but that's a good thing because it slows traffic to a nice leisurely pace.

The View, the only hotel on Navajo land, features an accessible room with a patio that opens up to the majestic valley. The room, with a roll-in shower and private balcony, starts at \$150 per night. There is an on-site restaurant and trading post for supplies. Local dining options are limited to the restaurant at the View, or the dining room at the famous Goulding's Lodge just outside the Tribal Park. Goulding's barrier-free trading post and grounds are a perfect backdrop for feasting on a menu of Navajo frybread with a side of beef stew, spicy pork green chile or chili con carne.

Nearby attractions include Goosenecks State Park, a half-hour drive from Monument Valley. It features a paved road that ends at a scenic overlook with amazing views about 1,000 feet above the winding San Juan River and switchback formations the river carved out of the rocky area. Another half hour from Goosenecks is the Valley of the Gods. A 17-mile dirt and gravel road, passable in a family car when the weather is dry, winds through the valley. The sandy, bumpy, often steep drive is usually deserted — and that's a good thing.

The Moki Dugway — just northwest of the Valley of the Gods — is a staggering, graded dirt switchback road carved into the face of the cliff edge of Cedar Mesa. It consists of three miles of steep, unpaved switchbacks that wind 1,200 feet from Cedar Mesa to the valley



Heidi Wright gazes over Monument Valley.

Photo by Steve Wright

floor. This white knuckle route provides breathtaking views of some of Utah's most beautiful sites. But nothing compares to Monument Valley. Poets, priests and great writers of prose have failed to coin words worthy of the spiritual feeling that overtakes every person who gazes upon its majesty.

Cajun Country - **SOUTHWEST LOUISIANA**

Cajun doesn't get any more authentic than life in Breaux Bridge, Louisiana. Named for the wooden footbridge built over Bayou Teche by Acadian pioneer Fermin Breaux, the tiny community is famous for music and food. Both can be had every Saturday morning at Café des

Amis, in the center of town. A ramped entrance leads into a decent-sized bar, restaurant, stage and dance floor. Zydeco is the big draw, as it has been for years.

Saturdays mean zydeco breakfast, from 7:30 a.m. to 11 a.m., every Saturday except those that fall on a major holiday. They don't take reservations, so come early. Crowd in on the sidelines and drink a dirt cheap, stiff Bloody Mary while watching a great harmony of sweaty bodies dancing up a storm to zydeco, a purely American music that started in rural Louisiana in the early 20th century. Twirl to the sounds of accordion, fiddle, drums, guitar, bass and vest frottoir — a percussion instrument fashioned from pressed, corrugated steel and worn over the shoulders.

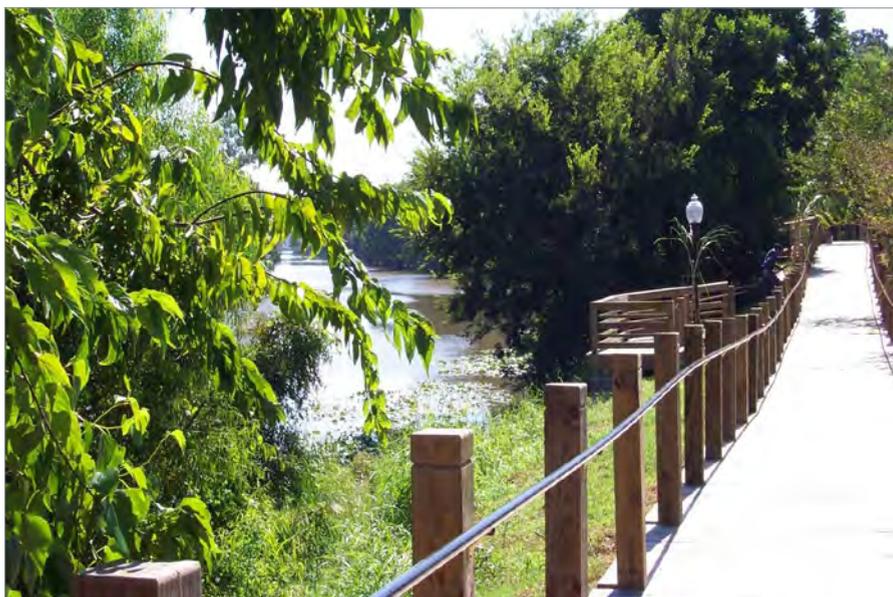


Photo courtesy of City of New Iberia

Roll off all those beignets, biscuits and andouille grits with a stroll along the Bayou Teche.

Beignets, biscuits and andouille cheese grits highlight a menu that also features couche couche (Cajun cereal made of cornmeal and milk with syrup and sugar) and the inimitable oreille de cochon (boudin-stuffed beignet dough shaped like pigs' ears with powdered sugar) — mmmm. After breakfast, roll over to swampy Bayou Teche. Check out the 19th century buildings and visit Breaux Bridge Antique Mall. It's your typical musty, shelf-stuffed place — with some aisles accessible and a few too narrow to negotiate by wheelchair.

Breaux Bridge is the Crawfish Capital of the World and Café des Amis serves 'dem mudbugs in eggs for breakfast, in po boy sandwiches at lunch and as crawfish pies and platters of half etouffe/half fried crawfish for dinner. For less formal dining in a barrier-free setting, head to Poche's Market Restaurant and Smokehouse for spicy boudin, cracklins, fried catfish, fried shrimp, crawfish etouffe and weekend barbecue plates.

New Iberia, about 25 miles from Breaux Bridge, offers the accessible Bayou Teche boardwalk between Weeks Street and the Duperier Street Bridge — behind the Shadows-on-the-Teche historic attraction. City Park has a new, accessible deck on the water. Main Street itself is packed with historical buildings, served by accessible sidewalks with curb ramps. Spanish Lake, just a few miles out of New Iberia's center, features five accessible fishing piers on its main levee road. Bayou Carlin Cove in Delcambre, about 15 miles from New Iberia, has a new boat dock/fishing pier constructed to be wheelchair accessible.

St. Martinville, about 15 miles from Breaux Bridge, pays tribute to Henry Wadsworth Longfellow's epic poem, "Evangeline," about the heartbreaks



Get your heart pumping on Saturday morning with Café des Amis' zydeco breakfast.



encountered by the Acadian people's expulsion from Canada and grueling resettlement in Louisiana. The Longfellow-Evangeline State Historic Site visitor's center has outstanding accessible restrooms. The first floor of Maison Olivier, an 1815 plantation house, is wheelchair accessible. The entire Attakapas Trail, named for the Attakapas Native Americans that inhabited the area before the Acadians, is paved and accessible.

Maison des Amis has limited access in one of its rooms. The grounds of this bed and breakfast right next to the historic district are accessible. For a 100 percent accessible room, book one of three rooms with roll-in shower at the Staybridge Suites in Lafayette, about 11 miles from Breaux Bridge.

Hocking Hills - OHIO HEARTLAND

Sometimes the place of lodging is simply a small room for sleeping. Sometimes the place of lodging is the attraction. The Inn & Spa at Cedar Falls, in the heart of

the Hocking Hills, is such a place. Long-time innkeeper Ellen Grinsfelder created this accessible paradise when she invited a friend who uses a wheelchair to do a walk-through. The result is wonderfully accessible accommodations nestled along a gorgeous, wooded ravine where the nighttime sky dazzles with its display of heavenly bodies so bright that visitors feel as if they've entered a brilliant cathedral of stars.

A roll-in shower, with grab bars and space enough to allow sufficient room for both a wheelchair user and personal care attendant, is the main feature of the Redbud cabin. The cabin itself is big enough to live in, with a full kitchen, sitting area and accessible bedroom on the first floor reached by a ramp. Kitchen items — flatware, silverware, tea bags, salt and pepper, even flashlights — are located where they can be accessed from a seated position.

One can linger outside, day dreaming on the porch swing and taking in the wooded vista, or come inside to the aroma of cedar and a plate of homemade cookies on the kitchen table. Take a seat



Not all of the trails in Hocking Hill state park are accessible, but the quarter-mile hike to the stunning water fall in Conkles Hollow is.

in the cozy living room by the gas fireplace. Forget the distraction of television — there is none in the cabin, but it does have wi-fi for those who cannot entirely unplug from civilization.

The spa, meeting place and dining room are all accessible. Breakfast includes fare such as: fresh fruit, homemade granola, Applewood smoked bacon, potato scallion soufflé and house made muffins or breads. Seasonal lunch and dinner features soups, salads, sandwiches and entrees ranging from crispy striped bass to spiced rack of lamb.

Lake Hope Lodge offers another dining opportunity focused on locally-sourced comfort food. The accessible lodge, located in a state park, has a famous Sunday brunch with made-from-scratch buttermilk biscuits, cinnamon rolls, brisket hash, pulled pork, smoked turkey and berry cobbler with fresh whipped cream. Lunch and dinner feature scratch made soups and chili, grilled Ohio chicken, beef brisket, fried catfish and wood-smoked ribs.

While the majority of the glacier-carved area's state park trails are too rugged for the average wheelchair user to negotiate, the quarter-mile paved trail to Ash Cave is very wheelchair-friendly. Commencing at accessible parking spaces, the trail ends at a massive shelter cave and 90-foot waterfall. The Conkles Hollow Gorge Trail extends a half mile from the parking area on Big Pine Road into the upper end of the gorge, below a waterfall. It is paved, very easy for wheelers to roll along and is an absolute must-do with the deepest gorge and the highest cliffs in the Hocking Hills. The Hockhocking Adena bikeway is a paved, level bike path located on the old Columbus and Hocking Valley Railroad bed. It runs from the Nelsonville Historic Square Arts District 22 miles south into Athens, home of Ohio University.

This area, at the foothills of the Appalachians, has no shortage of roots music. Every year, from Friday through Sunday

This area, at the foothills of the Appalachians, has no shortage of roots music. Every year, from Friday through Sunday of Father's Day weekend, the downtown streets of Logan come alive with the celebration of the washboard as a musical instrument.

of Father's Day weekend, the downtown streets of Logan come alive with the celebration of the washboard as a musical instrument. Everything from jug bands to Dixieland groups play the Washboard Music Festival in the hometown of the Columbus Washboard Company, the only remaining washboard manufacturing company in the U.S.

Over four days, usually in late May or early June, the Nelsonville Music Festival offers multiple stages of music along with local art vendors, food and a beer garden. The eclectic list of past performers — Wilco, The Flaming Lips, Willie Nelson, Loretta Lynn, John Prine, Dinosaur Jr., Yo La Tengo, George Jones and Gogol Bordello — is a slice of Americana in itself. **MI**

Resources

Listed first after each destination name is the approximate cost for three days, two nights including lodging, six meals, park admissions and gas money to drive between attractions.

Cajun Country — \$420-\$500

- Breaux Bridge, breauxbridgela.net
- Café des Amis (breakfast from \$10, lunch/dinner entrees from \$17); 337/332-5273, www.cafedesamis.com
- Poche's Market Restaurant and Smokehouse (plate lunches for \$12); 800/376-2437, www.pochesmarket.com
- New Iberia, www.cityofnewiberia.com
- Longfellow-Evangeline State

Historic Site (admission \$4); 888/677-2900, www.crt.state.la.us/louisiana-state-parks/historic-sites/longfellow-evangeline-state-historic-site

- Maison des Amis (rooms from \$125); 337/507-3399, www.maisondesamis.com
- Staybridge Suites Lafayette (suites from \$140); 800/238-8889, www.staybridge.com

Hocking Hills — \$410-\$500

- Hocking Hills – Ash Cave & Conkles Hollow (free admission); 740/285-6842, parks.ohiodnr.gov/hockinghills
- The Inn & Spa at Cedar Falls (Redbud ADA cabin — big enough to split cost with second,

- nonbodied family sleeping upstairs — from \$170 low season, Sumac accessible cottage — smaller than cabin — \$40 cheaper per night than Redbud); 800/653-2557, innatcedarfalls.com
- Hockhocking-Adena Bikeway (free admission); athensohio.com/wheretoplay/hockhocking-adena-bikeway-2
- Lake Hope Lodge (Sunday brunch \$15); 740/596-0601, lakehopelodge.com
- Washboard Music Festival (free admission); 740/380-2752, www.washboardmusicfestival.com
- Nelsonville Music Festival (\$75 one day admission); 740/753-1924, nelsonvillefest.org

Monument Valley — \$400-\$500

- Monument Valley Tribal Park (entry fee is \$20 per car, up to four people); www.navajonationparks.org/htm/monument-valley.htm
- The View Hotel (accessible room with roll-in shower from \$150); 435/727-5555, monumentvalleyview.com
- Goulding's Lodge (lunches from \$12); 435/727-3231, www.gouldings.com/dining-room
- Goosenecks State Park (free admission); 435/678-2238, utah.com/goosenecks-state-park
- Valley of the Gods (free admission); utah.com/monument-valley/valley-of-the-gods



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Mark "Wheelchair Junkie" Smith



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 **M. Henson** I'm just weeks away from getting this chair and I can't wait. I've had an opportunity to use a demo for a week and this chair is a game changer.

 **D. Heilman** Flipping fantastic! Everyone deserves to look at another eye-to-eye... not up or down.

 **L. Boccuti** This is so great. My husband felt claustrophobic in his chair in a crowd because he was so far down. This would have helped that so much.



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CAN WALKING

UNLOCK SCI DAMAGE ?

BY IAN RUDER

There have been some exciting developments around SCI research in the last few years (see “U.S. Stem Cell Trials Show Encouraging Results,” June NM), but Dr. Wise Young is far from satisfied.

“We need to bring spinal cord injury back into the mainstream of medicine,” he says. “We’ve been shut out because for the last 12-15 years, there have been no clinical trials of anything. It’s just a bunch of people sticking things into the spinal cord and not doing any control studies, and being criticized.”

For Young, the director of the W.M. Keck Center for Collaborative Neuroscience at Rutgers University, and one of

the most visible and educated faces on SCI research, satisfaction and progress are both tied to the same thing: rigorous clinical trials. Young and a huge team of doctors and researchers have been working on just that for the last five years in China, and thanks to some exciting and unexpected results, he is optimistic that the tide may be about to turn.

WHAT WE ARE LEARNING FROM CHINA TRIALS

If you’ve heard Young speak over the last few years, or paid close attention to the releases from the Keck Center or

ChinaSCINet — the clinical trial group Young has helped establish in China — you’ve likely heard bits and pieces of the promising findings from his trials there: complete injuries walking again, people regaining bowel and bladder control years after injury. All of the results were published this May in an article in the medical journal *Cell Transplant* entitled, “Phase I-II Clinical Trial Assessing Safety and Efficacy of Umbilical Cord Blood Mononuclear Cell Transplant Therapy of Chronic Complete Spinal Cord Injury.”

Phase one of the study consisted of eight participants at a site in Hong Kong, while phase two included 20 participants in Kunming, located in China’s south-



We believe enough fibers have grown across the injury site to activate the central pattern generator in the lumbosacral spinal cord. The CPG in the lumbosacral spinal cord contains all the programmed walking motions, and we believe that enough fibers have grown across to activate the CPG so that the person can start and stop [walking].



for three to six months, covering long distances with a rolling walker — while those in Hong Kong did not.

The phase one results showed the processes were safe, and imaging of the spinal cords suggested some regeneration, but no participants recovered motor function. That set the stage for phase two's surprising results. "We were not expecting very much," says Young. "However, in Kunming, it rapidly became clear that a majority of the participants were recovering function."

Young broke down the results in a May letter from the Keck Center:

At one year after treatment, 75 percent (15/20) of the participants in Kunming recovered the ability to walk long distances in a rolling walker with minimal assistance. Thirty-five percent (7/20) could walk without such assistance using either a four-point walker or a crutches. None of the participants could walk more than 10 meters without substantial assistance at the beginning of the trial and a majority were not even able to stand without help. When they went home, some of them did not have devices or

ern Yunnan Province. All but one of the participants had ASIA A, or complete, SCI injuries ranging from C3 to T11, and they averaged 14 years post-injury in Hong Kong and seven years post-injury in Kunming. Participants at both sites received injections of umbilical cord blood mononuclear cells (UCBMNC) above

and below their injuries, in addition to surgery to de-tether their spinal cords and a large dose of methylprednisolone. The big difference between the two phases was that the Kunming participants also underwent what Young called the "most intensive walking program in the world" — six hours a day, six days a week



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people to help them walk and several regressed. However, 35 percent continued to walk and became household walkers, preferring to walk for distances up to 100 meters, but using their wheelchairs for longer distances. Another unexpected finding was that 60 percent of the participants became completely independent including no longer needing any help for bladder and bowel function. In fact, 55 percent stopped using catheters.

"We were quite stunned by these results," he says. He says he was also intrigued to find that the same participants who had no trouble walking long distances were unable to move their legs if they lay down. "In other words, voluntary movement of the legs is very weak."

"We believe that what is happening is enough fibers have grown across the injury site to activate the central pattern generator in the lumbosacral spinal cord," explains Young. "The CPG in the lumbosacral spinal cord contains all the programmed walking motions, and we believe that enough fibers have grown across to activate the CPG so that the

person can start and stop the CPG, but not enough fibers have grown across so that they can move their legs at will. They can't wiggle their toes, they can't straighten out their legs. But on the other hand, once they start walking, the CPG takes over and they can start and stop and turn — useful walking."

Young says he thinks the results raise a very important question for future studies to investigate.

"It really opens up the question whether more therapies would work if people actually trained [with intensive locomotor training]," he says. "There are a lot of studies of olfactory and sheathing glial cells in China and studies of bone marrow transplants, but none of these studies have done any walking of the participant. And so it could very well be that those therapies could have worked if they had walked the participant."

Young says an ongoing trial in China is looking at whether the UCBMNC are even needed. Participants in that study will receive six months of the intensive walking regimen but no cell transplants.

THE FUTURE OF CLINICAL TRIALS IN THE UNITED STATES

As excited as Young is about the results, he seems even more excited about launching similar trials here in the United States as part of a multi-center, worldwide effort. In addition to China and the U.S., trials would occur in Norway and India. His team met with the FDA in January to review the U.S. proposal and came away with an agreement about how to proceed.

With the money already raised, Young hopes that his team could begin phase two trials in the U.S. by the end of the year. Multi-center phase three trials would be launched around a year later, possibly before the end of 2017.

"So we are estimating that probably the phase three trial will require about 120 patients," says Young. "We need to do two of them ... one, which we want to do with the U.S., Norway, and India,



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and then a second one that we'll do all in China. [Another] 120. So it will be a total of 240 participants. And it will be the same one-year long trial. We may find out things from the phase two trial that may change the plan. But we're hoping that our phase two trials will show that the walking is beneficial."

One issue Young is working on is shortening the amount of locomotor training required. "6-6-6 is scaring everybody in the U.S.! ... To walk somebody six hours a day, six days a week for six months is a multi-million dollar therapy," he says. "So we are trying to develop ways, including stimulation, [with] which we can shorten this time." Young didn't delve into specifics about what types of stimulation his team was looking at, but he expressed admiration and interest in the work of Dr. Susan Harkema and Dr. Reggie Edgerton, leading researchers in epidural stimulation.

Even more than the time demands, the cost of trials could be prohibitive. "The thing that's holding us back is for every one of these trials, we have to raise the money — it's not a trivial amount. We have to raise about \$60 billion for

the trials. And this is not being helped by any company or by the government," he says. "Right now, all the clinical trials are going on overseas. In the U.S., there's zero help for the clinical trials to go forward." Young has made the case for increased funding for SCI research all over America, including the halls of Congress, and hopes a successful U.S. trial will help turn the tide of public opinion.

"We're going to try our very best to

make these trials go ahead and convince people that they're being done properly," he says. "We want to make sure we do this right. And as soon as that happens, I'm hoping that there will be many clinical trials. Not just our clinical trials. But there will be maybe half a dozen or a dozen clinical trials going on simultaneously around the world. People will get excited. It's just like how the first AIDS therapy triggered a dozen other therapies." **M**



The thing that's holding us back is for every one of these trials, we have to raise the money — it's not a trivial amount. We have to raise about \$60 billion for the trials. And this is not being helped by any company or by the government. Right now, all the clinical trials are going on overseas.



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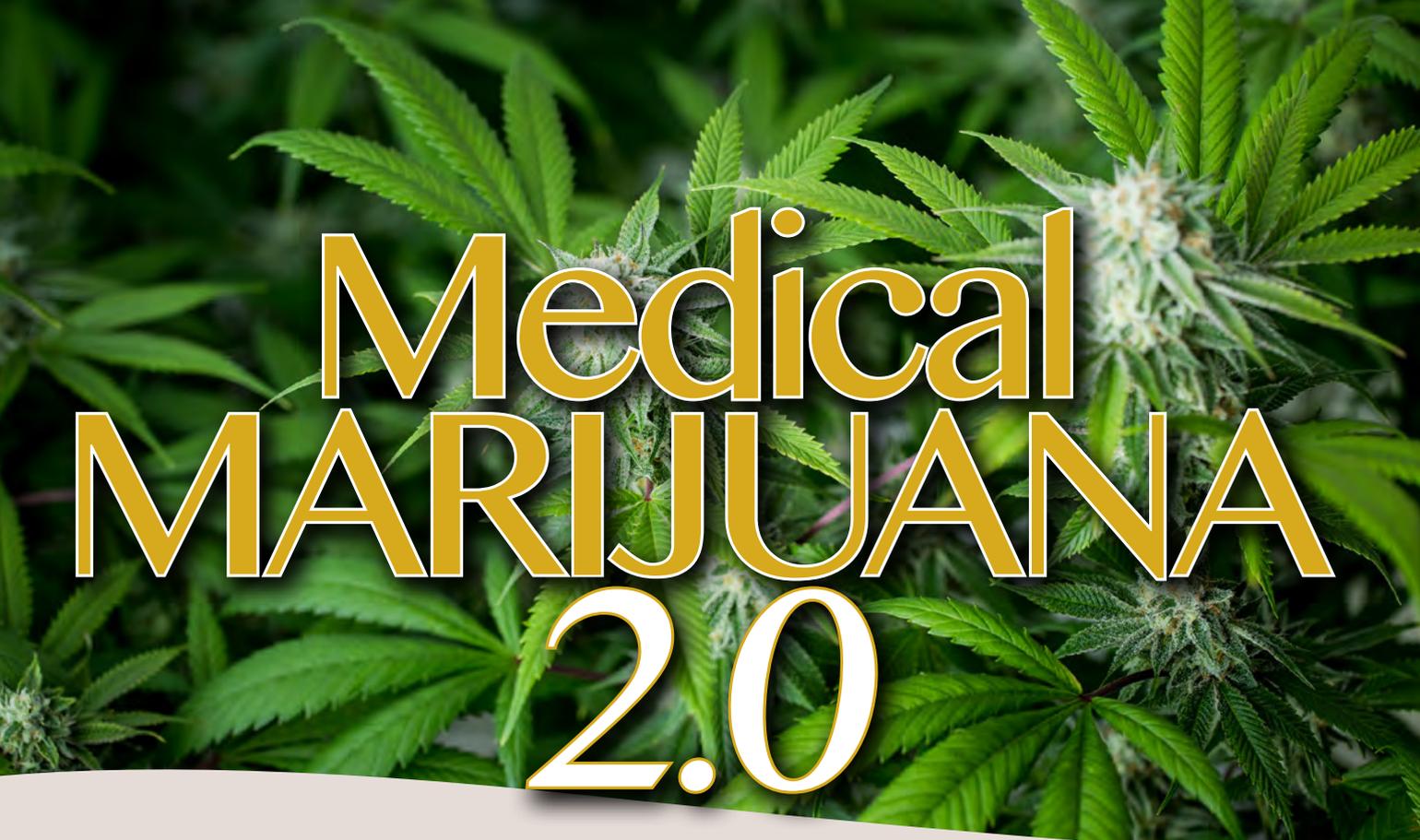
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Medical MARIJUANA 2.0

—Stirring the Pot

BY MARK MATHEW BRAUNSTEIN

The War on Drugs is losing, and pot is winning. And people who use medical marijuana are winning the right to choose. All of Canada, most of Western Europe, and half of the states of the United States have legalized medical marijuana. Its expanded use, growing support for legalizing its use, further innovation in its safe use, and deepening research into why to use it — all herald an upgrade to Medical Marijuana 2.0.

Trailblazers and Troublemakers

In 1996, the tide turned in the War on *some* Drugs when California voters legalized medical marijuana. Since then, citizens have joined crusades in other states by testifying about their own medicinal, though illegal, use of cannabis. Wheelchair users have often very visibly led the marijuana march. If you research the online archives of public hearings for bills legalizing medical marijuana in your own state, you are sure to find testimonies from wheelers with MS and SCI among them. Rather than simply light up and shut up, wheelers have chosen to light a fire to drug law reform.

Many unsung heroes preceded, and therefore have eluded,

the reach of the internet. Our nation's earliest documented medical marijuana users gave testimony at hearings before the U.S. Drug Enforcement Administration from 1986 to 1988. Valerie Cover of California, Martha Hirsch of Massachusetts, and Greg Paufler of New York, all living with MS, testified to their cannabis "crimes." Two quadriplegics bravely joined that chorus. G. Fred McBee of Florida, while horseback riding, fell off his horse and then the horse fell on him. But due to his subsequent use of cannabis rather than opioid-based painkillers, McBee never fell off the wagon. David Branstetter of Missouri was arrested and threatened with incarceration unless he ceased confessing about his use of cannabis to his parole officer. Yet Branstetter traveled to Washington, D.C., to sit before the DEA to confess still more.

The 1980s and early 90s were dark times for cannabis consumers. Those who pushed the envelope did so at risk of that envelope containing warrants for their arrests. Nowadays, we easily forget the risk ever existed. Yet even where it is legal, social stigma may hang in the air. (Such stigma may explain why, despite multiple calls for submissions, so few cannabis users with SCI or MS were willing to share their stories here.)

The Grim Wheeler has led many people down wheelchair paths they would never have explored on foot. Only after their SCIs did Ethan Ruby and Dr. Gary Witman allow their lives to "go to pot."



Photos by Matt Wong



The Pot Doc

To some people's thinking, doctors are super-humans who never fall ill, never suffer injuries, and never die within our own lifetimes. In reality, even doctors have doctors, and doctors do become patients. Gary Witman, M.D., was head of emergency care at a Massachusetts hospital when in a cruel role reversal he was ambulated to the ER of a Rhode Island hospital. He had been enjoying a summer day wading in the ocean when a

rogue wave knocked him down and flipped him on his head. He fractured several upper vertebrae and injured his spinal cord at C3-4, leaving him paralyzed below the chest and with limited use of his hands.

Witman recounts this story from six years ago while seated in his power chair. He speaks eloquently and deliberately, as might a doctor sharing an unwelcomed diagnosis with his ailing patient, except that he is the patient about whom he speaks. "At the time of my injury," he says, "I was immediately fired." So he took fate into his own hands.

For the next five years, Witman sought but was unable to obtain employment, not even with the VA. Everyone told him he was eminently qualified but too disabled. Finally, a year ago he secured a full-time position with Canna Care Docs. He treats Massachusetts and Rhode Island residents to evaluate whether their conditions might qualify them for state permits to medicate with cannabis. If so, he advises dosage and usage. He dismisses the honorific (or onerous) nickname "pot doc." Anyhow, no one has ever called him that. He counters, "It is my belief that to appropriately recommend this medicine requires a physician who specializes in either pharmacology or internal medicine, and who understands the risks as well as the benefits."

About cannabis' benefits, he says, "I have not found anything superior for the treatment of either pain or neuropathy, and it is far superior to the utilization of narcotics." While more than a thousand strains of cannabis have been cultivated, the six dispensaries in Massachusetts currently offer hardly more than 33. Among those, Witman recommends two specific strains that



Dr. Gary Witman says he has not found anything superior to marijuana for treating pain or neuropathy.

most effectively alleviate spasms, Purple Haze and Sour Diesel (more about Sour Diesel later). “Most people get the greatest benefit for spasms from CBDs.” And those two strains have the highest ratios of CBD. He adds, “My patients are not looking for THC.” (See sidebar, next page.)

Witman’s recommended modes of delivery are marijuana edibles (medibles) and vaping, but not smoking. “I do not believe that there is any indication for smoking.” He says that vaping releases all the medicinal cannabinoid compounds at below 400 degrees F (204 C), whereas smoking above that threshold produces tar and ash, both proven carcinogens.

Eight percent of the people he sees have SCI and 4 percent have MS. While everyone responds differently, Witman does outline one generalized protocol for those with MS or SCI. “I recommend they use a vaporized sativa strain, two to three puffs, to be administered every three to four hours, during the day. Nighttime, edibles are to be administered one hour prior to sleep, to take as required to get seven hours of continuous sleep.”

He voices concerns about legalizing recreational pot because that might lead to increased risk of cancer for those who smoke tobacco and to more traffic accidents by those who mix pot with alcohol. Further, the purity and potency of medical cannabis might be compromised if growers redirect their efforts to the recreational market by growing strains with higher THC. That in turn might detract from cannabis being taken seriously as a pharmaceutical agent.

Had he ever used marijuana recreationally as a youth? He answers frankly, “I certainly have.” Oddly enough, he does not presently use cannabis because he says he has none of the indications which cannabis might medicate. He leaves his spasms untreated. And with no sensation below the chest, his pains from spasms go unnoticed.

But Witman has not gone unnoticed. He is president of the



“I recommend they use a vaporized sativa strain, two to three puffs, to be administered every three to four hours, during the day. Nighttime, edibles are to be administered one hour prior to sleep, to take as required to get seven hours.”

Rhode Island chapter of United Spinal Association, and serves on several state government agencies and committees. He awakens every morning with an urgent desire to serve and to care. “Every day is such a beautiful experience,” he says. “The ability to be alive is spectacular.”



A card-carrying member of the medical marijuana community, Ethan Ruby is also CEO of Theraplant, which makes the medicine.

The CEO of CBD

Ten years ago, if you had told Ethan Ruby that he was destined to become an herb farmer, he would have wondered what herb you’d been smoking.

His circuitous route to running a huge indoor herb farm began 16 years ago when a typically aggressive Manhattan driver ran a red light, rammed a car, and that car in turn struck Ruby on a crosswalk. The last domino to fall in that effect was Ruby’s T6 vertebra. At that time in New York City, pedestrian traffic signals commanded in bold letters and in plain English either WALK or DONT WALK (no apostrophe). When he crossed that fateful street corner, Ruby’s traffic signal read WALK.

Now, rather than walk, Ruby has kept busy doing many other things. Formerly a star sports athlete and equities trader, he turned to another form of gambling post-paraplegia. Seated in his cool new wheelchair, he rolled up to the poker table and competed on a level playing field where all the other players were seated, too. He even ascended to the world series of poker tournaments. Then he founded Poker4Life, which hosts poker tournaments to fundraise for nonprofits, including for the Buoniconti Fund, a fundraising arm of the Miami Project to Cure Paralysis. He also invented and patented Wheel Comfort padded footplates for wheelchair users who like to roll barefoot.

Other business and charitable ventures preceded and followed, but now his attention centers around medical marijuana.

As an inveterate entrepreneur, Ruby foresaw cannabis as an emerging industry. When Connecticut legalized medical marijuana in 2013, he competed with 15 other applicants for the state's four costly producer permits. Applicants were rated and Ruby's company scored highest. Theraplant was born, and Ruby became its CEO.

A Plant Pharmaceutical Plant

On Google or Bing Maps, aerial views of Theraplant's pharmaceutical plant look hardly different from its neighboring industrial plants. Those include a plastics factory, a computer components maker whose computer business model is probably making plans for its move to China, an adhesive manufacturer that is still sticking around, several tool and metalwork machine shops, and FedEx and UPS competing distribution depots. But those online aerial views of the former paint factory are several years old. Today, Theraplant has transformed that 1.5 acre factory and 10 acre property into a Fort Knox. The State of Connecticut mandates that.

"Connecticut was the first state that was really treating cannabis like a pharmaceutical," explains Ruby, "so that's why I felt comfortable getting involved with the industry here."

Industry indeed. Ten years ago, people with disabilities and caregivers rhapsodized in blogs and newsletters about the med-

ical marijuana community. Now, cultivation laboratories and dispensaries tabulate in spreadsheets and annual reports about the medical marijuana industry. The sense of community may be waning, but safety, purity, and yes, even potency, are gaining. We all can legally brew beer in our garages or make wine in our cellars, but instead we pay breweries and vintners to get all messy for us. "To make medicine that passes the very strict laboratory testing here," says Ruby, "we spend millions of dollars on environmental controls."

Ruby credits demand with guiding grow lab supply. "Originally, customers were chasing THC. But as they become more educated in understanding terpene profiles and the benefits of other cannabinoids, they are starting to demand more CBD-based medications. And more people are demanding indica blends than sativa blends. When we first started it was 80 percent flower, 20 percent everything else, including edibles, capsules, waxes, vape oils, extracts. Now it's 60 percent flower. And more people are vaping oils or wax rather than flowers."

Unlike Witman, Ruby is a card-carrying member of the medical marijuana community. "Yes, I purchase my monthly supply of medicine at a dispensary just like any other patient in Connecticut. I use various forms of medical cannabis to treat different ailments. Due to SCI, I suffer from pain, PTSD, skin breakdowns, intestinal distress, to name a few. Cannabis provides a safe and natural treatment option. Typically, I use CBD-dominant strains as they provide relief without the 'high' effect associated with THC strains. I prefer indica-dominant strains at night to help relax my body and lessen the pain. This relief

The ABCs of THC and CBD

The tiresome, old question, "Does marijuana really work?" has been supplanted by "What strains work best?"

The two most widely cultivated species of cannabis are *Cannabis indica* and *Cannabis sativa*. Ethnobotanists debate the differences between the two, while cannabis consumers agree at least that each produces different effects. *Sativa* has traditionally been a stimulant and intoxicant, producing a head high that is uplifting and cerebral, and is best suited for day use. *Indica* has been more of a sedative and analgesic, producing a body buzz that is calming and sensual, and best for night use.

Cannabinoids contain the psychoactive and medicinal components of cannabis. While 80 different cannabinoids have been identified (with more on the way), the two that get the most press are THC (tetrahydrocannabinol) and CBD (cannabidiol).

Initially *sativas* had a richer THC content than did *indicas*, while *indicas* were higher in CBD than were *sativas*. Cross-breeding has since blurred those boundaries and produced a wide variety of hybrids, each strain with distinct characteristics that have been described by wildly imaginative names, for instance Purple Haze and Sour Diesel. "Strains" is a colloquial term for "cultivars," variations within a species that exhibit different appearances and properties. Thus Honey Crisp apples are cultivars good for eating raw, while Cortland apples are more suitable for baking.

During the past half century, the THC contents of both *sativas* and *indicas* have increased tenfold, thanks to intense efforts at hybridization. It's not your mother's marijuana anymore. Yet stoners do not get any higher, they just get to the same place with less huffing and puffing. When growers

hybridized strains with higher levels of THC, they unwittingly bred out the CBD. As CBD provides relief to many medical conditions such as spasms and pain, its lowered potency was a loss to medical users and accounted for mixed results in past human trials. But all was not lost because THC, too, has antispasmodic properties. Plus THC and CBD enhance each other's effects so are best consumed together.

With cannabis' medicalization, growers have cultivated higher levels of CBD back into strains that dispensaries now provide to medical marijuana card-holders. The new math of medicinal marijuana has opened new horizons. As a muscle relaxant, antispasmodic, and analgesic agent, CBD has stimulated long overdue interest from SCI, MS, and ALS medical researchers. Stay tuned as discoveries advance rapidly regarding the ABC's of THC and CBD.





Proponents say that Bud Rub, a topical salve, relieves aches and pain with no psychotropic side effects.

allows me to eat and achieve restful sleep. My preferred delivery method is vaporization.”

What Forms of Medicinal Marijuana Do People Use?

Despite Connecticut’s very rigorous criteria for qualifying a recipient of medical marijuana, enrollment in its four-year-old program has tripled in the past two years. “This speaks for the positive impact this medicine is having,” says Ruby. “More and more doctors are looking at the literature and listening to their patients.” Here are usage protocols from three of them.

Tim Fournier

Tim Fournier was a 19-year-old sailor in the Navy when a freak accident recruited him into the ranks of SCI. While C6-7 quadriplegia took the wind out of his sails, it did not sink him. He has navigated the sometimes choppy seas of quadriplegia for 30 years now. Though lacking dexterity in his fingers, he uses a manual wheelchair, only recently upgrading it with power-assist. A salesperson for an automotive company that outfits vans for the disability community, Fournier is also the VP of the Connecticut chapter of United Spinal Association.

His muscle spasms and tone are so severe that to treat them he had administered Baclofen both orally from pills and internally from a pump implant. Cannabis now enables him to eliminate his oral use of Baclofen, yet the herb has not provided a total panacea. Occasionally he still switches on the pump, though more dialed down than before. Because of cannabis, he need not resort to any pharmaceutical painkillers.

Fournier registered with Connecticut’s medical marijuana program upon its inauguration in 2012. Until the dispensaries first began dispensing two years later, he procured his cannabis clandestinely from “the street,” same as everyone else did. Now he purchases all his herbal meds from the dispensaries and is appreciative of the many strains they offer. He seeks those high in CBD, which quells spasms and tone the best. His favorite CBD strain is Sour Diesel. For day use, he prefers to partake in cannabis via oil syringes and vape pens. For night use, he consumes edibles just before going to sleep. Unbeknownst to Fournier, he follows the very regimen and prefers the same strain as recommended by Witman.

Fournier welcomes full legalization for recreational use because he happens to enjoy one of cannabis’s side effects, namely euphoria, and believes everyone else deserves the choice to be appropriately medicated, too. Did he use cannabis recreationally before using it medicinally? “Absolutely!”

Alex

Alex lives in the dim twilight between state and federal laws, so he wishes to remain anonymous. Medicinal cannabis is fully legal in his home state, but he is employed full time by a federal agency, and under federal law cannabis is still banned as a Schedule I drug. If he publically confessed his “crimes,” he could risk losing his job. Ironically, as a mental health professional, one of his duties is drug counseling.

In 2004, Alex severed his spinal cord at T5 in a motorbike crash. When he was in the rehab ward, his friends smuggled in cannabis edibles for him. From his earliest days as a paraplegic, he was aware of cannabis’ therapeutic value. He moved in 2006 to the state in which he presently resides and the next year enrolled in its cannabis program. But because of the threat posed by the feds, Alex continues to smuggle his stash into his own home.

He medicates to alleviate the extreme spasticity and stiffness (tone) in his legs and to quell the accompanying pain. Cannabis helps a lot but not enough, so during the day, for spasms



Medicinal marijuana is, well, medicine. As such, it can come in capsules to enhance time-released pain relief.

he supplements with oral Baclofen. Before his use of cannabis, his daily regimen of Baclofen was 120mg. Cannabis has enabled him to reduce that dosage to half and to eliminate usage of all other pharmaceutical drugs.

Preferring strains high in CBD, he seeks Sour Diesel (again Sour Diesel!) and ACDC, always organically grown. The owner of his dispensary personally assures Alex of its organic origin, as the USDA does not certify organic cannabis. Alex's usual methods of delivery are edibles and smoking. He smokes either pipes or joints. In light of innovations with vaporizing, smoking may be nostalgic, as he smoked pot as a teenager. Then he abstained during 12 years in the military. As though making up for lost time, he insists, "I enjoy the psychoactive properties, but not when I'm at my workplace."

Since his motorcycle accident, if his life were a book, Alex might title it, *Zen and the Art of Wheelchair Maintenance*. Above all, he values human relationships as a manifestation that we all are intimately connected. And he believes that medical marijuana is equally connected to recreational pot. "I love the fact that people have the good sense to make it legal both medically and recreationally."

Paula Ghergia

Formerly a UPI photojournalist, Paula Ghergia of Somerville, Massachusetts, juggles three new jobs. Part-time, she is employed at a café. Double-time, she serves as the primary care-

giver for her 89-year-old mother who has dementia. And full-time, she manages her MS, which was diagnosed six years ago. While she has not yet reached the stage of impaired mobility, she suffers constant fatigue and periodic spasms and pain.

When Paula tried pot as a teenager, it only made her feel silly, so she quickly lost interest in it. Now in her early 50s, she enlisted in Massachusetts' medical program nearly two years ago. She says cannabis quells the spasms, alleviates the pain, and no longer makes her feel silly. In fact, it now enables her to feel quite normal.

She prefers cannabis in its natural form as a wholesome herb, which she either vapes or smokes. In the morning, she imbibes in strains high in THC to give her a lift before going off to work, while in the evening she prefers CBD strains to relax her fatigued muscles and to impart more restful sleep.

Until a dispensary opens near to her, Paula procures her supply from a legal grower who delivers right to her home. She does not grow her own because she is too busy with her jobs. And no shady drug deals in dark alleys or parking lots. She is thankful to Massachusetts for its medical cannabis program, and supports efforts to legalize its recreational use, which she thinks will further legitimize and stabilize its medical use. Her advice to medical and recreational users alike: "Be safe and be smart."

Medical Marijuana 3.0

All drugs pose risks. Whether medicinal or recreational, herbal or pharmaceutical, legal or illicit, every drug harbors undesir-

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able and potentially harmful side effects. Inhaling cannabis smoke can compromise human health. While vaping bud is widely acknowledged to be less harmful than smoking, vaping still poses some health risks that varies with the brand of vaporizer. “Vaporization technology is still growing,” says Ruby, “and is going to keep escalating.”

Due to the inherent dangers of smoking and even vaping, many alternative methods of delivering cannabinoids now are sold nationwide. These include oral sprays, alcohol tinctures, topical creams (for psoriasis), transdermal patches, sublingual strips, oil extracts, eye drops (for glaucoma), time-released capsules, waxes, salves, and a whole smorgasbord of edibles. “The future of the industry is heading toward extracts with standardization of measurement and exact dosing,” says Ruby. “And a whole new area of delivery is being affected by transdermal patches and creams.” Despite this treasure trove, most recreational users still smoke or vape the bud because they are banished from legal access to more healthful cannabis-derived alternatives. (What’s wrong with this picture?)

Some ill or injured folks who still live under state prohibition may wonder if cannabis might provide them with the relief they seek. The short answer is that not everyone benefits from any single drug, and no one drug benefits everyone. Hence the hundreds of prescription drugs and hundreds more non-prescription drugs sold just to assuage pain. Everyone can gain by broadening their choices and by weighing the risks posed by each choice. If people choose cannabis, then as expanding research weeds out all the myths, medicinal users will benefit further.

We Live in a Medicinal World

Future generations of Americans will find it incomprehensible that cannabis was briefly illegal in the United States, a blink of the eye compared to the millennia that the weed has flourished

on the planet. In 1937 when it was first banned, the AMA protested that it wanted to keep the herb in its cornucopia of drugs in order to retain doctors’ options and patients’ choices.

Freedom is synonymous with choice. Prohibitionists denounce efforts to legalize any medicinal use of cannabis as mere ploys to eventually legalize its recreational use. Guilty as charged. Drug law reformers indeed view medical marijuana as a wedge issue, as the foot in the door. Without the funding and lobbying efforts from NORML, MPP, and Drug Policy Alliance, medical marijuana’s legal status would still be stuck in the 20th century. Medicinal users who may have been their stooges nevertheless have gained from its legalization.

Even prohibitionist legislators who have voted against it stand to gain from further legalization of medical marijuana. While they will not very likely suffer SCI or contract MS, many of them indeed will be afflicted by and die from cancer. And when they undergo chemotherapy, they will be thankful when given the option of using cannabis to quell their nausea and to ease their pain.

In a sense, we are all patients. What line can be drawn between the terminally ill who will die in a month or a year and the rest of us who will die in 10 years or 50? It is a fact of life that we all get sick, and that if we grow old enough, we all will become disabled, and that young or old, we all will die. ■

Resources

The legal status of cannabis is rapidly evolving, so it is best to consult your own state government’s medical marijuana program for policy updates. Meanwhile, two websites provide useful overviews.

- National Organization for the Reform of Marijuana Laws (NORML), norml.org/legal/medical-marijuana-2
- Marijuana Policy Project, www.mpp.org/states



Using oral tinctures or vaporizers is generally considered safer than smoking marijuana.

Photo by Monique Chevallier

Legalized Marijuana Expands in Oregon

Promise of Big Bucks Recreationally May Be Undermining Medical Pot

BY IAN RUDER

These days you can't roll too far in Portland, Oregon, without stumbling upon a marijuana dispensary. Medical marijuana has been legal in Oregon since 1998, but since the voters of Oregon overwhelmingly voted to legalize recreational marijuana in November 2014, the industry has caught fire faster than a perfectly rolled joint. With a whopping 167 dispensaries within the city limits, the green cross identifying the businesses has become one of the city's most ubiquitous signs. With literally thousands of people applying for licenses to sell recreational marijuana statewide, there are millions of dollars pouring into the industry, and also into the state's coffers — the state collected \$3.48 million in taxes in January 2016 alone, far surpassing its wildest estimates. It is easier than ever before to get marijuana in Oregon.

So you can imagine Jeremy John Robbins' surprise when he received a certified letter from the owner of the farm that had grown his medical marijuana, informing him that he would no longer be able to grow for him. The grower had decided to focus on the burgeoning recreational market and had to declare that he would no longer grow medicinal marijuana. Robbins, 40, has used medical marijuana since 2001 to reduce his spasms, help his neurological pain and cope with PTSD since he was paralyzed in 1999. He swears by the benefits and has become a staunch and well informed advocate for making cannabis more available to the public. Still, he was caught off guard by the letter. "I didn't see it coming," he said. "I thought legalization would increase access, and it has, but that has come with regulations and a lot of uncertainty."

Oregon is one of only four states to have legalized recreational marijuana,



Photo by Montique Chevallier

For treating neurological pain, Jeremy John Robbins says nothing is better than medical marijuana.

but 25 states have legalized some sort of medical marijuana, including 10 in the last five years. As more and more states evaluate legalizing marijuana, eyes are on Oregon, Washington, Colorado and Alaska to see how legalization plays out and how medical and recreational programs work, or don't work, side by side.

"I think a lot of people take it for granted that marijuana is just going to be there, but unfortunately I think that a lot of medicinal users are going to be in for a really rude awakening," says Charley Flynn, a Portland grower.

For Robbins, and some other long time medicinal users, legalization has actually complicated his ability to procure the medicine they need. Robbins is one of thousands in Oregon with a medical marijuana card. Cardholders are allowed to have up to 24 ounces of usable marijuana,

na. Many people simply buy their medicine tax-free at one of Oregon's many dispensaries, but some take advantage of the law's provision allowing cardholders to have six plants. Cardholders can register to grow for themselves, but growing medical quality product can be expensive and difficult. For some, like Robbins, who lives in public housing, it is not an option. Instead, he had an agreement with his registered grower where the grower would provide him an ounce a month from his six plants. With an ounce selling for anywhere from \$200-\$300 at a dispensary, depending on the strain, the deal saved Robbins significant money each month and allowed the grower to recoup some of the costs of growing by selling excess product to dispensaries. When he found out his grower was moving to the recreational market, Robbins was forced to

find a new grower. He has, but has yet to receive any medicine as the grower deals with startup issues. That means Robbins has to pay market prices for his medicine on his already tight budget.

Like many medical users, Robbins rarely ingests his allotment via smoking. He has found the most benefit from concentrates, applying a small drop under the tongue. That too was thrown into jeopardy earlier this year when the state health authority's draft regulations made

the manufacture or possession of concentrates a Class B felony. Revisions now allow concentrate manufacturers or users to apply for a permit, but the application costs \$4,000, again too steep for many.

Those changes are part of the state health authority's attempt to rein in an industry that has gone largely unregulated since its inception. The majority of the regulations are focused on health and safety issues, like ensuring safe dosages and uniform quality, but they extend to

how grow sites are managed and issues like security and water use.

Troy Moore has been involved with the Oregon marijuana scene's rapid growth from the beginning. He started the first state-licensed medical dispensary, Oregon's Finest, in 2012, and is about to open his third store. He also co-owns Ideal Farms, a grow farm in a nondescript building in downtown Portland that grows medicinal marijuana for a number of medicinal users. That will change later this year or early next year once Moore applies for a recreational growing permit and ceases to grow medical cannabis. "They're forcing a lot of growers to make a decision to be recreational or medical," says Moore, citing the high cost of mandated security equipment and other regulations. "It's tough to make money in the medical market anyway, and these are probably costs most small medical growers cannot afford."

The Lure of Recreational Growing

In Oregon, the decision to focus on the recreational market instead of the medical market makes obvious business sense. Medical growers are limited to growing for four cardholders, with each cardholder entitled to six plants. Even with multiple growers working at the same registered grow site, a frowned-upon practice known as card stacking, growers' profits were limited. Recreational licenses are divided into two tiers for indoor and outdoor production. Indoors, a Tier I license allows for up to 5,000 square feet of canopy, while a Tier II allows for 5,001-10,000 square feet. Outdoors, Tier I allows for up to 20,000 square feet and Tier II allows for 20,001-40,000 square feet. That's up to about one acre of outdoor ground, a lot more space and a lot more potential revenue.

"I feel really disappointed in the direction that things are going," says Flynn, who grows for Moore's Ideal Farms. "I think that a lot of the voters were duped by legislators saying they weren't going to touch medical, but by every indication, the medical system is probably going to get dismantled to the point where it's going to be ineffective or force people into

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Fifty-six percent of Oregonians voted for Measure 91 in 2014 to legalize recreational marijuana. The law allows adults over 21 to possess up to 8 ounces of dried marijuana and to grow up to four plants per household. The law allowed counties where 55 percent or more of voters opposed the measure to ban marijuana sales. Fifteen counties in Oregon did so. Legal sales of recreational marijuana began Oct. 15, 2015, but were limited to flowers and joints. Edibles and other delivery methods became recreationally legal June 1, 2016.

the recreational.”

Moore isn't as pessimistic, but he does profess to be unsure of how medical and recreational marijuana will coexist. “They're going to try to coexist in the same building, which is hopeful, but they keep changing the rules all the time, so it's hard to predict.”

One thing everyone seems to agree on is that legalization has brought a lot of new users into the fold, many of whom now seem more open to exploring marijuana's medicinal benefits. “More and more people that have genuine medical issues are looking to it as relief for those medical issues because the stigma around it is not what it was,” says Moore. “Are they people that would have joined

the medical system? No, but suddenly they are on board and find relief and are like, ‘Wow.’”

A visit to one of Oregon's Finest dispensaries can be equally eye opening. After showing your ID, visitors enter a secure area that is both comfortable and tasteful, where they can see and learn about all of the different strains and different delivery methods. They carry patches, sprays, tinctures, rubs, massage and body oils and a variety of delicious-looking edibles ranging from gummy candies to caramel corn to cake balls. Everything is packaged with specific details on dosages and what is in it. There are also shelves of labeled jars, flush with well over 20 varieties of cannabis cov-

ering the spectrum of CBD and THC content. There are attendants on hand to answer any questions and help guide you to the best products for your needs. The whole experience is designed to remove any discomfort from the buying process for people who might have reservations, and it works.

Robbins is hopeful that the increased exposure to the medical benefits of marijuana will continue to grow the drug's acceptance and in turn fuel more education and research about its potential.

“Cannabis has been able to help me in ways that more traditional drugs have not, and I really think it can do the same for other wheelchair users who struggle with the same kind of issues I do,” he says. “It's time people start moving past tired old conceptions to embrace its potential and improve their lives.”

Fun fact

Portland now has 167 marijuana dispensaries overseen by the state and only 33 state-run liquor stores. MI



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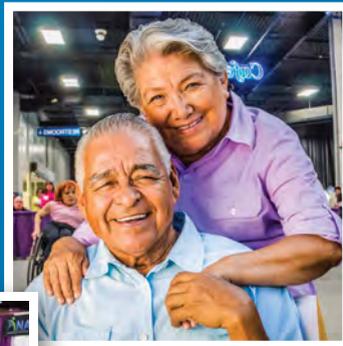



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Sept. 16-18, 2016

Bay Area
Nov. 18-20, 2016

DC Metro
Dec. 2-4, 2016

Toronto
January 20-22, 2017

Los Angeles
March 24-26, 2017

New York Metro
May 5-7, 2017

Chicago
June 23-25, 2017

MY TAKE

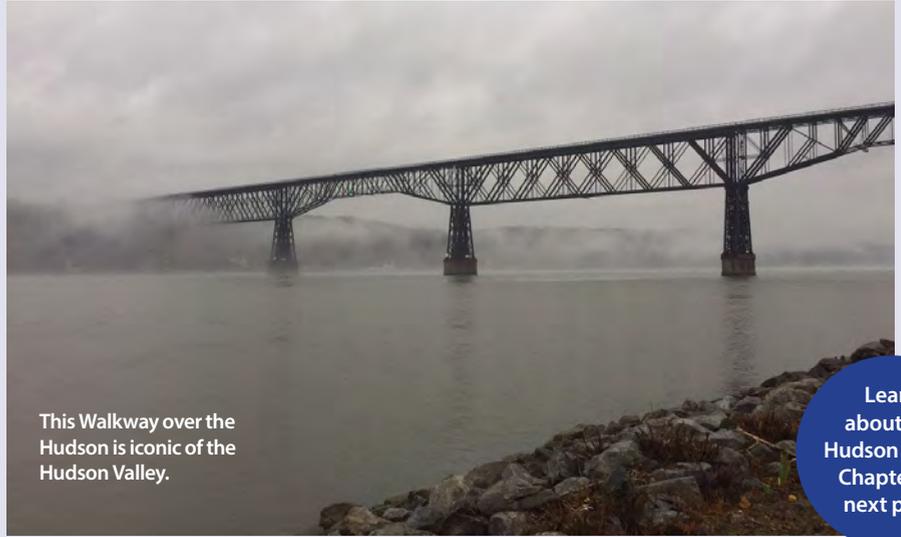
The Hudson Valley is blessed with a number of wonderful state parks, but there are two that really stand out for the breadth of their accessible options: Harriman State Park and Bear Mountain State Park. The two parks are located less than seven miles from each other and are bound to offer something you'll enjoy.

Harriman State Park has 31 lakes and reservoirs and a number of accessible options on the water, including fishing and kayaking. Bear Mountain State Park also offers lots of water recreation, including accessible boat rentals.

One of my favorite things to do is take a picnic to Bear Mountain and make a day of it with my family. There's a great zoo that is accessible, a newly renovated lodge and plenty to keep the kids entertained while the adults relax. While you're there, don't miss the breathtaking views of the Hudson Valley from the many scenic viewpoints.

SKINNY ON THE AREA

You'll hardly believe you're only 50 miles away from America's biggest, most urban city when you visit New York's Hudson Valley. I've lived in the region my whole life, for the last 13 years as a wheelchair user, and have grown to appreciate the bounty of nature and beautiful, accessible recreational opportunities.



This Walkway over the Hudson is iconic of the Hudson Valley.

Photo by Ziggi Landsman

Learn about the Hudson Valley Chapter on next page

PLACES TO GO

Whether you were a hippie, you love music or you just want to have a good time, don't miss the Bethel Woods Center for the Arts. Located on the famed grounds

MUST SEE, MUST DO

Walkway Over the Hudson: A non-profit transformed the abandoned Poughkeepsie-Highland Railroad Bridge into a beautiful state park and what is now the best way to handcycle, walk or roll across the Hudson River. You can't beat the views or the access.

Shopping: If you're done with the arts and culture, or just want to shop 'til you drop, the Palisades Center has you covered. The country's eighth largest mall also has a number of good restaurants. Another great local option is Woodbury Commons Premium Outlets, one of the country's largest outlet centers. The sprawling center is fully accessible and features just about every major shop you could want.

where Woodstock took place in 1969, Bethel Woods has transformed the once farmland area into a wonderful nonprofit performing arts center and museum with great, regularly scheduled concerts and lots of history without destroying the vibe that helped draw so many people almost 50 years ago.

They've made a real effort to make everything accessible, as seen in the solid seating options at the amphitheater, the accessible shuttle that can take you around the sprawling grounds in your wheelchair and well-marked accessible pathways. To top it off, the events are usually reasonably priced, so you don't have to break the bank.

If you're looking for good food and wine, you may want to check out the Culinary Institute of America, in Hyde Park, New York, or one of the Valley's many wineries. There are a number of restaurants on the culinary institute campus offering high end cuisine, and you will save a few bucks since the students and staff are also the chefs. The Valley's wineries aren't always fully accessible, but I've found the proprietors are very willing to accommodate wheelchair users and make it a great experience.

AVAILABLE HEALTH CARE

Helen Hayes Hospital in Haverstraw, New York, is the biggest and best rehab option in the area. With 155 beds, the hospital draws from a huge swath of New York. Thanks to a long history as one of America's earliest rehab hospitals, Helen Hayes has developed many beneficial programs for both inpatients and community members. I oversee our adaptive sports program which has year-round offerings in 17 sports (see Chapter Check In, next page). The hospital also offers peer mentoring and support groups.

GETTING AROUND

There are some accessible cabs in the area and even visitors can arrange for paratransit, but if you really want to get around and see the Valley, you're probably better off renting a vehicle. Metro North Railroad does have some accessible stations, making it relatively easy to hop a train and head into New York City should you desire. There are also accessible buses you can use to explore the region.

Hudson Valley Chapter: Instilling HOPE

The first two steps for almost any successful chapter are to develop and fully embrace a mission and then to figure out how to serve that mission. The Hudson Valley Chapter of United Spinal devised a great mission (with an even cooler acronym) — H.O.P.E — Health and wellness after SCI; Opportunity to fulfill goals and dreams; Peer support; Empowering individuals to achieve independence. Now they are working on fundraising to support an exciting new event to bring that mission to life.

That event is tentatively titled the Spinal Cord Injury Empowerment Weekend Retreat, and would consist of a three-day retreat on

President Matthew Castelluccio tossed out the following ideas: a keynote speaker on SCI research, panels on sexuality, and a dinner dance with local adaptive dancers.

“We’d invite individuals here for a three-day weekend where they’d be exposed to adaptive sports, lectures on research, seminars on wound care prevention, bladder management, equipment maintenance and more. They’d get the opportunity to stay here or at an area hotel and we would provide assistance for them,” explains Castelluccio. “It’d be a full experience for them. For many it’d be the first time out of their house, so that’d be a whole new experience. We want to give them a foundation of knowledge and experience to help them better adjust to their lives.”

Castelluccio, who has a C6 incomplete and T6 complete injury, says the chapter has been developing the idea since soon after its inception almost two years ago, and it is hoping to hold the event next spring or summer. He has done similar empowerment weekends with other organizations and thinks the chapter is uniquely positioned to have a big impact on attendees.

“Living with a disability myself, I try to think about where in my life there have been things I would have liked to know more about and things that would have been beneficial to me,” he says. “The retreat is a way to help individuals get those things.”

Castelluccio says the retreat will be open to people from all over the area, with around 11 openings to start with, depending on how much money the chapter can raise. The chapter is holding two major fundraisers this summer to support the event: a June 9 all-



Helen Hayes Rehab offered an adaptive baseball workshop this past June.

inclusive Zumba-thon; and a July 10 music festival at a local winery, featuring tastings, a raffle and more.

Beyond the Retreat

When he’s not helping plan the retreat, Castelluccio works as the adaptive sports and peer mentor coordinator for Helen Hayes Hospital. He grew up in the area, was injured in a motorcycle accident just miles from the hospital and rehabbed there, making him a natural fit for the position when it became available. He oversees a robust adaptive sports program in his dual roles with the hospital and chapter. With year-round offerings in 17 sports, including sailing, kayaking, skiing, waterskiing, yoga, bowling and much more, there is always something going on. Seeing people respond to the activities has been rewarding for Castelluccio.

“It’s been a great bridge to connecting with people and helping them connect with each other,” he says. “It’s amazing to see how some people who are not that into a support group environment react. When they come to a recreational activity that they enjoy, it develops into a support environment.”

With members located as far as six hours away, developing support communities where everyone can participate and feel comfortable can be a challenge. “We have to be a little more creative because our members don’t always have access to get down here for our meetings.” One solution Castelluccio has utilized is Skype, videoconferencing long-distance members into the chapter’s monthly meetings. “Our goal is to merge our two communities — inpatients and community members — so that the inpatients can learn from the community members. Skype is one way to do that.”

Find out more about the Hudson Valley Chapter at www.unitedspinalhudsonvalley.org or call 845/786-4590.



Handcycling is one of 17 sports offered.

the campus of Helen Hayes Hospital in West Haverstraw, New York, where members of the local SCI community would receive a comprehensive, education-filled overview of helpful topics and local resources.

The chapter’s board is creating a survey to seek members’ input on what specifically should be focused on and offered. Chapter



The Hudson Valley Chapter’s robust adaptive sports program builds community.

South Carolina: A Whole New Feat ... On Their Feet

Shouts of congratulations and waves of applause could be heard along the entire race route from runners and spectators alike as Marka Danielle Rodgers and Adam Gorlitsky walked in the 10k/6.2 mile Cooper River Bridge Run April 2 in Charleston, South Carolina. The unique reason for all of the support is that both of them have spinal cord injuries.

Rodgers, a C3-7 incomplete quad and an active member of the South Carolina Spinal Cord Injury Association, walked the bridge using E-MAG Active Stance Control knee, foot and ankle orthotic braces while Gorlitsky, a T9 complete para, used the ReWalk Exoskeleton. Neither of them had participated in the race before and figured this was as good a time as any to take on the challenge.

They were the first people with SCI to walk in the Bridge Run, ascending up the steep incline of the bridge and crossing the finish line with nearly 35,000 other participants – all while dodging early-morning raindrops. The two promoted their progress through social media campaigns and created T-shirts with the slogans “Purple Legs Up” and “I Got Legs,” respectively.

Purple Legs Up

Rodgers’ purple E-MAG Active Stance Control braces are not considered an exoskeleton, but are braces that can bend at the knee thanks to technology that uses sensors, gyroscopes and magnets. Crutches provide assistance while she is able to balance and walk with a natural gait. “As I step forward, I sense the vibration under my arms through the latissimi dorsi muscles and my ribcage,” Rodgers said, adding, “The vibration is how I know the crutch has hit the floor. That feedback tells me where I am in space.”

The 59-year-old Rodgers was classically trained as a ballet dancer before her injury and continues to teach and live by the ballet lifestyle. She said body awareness is so important. “You learn to understand what you can feel and how to use that for what you can’t feel.”

While working with therapists, Rodgers learned to balance herself using the Nintendo Wii Fit and balance board. Standing with a walker, she is able to do weight shifts and other exercises, and has created the same set-up in her home.



Sensors in the E-MAG allow Marka Danielle Rodgers to have better lower body awareness.

Similar to how this technology supports them while they walk, Rodgers and Gorlitsky had a team of supporters who stood with them along the way, including physical therapists from Roper Rehabilitation Hospital in Charleston. Physical therapist Kyle Cooper said both of them are hardworking individuals; they have the determination to accomplish what they’ve set out to achieve. Cooper appreciated when Rodgers was looking for additional challenges, and they would think outside of the box for new exercises. One idea included a trial run on the bridge’s pedestrian walkway weeks before race day, which she successfully completed.

Susan Newman, a faculty member who does spinal cord injury research at the Medical University of South Carolina’s College of Nursing, said, “Marka is one of the most hard working, determined people I have ever met. I never doubted for one minute that she would complete the bridge walk.”

Gorlitsky’s team included ReWalk’s CEO Larry Jasinski and a technician from the company. Friends and family also walked with him on the bridge. Noting Gorlitsky’s determination, “You have to be stronger than the average person to do this,” said Bridge Run director Julian Smith in a news article.

Completing the Bridge Run was a personal goal for the duo, but they also wanted to promote awareness to insurance companies — which do not cover these devices — showing this technology is beneficial to people with spinal cord injury to help improve their quality of life.

— ALEX JACKSON

I Got Legs

Working out in the gym is part of Gorlitsky’s ReWalk exoskeleton training. The 29-year-old appreciates lifting up on the pull-up bar and shooting hoops while standing. He describes his exoskeleton as a mash-up between Ironman and Terminator. To get into the “suit,” Gorlitsky transfers from his manual chair into the device by strapping braces to his legs. With a battery pack on his back and a watch-like device on his wrist, he presses a button to stand up, while another button activates the walking mode.

Gorlitsky guides himself using crutches, driving his hips forward. Sensors in the device measure the weight shift and kick in a motor to help move his legs. The former high school basketball player said, “Having the option to walk is an amazing feeling, and I feel a little more secure in my manhood.”

The ReWalk is a mash-up between Ironman and Terminator, says Adam Gorlitsky.





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LEARNING “YES” TO SAY YES

My Journey from SCI to a New Life



Over the first couple of years post-injury, I underwent an attitudinal shift that is continuing to this day. It is as if my wheels have set me free to think and be in the world in new ways.

BY STEVE DALTON

I am 14 years post-injury now, but I can honestly say that at five years post I had a better life after my accident than I did before it. Living with a T4 spinal cord injury made me do things I never would have in the course of my ordinary life. I have a circle of friends and colleagues that I would not have come into contact with were it not for my course-altering SCI. I began to live differently after my injury, and it wasn't just that I was now living with a disability. Over the first couple of years post-injury, I underwent an attitudinal shift that is continuing to this day. It is as if my wheels had set me free to think and be in the world in new ways.

About three months after going home from rehab at Santa Clara Valley Medical Center, my mom, who was staying nearby to help my then-wife, Tracy, and I with all of the post-

injury transitions, came to our house and said, "My friend just told me about a kayak program in Sausalito that can accommodate wheelchairs. Do you want to try it with me?" I thought to myself, "I never really wanted to kayak." Then, a comment made by an SCI peer named Kirk came to mind. He had said, "My spinal cord injury has taught me to say 'yes' more." So I said yes to Mom.

Following the kayak outing with my mom, I tried more and more adaptive sports. Over the next couple of years, I went water skiing, downhill mountain biking (also known as four cross), and snow skiing, along with trying the more traditional court sports of basketball, tennis, and murderball (rugby). On a rec therapy outing to a National Wheelchair Basketball Association tournament, one of the Denver players had said



Above: Flying a glider is an example of an activity Dalton probably would never have tried before his injury.

Left: Using a wheelchair is no obstacle to enjoying a hike over rugged terrain. It just takes practice, all-terrain tires, acceptance that falls may happen, and the willingness to try.



The author married his second wife, Sydney, in 2010, and they couldn't be happier.

to me, "I really learned how to use a chair when I started playing basketball." He told me he was five years post-injury before playing basketball. His words stuck with me as each adaptive sport I tried made me more familiar with my "new" body — teaching me new transfer skills when getting into the varied equipment, or giving me a greater mastery of my balance

and agility as I learned to execute the moves each sport required.

These adventures built my confidence as well. The Tahoe Adaptive Ski School, now Achieve Tahoe, had a banner in their ski hut that read, "If I can do this, I can do anything!" And into my second year as a para I really began to believe that for myself. But my relationship with Tracy, which had been a struggle for a while before my accident, didn't get any easier afterwards.

Finding the Path to Recovery

Due to issues of logistics and emotional trauma, Tracy wasn't there for much of my inpatient rehab. We lived two hours north of SCVMC, and she worked Monday through Friday, so the weekends were the only time she could come down to join in. Once there, she struggled to participate in the rehab sessions, admitting how hard this was, saying things like, "You used to be able to do anything, everything, and now you can't roll over without help."

It became that much harder when I told her that within the first week of my injury I felt as if my body had told me I wouldn't walk again. Her response? "I can't believe you're giving up! We're all counting on you walking out of the hospital,

and you're giving up." While for me that realization had allowed me to focus on the step-by-step process of rehab toward healing from my accident, for Tracy it obliterated all hope of recovery.

When I came home, we continued to wrestle with our responses to my paralysis. She was protective and scared for me because she had so little exposure to the gains I had made in the hospital, while I was ready to keep pushing my limits. When I got home, I wanted to try walking our two big dogs, so I leashed them up and wheeled out with them. Alone. As soon as we were around the corner, they pulled me off the sidewalk and into a hole in some deep grass. After about 10 minutes I figured out how to get out of my predicament and get home. For Tracy, this mishap was proof that things would continue to go wrong now that I was home, while I saw it as a triumph. After all, I made it back with the dogs, didn't I? A few months after coming home, at a local art and wine festival, she stormed off because I was practicing wheelies. "What if you fall out of your chair?" she seethed. "Someone will help me," was my simple, but insensitive, response. We just never got comfortable with each other after my SCI.

In early November 2003, I attended the Bay Area Abilities Expo. At this point in my recovery, I was essentially on par with my peers — driving on my own, done with outpatient rehab, and back to work. On the first day of the Expo I met a couple of members of the U.S. Women's Paralympic Fencing Team who were based out of Atlanta. They were at the event to do wheelchair fencing demonstrations. We kept bumping into one another, and over the next three days we struck up a real friendship. As accomplished as I thought I was, these women were at the next level. They routinely traveled the world for competitions, which was impressive since I had yet to fly with my wheelchair. I was enthralled by their stories of mishaps and creative solutions. More importantly, their attitudes impressed me; they lived as if they could do anything. They seemed unstoppable, and I wanted that for myself. Over dinner we agreed that my first flight would be to Atlanta.

Tracy and I were still not in sync leading up to our second Thanksgiving post-injury. Since the Expo I kept returning to

how uplifted and optimistic I felt with the Paralympians. It was such a contrast to how hard I had to work at home to keep positive about my recovery while trying to bring Tracy around to my way of thinking about our lives post-injury. I was insistent that I could do everything for myself and she didn't need to worry, but she just couldn't see the incremental steps I had made as successes. We still didn't have our old life back, and we never would. So, the day before Thanksgiving, I asked Tracy for a divorce. As difficult as that was, it arose from a faith that my life did not have to be smaller just because of my injury.

Embracing Independence and Growth

My first flight wasn't to Atlanta. Instead I flew to New Jersey, for my grandmother's funeral. My dad and I traveled together and successfully put to use all of the advice I'd solicited from SCI peers on how to go through TSA, gate-checking my chair, and boarding on an aisle chair. That experience was the perfect primer for flying alone in the future. Through 2004 and 2005 I did make that first journey, and several more, to Atlanta. Over the course of many long weekends staying with my friend, Carol, I learned how to live independently as a wheelchair user.



Learning to master his wheelchair showed Dalton he could master his SCI.

When I was there I inhabited her regular life. We spent time outdoors or at the gym, we went grocery shopping and ran errands, entertained at her house or went to visit friends. It was an effortless education in integrating life with a spinal cord injury with plain old life.

About that time I was asked by my original SCVMC physical therapist, Darrell, to come into a class he was teaching at a local medical college. He wanted to give the PT students in his spinal cord injury module the chance to practice their skills on real SCI clients rather than each other — “OK, now pretend you can't feel this.” ... Since the students would be doing muscle and sensation testing and I had not been in PT for

a while, I thought it would be a great opportunity to see how I was progressing, and if anything had changed for me and my injury, so I readily agreed.

On the day of the class, three other guys with SCIs and I spent the afternoon with about 25 PT students. None of us told them our level of injury or ASIA score; their job was to figure those out using their diagnostic skills and watching us move about on the mats or in our chairs. They swiped my skin with Q-tips and safety pins or asked me to “resist as hard as you can.” Towards the end of the class, the students put forth their hypothesis of our injury levels and the four of us revealed our diagnosed level of injury. The students were pretty close on mine. Their results confirmed my suspicion that although I had regained some sensation below my level of injury, there was no real functional neurological change.

“Give it a year,” I had been told by another peer. And I shared this with the students as we talked. I told them that although there was little change for me in terms of my injury, there had been tremendous change in terms of my ability. I became physically independent, responsible for all of my self-care, mobility, and household chores. More importantly, I had become comfortable and confident in my skin as a wheeler. I had more of a sense now of who I was than I ever had before in my life.

At dinner that evening, Darrell asked the four of us a question that clarified all that I'd been through in those initial years. “If there was a pill that would completely cure you of your injury, but the cost would be that everything you have learned and experienced since your injury would be lost to you, would you take it?” One of my companions blurted out, “Walking isn't that important!” I found myself in agreement that the cure would be a net loss.

When I decided to complete my long-neglected bachelor's degree in 2009, I learned that in the 1990s the field of psychology had coined a term for my companion's enthusiastic response and my reluctance to return to my pre-injury life. Psychologists use the term “posttraumatic growth” to describe what I went through. I came to value the unexpected rewards of how I learned to live my life following my spinal cord injury. The research identifies five possible areas of growth: an appreciation for life; a spiritual change; new ways of relating to others; personal growth; and/or the realization of new possibilities for one's life. In my own case, I can easily say three of the five came about quickly because of the experiences I had in recovery and the people around me who helped me figure things out along the way.

Recently I've been watching a lot of films about ultra-endurance events. *The Barkley Marathons: The Race That Eats Its Young*, *Desert Runners*, and *Inspired to Ride* all chronicle races in which the competitors are pushed right up to, and often beyond, physical and mental failure. Lazarus Lake, the founder of the Barkley, says towards the close of the film, “I think that people that go through this, they're better for it. They're not made of better stuff than other people, but they're better for what they've asked of themselves.”

While I'm certainly no SCI oldtimer, I feel like I have enough miles under my Kevlar-belted tires to suggest that Lazarus' words in relation to his ultra-marathon are similar to what I would say about myself.

MI



By Mark E. Smith

New Wheel Technology

The cliché is, “There’s no need to reinvent the wheel.” This has for the most part held true for ultralight manual wheelchairs, where only a few wheel innovations have dramatically improved performance over the decades. However, there are new wheel technologies that really have reinvented aspects of the wheel — with notable benefits for ultralight wheelchair users.

The Historical Issues with Wheeled Propulsion

In recent decades, as technology and social inclusion increased, ultralight wheelchair use also increased. In the process, the study of biomechanics in manual wheelchair propulsion became a field unto itself. Two primary findings emerged. First, ultralight manual

wheelchair propulsion in the long term can be hard on the body, where the traditional forward pushing motion has a correlation to joint strain, especially at the shoulders and wrists. Second, because ultralight wheelchairs traditionally use stiff frames, without suspension, they can prove very jarring, exacerbating such conditions as back pain and muscle spasms. So, how are new wheel technologies addressing these two significant issues?

When Backward Becomes Forward

Since the invention of the manual wheelchair, propulsion has been via a forward push of the drive wheels. After all, if you want to roll a wheel forward, you logically push it forward. This has been the method of mobility for millions, for centuries. However, biomechanically speaking, this hasn’t ultimately proven to be the best form. Primarily, only the triceps are used, and tremendous strain is put on the shoulder and wrist joints.

The engineers behind Rowheel, manufacturers of an aftermarket ultralight wheelchair wheel that can be propelled forward with a pulling motion, evolved a solution that dramatically improves biomechanics. The Rowheel uses sophisticated gearing within an ultralight wheelchair wheel, so that when you pull back on the handrim, the wheelchair propels forward. To steer, you counter-rotate the wheels, but in opposite directions of standard wheels. For braking, you press inward on the handrims. I realize this all may sound a bit counterintuitive, but once you try Rowheels, you will understand a simple



Pulling instead of pushing on Rowheels could prevent shoulder and wrist strain.

reality: they work extremely well.

The magic is in the “rowing” or pulling motion. Instead of using primarily your triceps and straining shoulder and wrist joints, the Rowheel keeps joints stable and uses your biceps, deltoids, traps, and lats — that is, approximately four times more muscles than during a forward push. The result is overall easier propulsion, with less immediate fatigue and better joint health over the years. Additionally, the biomechanics of pulling versus pushing intrinsically improves posture by allowing you to remain upright, with your shoulders thrust back during propulsion.

Beyond the biomechanics of Rowheels, built-in gearing allows approximately one-third farther propulsion per stroke. When you combine the gearing with the biomechanics of Rowheels, the result is dramatically greater efficiency in propulsion.

Rowheels are available in wheel sizes from 22 to 26 inches (in two-inch increments), and can be retrofitted to all major brand ultralight wheelchairs.



To use the Rowheel, you pull instead of push.

Put a Little Padding in Your Push

Another unintended problem that has developed with wheelchair wheels is the general lack of shock absorption. If you've spent any time on varied outdoor terrain, you know that no matter how high the quality of your ultralight manual wheelchair, the ride can be rough at best, teeth chattering at worst. For those prone to pain or spasms, the rough ride can exacerbate symptoms. Softwheel, a revolutionary wheel design, ingeniously addresses the need for shock absorption.

The Softwheel replaces traditional spokes with three shock absorbers that connect the hub to the rim. The wheel functions as a normal push wheel until it hits a bump. The shock-spokes then compress, allowing the hub to travel from the center of the wheel, where it absorbs the bump, then returns to the center. The secret to the Softwheel's success is that it uses a totally rigid rim and handrim, so there's no flexing or energy loss as you push. It's only when the wheel itself encounters an obstacle or bumpy



There are three shock absorbers that connect the Softwheel's hub to its rim. They're easy to install, too — just plug and play.

surface that the wheel rim compresses the shocks, enabling the hub to travel off center for absorption.

With the Softwheel weighing only 3.5 pounds, you get the benefits of true absorbing suspension without adding bulk to an ultralight wheelchair.

Available in 24-inch and 25-inch sizes, the Softwheel is plug-and-play on most ultralight wheelchairs.

Seeing is Believing

Both the Rowheel and Softwheel technologies are so simple in use, yet esoteric in design theory, that they're among those rare products where seeing is believing. Jump online and check out the videos — seeing how they work mechanically is fascinating. Also, if there's an annual Abilities Expo in your area, that's a great venue to test them for yourself. After all, when it comes to these mind-boggling technologies that actually improve our lives as wheelers, the one experience better than seeing them, is trying them.

Beware, innovation comes at a steep cost. Rowheels are listed at \$5,400 online, though different sites offered them for as low as \$3,495. The Softwheel ranges from \$2,650 to \$2,990.

Resources

- Rowheel, www.rowheels.com; 608/268-9760
- Softwheel, softwheel.technology

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Thirteen contestants, 13 weeks, one finally named 'America's Wheelchair Celebrity.' Sounds exciting, no?

By Allen Rucker

Wheelchair Celebrity Boot Camp

The time's they are a'changin' ... but not in the direction of scruffy ballads about peace and love. It's the brave new world of celebrities *uber alles*, and welcome to it. We crossed the threshold between fame and power with Ronald Reagan, and now we have obliterated it. The trend line is crystal clear — soon all public servants, from president to county auditor, will first be seen and celebrated in *People* before *The CBS Evening News*. Not just Reagan, Al Franken, Arnold the Governor, or this Trump fellow. All of them: mayors, governors, Supreme Court justices, the whole lot. Deal with it.

Political parties will now hold casting sessions to see which celebrity has the best chance of beating out another celebrity from the other party for any electable job. You'd begin the search with the show business bible called "Q Scores," basically a popularity poll to see who's the most liked. For instance, you wouldn't ask Bill Cosby or Miley Cyrus in to read for "U.S. Senator." Their Q Scores are at rock bottom. If you were smart, you'd probably only make one call — Tom Hanks. Is there a more humble, decent, honorable-seeming celeb in the world? Personally, I would also like to see the duo of Tina Fey and Amy Poehler in the running. They are as likeable as all get-out, plus they could good-cop-bad-cop poor Vladimir Putin.

You could fight this trend with honest, can-do political pros, but first, good

luck finding one, and second, you'd still lose. If you want good people in office, coax the celeb of your liking into running, and if he or she isn't available, create your own!

Which leads me to the connection between *Celebrity America* and wheelchair users like you and me. Unless you count the right-bending governor of Texas, there are no wheelchair-using celebrities of national import out there right now. If Christopher Reeve were still with us, he would be kicking Donald Trump's keister all over CNN, but it's not to be. As a community, we have to get pro-active and create our own, brand-new celebrities. The means for doing this is staring us right in our flat-screen faces — reality television.

The show I have in mind is called *Wheelchair Celebrity Boot Camp*. The setting is a big TV studio where contestants, all wheelers, must live and develop their God-given celebrity potential over a season. If *The Voice* can bring in "real" singers like Gwen Stefani or Blake Shelton to coach wannabe stars, then *Wheelchair Celebrity Boot Camp* (WCBC) can rope in "real" reality stars like any Kardashian in the phone book to teach the dark art of becoming famous by doing absolutely nothing! It's a rarified skill set: how to pose for the paparazzi — not wearing undergarments is a great start; making the right kind of bimbo celeb friends to lure TMZ into following you

around for no reason; and most of all, just believing in your inner star-ness, otherwise known as pathological narcissism. Thirteen contestants, 13 weeks, one eliminated per week, one finally named "America's Wheelchair Celebrity." Sounds exciting, no?

Now that you can bill yourself as a self-made celeb, beholden to no one for your justifiable self-importance, you quickly morph into a self-made politician who plays by no one's rules but their own. With your WCBC earnings, dozens of product pitches for "winners!" and wall-to-wall free media coverage, your campaign will fund itself. If you run into money problems, your legions of fans will foot the bill.

Even if your opponent is Tom Hanks, God forbid, and you lose — hey, once a celebrity, always a celebrity. You write books, take a regular seat on *The View*, and of course become a wildly popular coach on *Wheelchair Celebrity Boot Camp*.

Bottom line — the ultimate inclusion in America society is celebrity inclusion, and this is but one way to jumpstart it for wheelers. Maybe your way is make it big as a hotelier, develop a killer smirk, and marry great-looking airheads. In America anyone, absolutely anyone, can become famous, then become famous for being famous, then become a power broker.

Yakov Smirnoff said it best: "Whadda country!"

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We tweeted:

@MeBeforeYou says we're better off dead than disabled. That's wrong. Share pics and show them how you #LiveBoldly.

And here's what you shared:

cherry @oherryrae · Jun 3
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Dan & Jen Diggmann @DandJenDig · Jun 2
After we both got MS, we were married, earned our M.A. & inspired others. #LiveBoldly @NewMobilityMag @mebeforeyou



Ingrid Tischer @IngridTischer · May 27
@NewMobilityMag @mebeforeyou says #pwd suicide = #LiveBoldly. Silly me, I prefer wed to dead. #MeBeforeEuthanasia



Photo by Jamieson Dean

Featured in the article, Tim Rose and his wife founded the Rose Centre for Love, Sex and Disability in 2011.

SO ... CAN YOU HAVE SEX?

It's the question every nondisabled person wants to know. Now, when they bug you for an answer, send them to, "How People With Disabilities Have Sex." Published on Broadly, Vice.com's feminist channel this past September, it's making the rounds again and we shared it on our Facebook page on June 11. Our fans got creative with their comments:

Darren Sheens: It's usually in the top five questions, people are curious creatures. My partner has a shirt that says on the front, "NO, I'm not his carer," and on the back, "Yes, we do have sex."

Billy Lee Sharkey: Who asks that question? If asked, just say, "Get naked, I'll show ya."

Mystie Brook: My sexual preference is often. (The sticker on my wheelchair.)

Tony Hopstetter: I usually say, "once you go gimp, all others are limp," and that shuts them up.



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