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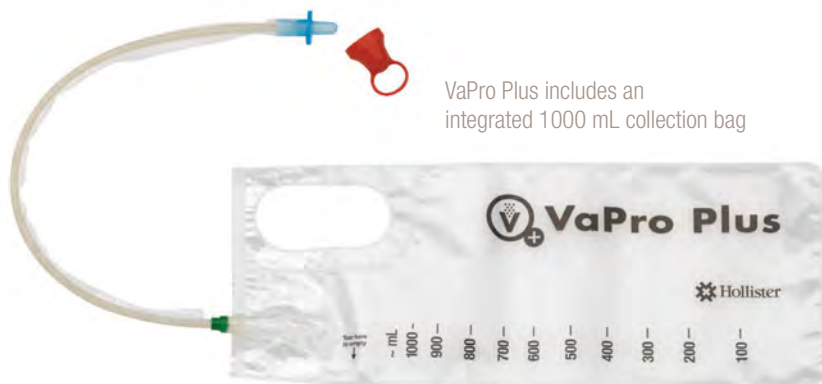
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FEATURES

**16 MOJAVE TALES** Two different driving stories, two different eras, one scorching desert. BY LEE GOLDSTEIN and CHERI VALLE

**21 NEW CHAIR ON THE BLOCK** NM asked four wheelers to test out the stylish new WHILL. Here's what they say. BY TIM GILMER AND IAN RUDER

**29 VLOGGING** A primer on video blogging — whether creating or watching — plus profiles of seven prolific vloggers. BY ROXANNE FURLONG

**53 KENYA'S KENNEDY** Artist, philanthropist, Facebook phenom: Kennedy Nganga, a C3-4 quad, loves his art and his people. BY MARK J. BOATMAN



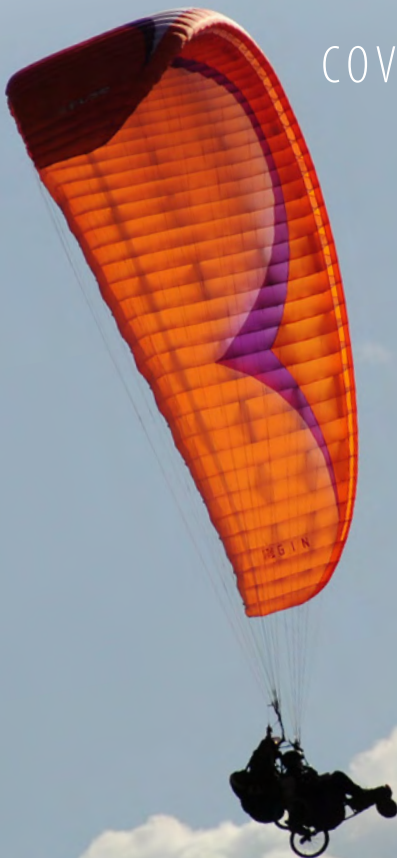
COVER STORY **OUTDOOR RECREATION: YOU CAN DO IT** 32

Admit it: if you knew you could jump out of a plane and land safely and not have a heart attack in the process, wouldn't you want to at least consider skydiving? What about paragliding, sailplane flying, and hang gliding? Soar with the eagles! Prefer water? There's whitewater rafting and surfing. Skimming over treetops? Ziplining! BOB VOGEL shows us how to do all of these safely, with little or no experience.

Cover Photo Courtesy of Jackson Hole Paragliding  
Contents Photo by Olivia Pelton

DEPARTMENTS

- |                        |                       |
|------------------------|-----------------------|
| 4 BULLY PULPIT         | 14 EVERYDAY ADVOCACY  |
| 5 CONTRIBUTORS         | 45 SPOTLIGHT          |
| 6 LETTERS              | 46 UNITED SPINAL NEWS |
| 8 NEWS                 | 58 OUTDOOR TRACKS     |
| 10 SCI LIFE            | 60 RAISING A RUCKUS   |
| 12 EAT WELL, LIVE WELL | 64 CRIP BUZZ          |





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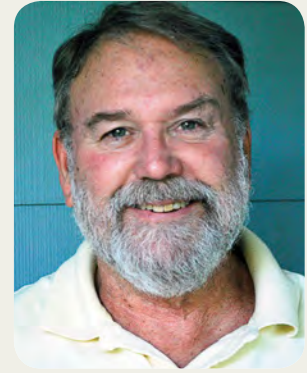
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# ( BULLY PULPIT )



## Outdoor Adventure for Wimps

August. Time to go into the wild. Test your courage. But if you're like me, you may be inclined to decline. I'm a certified stay-indoors wimp. People think my bald spot is due to age. Truth is, it's a terminal case of "recliner cap." But in the spirit of this issue, I've decided to take you on a tour of my Five Most Daring and Stupid Courageous Stunts.

### Head Planting

I used to serve on the board of SOAR — Shared Outdoor Adventure Recreation. On a monoskiing excursion, I drove four of us — all disabled — up a mountain. At 4,000 feet we encountered icy roads and falling snow — "Chains Required." I had never put chains on, and as a card-carrying para and wimp, I wanted someone else to do it. Peter, who had CP, couldn't hold his hands still enough. Max, the quad, had a better excuse than I did. That left José, the blind guy. Don't laugh. He was the mechanical wizard of the group. Houdini with hands. He worked his magic and we drove on. Then came the challenging part: I also had zero experience skiing. My best events were Ski Lift Wipeout, Shoulder Jamming and Extreme Head Planting.

### Bee Rescuing

Water sports are more my style. I love to float on my back and turn lazy somersaults underwater. But in the country where I live, there is still a sizable bee population, and for some reason they all want to swim with me. To protect myself and save them from drowning, I developed a kind of Kung Fu approach, believing I was somehow immune

from getting stung. I let them climb onto the back of my hand and did the one-handed sidestroke to the deck and placed them in the sun. Until I met an African bee who did not believe in Kung Fu.

### Stinging Nettle Surfing

I used to own a three-wheel all-terrain cycle for getting around on my property. Driving on sidehills requires caution, smarts, and skills. But I am deficient in at least one of these areas in any given moment. So I put a lot of time in practicing tumbling. Tumbling into thistle patches, bogs, poison ivy and stinging nettle. I never did find the kind of all-body spacesuit needed to stay free of welts, rashes and bruises.

### Mole Tossing

Moles enjoy the run of my property, so once in a while, just for fun, I attack them. Nothing works. One day I shoved a hose down a hole. It worked! A wet mole popped his head out, my golden retriever grabbed him with his soft mouth and dropped him on my leg. The powerful claws dug in. I screamed, tossed him frantically over my head and watched as he landed on the roof, rolled down and landed in my lap again. Moles always win.

### Wheelchair Rocketry

Ever try rolling as fast as you can downhill on a warped sidewalk and watching stupidly as your footplates bottom out? If you like being launched, I highly recommend it.

— TIM GILMER

# (CONTRIBUTORS)



AUGUST 2015

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Kirk Williams fell in love with a camera early on. After he broke his neck and became a C6-7 quadriplegic in 2009, things changed. But as an explorer and adventurer at heart, Kirk adopted aerial photography as a tool to get out there and experience as much as he can. He is founder of Birds Eye Optics and hopes to travel the world and share with others his unique experiences and belief that following what you love is what life is all about. For more images, check out [BirdsEyeOptics.com](http://BirdsEyeOptics.com).

Having retired at 50 after working in the computer industry for 30 years, Cheri Valle, now 62, stays busy as a board member of her local humane society. She also loves gardening and has a Victorian dress collection. She was born with spinocerebellar ataxia, a progressive neuromuscular illness, and started using a wheelchair 12 years ago. She has lived in Colorado most of her adult life, raised three children as a single mother and now lives in the Four Corners area of Colorado, which she dearly loves.



Koti Hu is a former independent professional recording musician, composer, and songwriter with three studio albums to his credit. In July of 2007 he sustained a C4 complete SCI when he was rear-ended by a pickup truck while stopped at a freeway onramp in Redmond, Wash. He now volunteers for a number of SCI peer support organizations, and is making a return to the music business. He is currently tracking his first single since the accident.

A writer, advocate and community organizer, Kenny Salvini went from being a top-tier athlete to a C3-4 complete quadriplegic after a snow skiing accident in February of 2004. His blog chronicling his struggle to adapt to life in a wheelchair — “Typical Guy, Atypical Situation” — became a viral hit in 2005. Most recently, he co-founded The Here and Now Project, a social support network for paralysis survivors and their supporters in the Northwest.

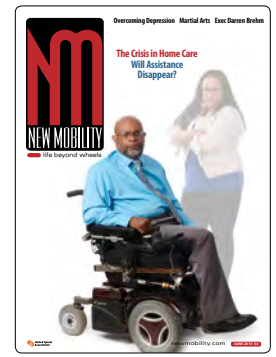


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# LETTERS

Clean, clear copy on the most relevant debate today for people with disabilities!



## Clarifying the Issue

Clean, clear copy on the most relevant debate today for people with disabilities! ["The Crisis in Home Care," June 2015]. I've been saying all along that my ADAPT peeps got this one wrong.

Michigan's legislature deemed it unlawful for our workers to not get overtime if they worked 40-plus hours way back in 2006! In our case, ADAPT is right that agencies have responded by capping hours at 40. I'm sure that's what will happen everywhere if all the agencies involved don't come together to raise the pot soon. This has undoubtedly necessitated the unwanted reconfiguration of some care plans and, to be honest, I'm sure some workers were unable to remain in the profession due to the cap. But those who really felt strongly that being a PCA was their calling — and teams of clients and aides who refused to be broken up — have found a way to work it out and remain together.

My aide works 49 hours for me, directly through Self Determination for 40 hours (at a higher rate than the agency pays), and through an agency for an additional nine hours. Another alternative, albeit inconvenient, is to have the aide work for two agencies. ADAPT got it wrong saying the sky is falling, but it's also true that the DOL didn't think this one through.

*Clark Goodrich*

*Founder, Grand Rapids ADAPT*

## More Than We Can Pay

This article is a good analysis of the situation ["The Crisis in Home Care"]. I'm sure that nearly everyone who has to hire a PCA has had the experience of answering a call from a recently posted "Help Wanted" advertisement where the caller goes into a rant wondering how I have the unmitigated

gall *not* to be paying \$18-\$20 per hour. I believe that a good caregiver is worth twice that — 10 times that — but I did not have that as a possibility to offer. Very few people ever would.

*Lisa Stapp*

*Via Facebook*

## Don't Want DOL Rule

My aides can work for two different agencies at once here in Minnesota. We are more fortunate in that PCA wages are higher here than some other states. I need 24-hour care. Staffing with the 40-hour rule made scheduling a nightmare. My aides *want* the 48-hour no overtime rule. If they don't get 48 hours with me, they cut their hours here. They go work for clients at agency B, plus me. This makes staffing and back-up a nightmare. I have never been in a nursing home in my 34 years on a vent. That is not going to change, either. That is how this debate affects me.

*Ines Gaudet*

*Via Facebook*

## Leave Us Alone!

Can someone better explain how this Home Care Rule, which will result in a general reduction of income for home care workers like me, produces a better and more "stable" work environment for us? Already most traditional home care agencies are capping work hours at 40 in anticipation of the rule change, and there's nothing compelling them to do otherwise, even if more money is added to the pot (which will not likely happen in the long run given the reality that the majority of us are immigrant women of color with little political clout). Please find some other community to rescue! Keep your fair wage and let us earn a *living* wage.

*Philip Zweig*

*Via Facebook*

## ABLE Act: A Good Thing

This type of legislation ["Why We Fight: The ABLE Act," United Spinal section, June 2015] is extremely important to the disabled community. It is fantastic that the hard work of so many individuals and agencies managed to get it passed. Unfortunately, it is limited to folks who were disabled at or before the age of 26 and leaves millions of other individuals without the ability to save money to replace their worn-out wheelchair van or repair the leaking roof on their home. With the asset limit at \$2,000 for Medicaid, the vast majority of disabled people are one problem away from ending up in an institution. Hopefully, the random choice of age to qualify may be reconsidered in the future.

Congratulations to all the young folks who can now save for college or to purchase a new home. It's wonderful for families to know that down the long road of disability their aging children may be able to obtain needed equipment and technology to live a more comfortable life.

*Thomas McNamara*

*Via newmobility.com*

## Real People, Real Magazine

I've been reading NM for more years than I can remember. Your covers and articles continue to be creative, honest, evocative and constant, realistic. We are real people with real disabilities and challenges that affect us physically, psychologically and spiritually. You offer amazing stories of recovery, struggle, survival, and our continuing fight to be seen as equal with accessibility everywhere. Please continue to inspire, inform and educate each of us!

*Teddy Lilley*

*Brea, Ohio*





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to win a free VMI conversion!

## United Spinal Appoints James Weisman President/CEO

On July 9, United Spinal Association announced James Weisman, current vice president and general counsel, as its new president and CEO.

Weisman is a dedicated advocate who for over 38 years has helped expand disability rights and ensure access to transportation for wheelchair users in New York City and across the country. He will replace Joseph Gaskins, who will take on the role of vice president for Strategic Development.

"We are very fortunate to have an individual with the experience and reputation of Jim Weisman; someone with a long history and track record of success, who can lead the organization and build upon the solid foundation we have established," says Gaskins.

"It is my honor to accept this new challenge and follow in the footsteps, or tread marks, of those dynamic, skilled and dedicated leaders that have come before me," says Weisman. "It has been my privilege to have worked for and with many creative and committed individuals who taught me that inclusion and integration of people with disabilities into the societal mainstream is a worthy personal and organizational goal."

Weisman has worked for United Spinal Association, formerly Eastern Paralyzed Veterans Association, since June 1979. He played a role in framing the Americans with Disabilities Act and took part in the signing ceremony.

Weisman helped craft United Spinal's lawsuits against the New York MTA and the Philadelphia transit authority, leading to improvements to bus and subway

accessibility and the creation of a para-transit program. Weisman was also central in the negotiations that have led to more wheelchair accessible New York City Taxis.

The settlements he helped achieve in New York and Philadelphia served as the model for the ADA's transportation regulations, opening transportation options for millions of Americans with disabilities.

## Inaccessible Food Truck Protested

Austin, Texas' Veracruz food trucks are known for their all-natural Tex-Mex offerings, and unfortunately also for being parked on lots of rocks and gravel, and having super-high windows that no wheelchair user could reach. In fact, Texas ADAPT activists complained they couldn't even be seen from the food truck windows.

But after 30 ADAPT activists showed up

## People in the News: Brandon Coats: Fired for Using Medical Pot

Brandon Coats thought holding a state-issued medical marijuana card meant his job was safe from random drug tests. Even though he did nothing illegal, he was wrong.

On June 15, the Colorado Supreme Court unanimously ruled that Dish Network was within its rights to fire quadriplegic Brandon Coats when he failed a random drug test in 2010,

even though he has a medical marijuana card and was never under the influence at work. Although marijuana is legal for both recreational and medical purposes in Colorado, it is still illegal under federal statute and employers can still have zero-tolerance drug policies.

"I'm obviously pretty disappointed as we've been fighting this case for five years," says Coats. "But it's not a total loss, because

before my case came into the media, nobody was talking about employment and medical marijuana."

Coats, 35, became a quadriplegic 19 years ago. After building a tolerance to traditional painkillers, he turned to marijuana to treat worsening spasms. "It calms my muscles down and I'm able to sit and do my normal daily things." He says nothing he has tried has been nearly as effective as marijuana.

Coats has set up an advocacy page on Facebook and is trying to educate state legislators on his situation and urge them to introduce new legislation to protect medicinal users from being fired. "We're talking millions of people now who aren't going to be able to find work unless they find an employer who is OK with them using marijuana. We can't have people here in America unemployable because they need a medicine."



Photo by Donna Scharfenberg

111,804

NUMBER OF MEDICINAL MARIJUANA CARD HOLDERS IN COLORADO

1,137,069

NUMBER OF MEDICINAL MARIJUANA CARD HOLDERS IN 19 MMJ STATES

— PROCON.ORG (OCT. 2014)



Food trucks are becoming increasingly popular in Austin and very many of them are inaccessible.

at one of the trucks on June 22 demanding better accessibility, Veracruz installed a ramp for that truck.

"We want everyone to be able to access our truck equally and as perfect as everyone can," said the daughter of the food truck's owner, to KVUE television.

Although Veracruz' accessibility is now better, the broader problem of inaccessible food trucks is getting worse, say activists.

"Initially there were just a handful of food trucks out there, but it has become a huge trend in Austin," says Renee Lopez of Texas ADAPT. "It has now become an issue of discrimination."

Julie Espinoza, another food truck protestor, says the accessibility issue isn't complicated to fix. She wants to see a lowered drive-thru style window where

customers with disabilities can get service. "It's ridiculous for mom and pop places to spend \$40,000 on a vehicle for public business and not think of customers with disabilities," she says.

### Lilypad Home Wheelchair Scale

The new Lilypad Scale, launched in June, is the first scale marketed for home use by wheelchair users.

Since there has not been a wheelchair accessible scale for in-home use before, many wheelchair users have only been able to weigh themselves infrequently at widespread medical clinics or hospitals, or worse. "We've heard stories of people using dog scales at their vet or a package scale at their local furniture store," says Lilypad co-founder Molly Farison. "One person even told us about using the morgue scale in the hospital they worked at."

The Lilypad is a 7-pound foldable foam pad with sensors that interface with a smart phone app. To use it, have someone push your wheelchair onto the pad so the app can register the weight of your wheelchair. Then, roll yourself back onto the pad, have

someone mark where your wheels are and attach sensors. Once it is completely set up, you simply roll to the same spot each time, and the app gives you your weight, first subtracting the weight of your chair.

For more information contact Lilypad Scales, 855/590-5459; www.lilypadscales.com. Retail price is \$628.

### Budget Impasse Closes Illinois CIL

Over 300 Illinoisans with disabilities went without the vital services of Northwestern Illinois Center for Independent Living after it temporarily closed on July 2 due to the state's ongoing budget impasse.

"We have to tell people we can't serve them," said Michele Miller, executive director of NICIL. "We can't incur or send in any expenses. As soon as the budget starts again, we can get back to work."

The center, in operation for 30 years, provides advocacy, peer support, community reintegration, independent living skills and personal assistance. Their current contract with the state of Illinois ended on June 30. A new contract can't start until a state budget is passed.



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By Tiffany Carlson



"It is the most all-inclusive sport there is."

### Rowing Is Her Passion

Now a six-time Guinness World Record holder in rowing, Angela Madsen, an L2 para, knew nothing about rowing when growing up in Fairborn, Ohio. But she did love swimming and diving. "I've been an athlete all my life," she says. "I was 6 feet tall by the time I reached sixth grade."

After high school she joined the Marines and was stationed in California. "I took up surfing, which kept me from moving back to Ohio." She also joined the Women's All Marine Corps basketball team, but she was injured during a game.

"I fell forward and someone landed on my back," says Madsen, now 55. "The accident ended my military career, but I could walk." Thirteen years later, her back needed surgery, but a mistake occurred. "The wrong disc was removed and my spinal cord was compromised in the surgery."

Madsen credits adapted sports for her ability to move on. "I was two years post-op before I found out about adaptive sports," she says. She started with wheelchair

basketball and then discovered rowing, winning gold in the Rowing National Championships 2000 through 2008. In 2008, she made her Paralympic debut, placing seventh in Rowing. She also returned to the Paralympics in 2012, winning gold in Shot Put.

Along the way, Madsen discovered ocean rowing. She's crossed several oceans nonstop without a support boat, including the Atlantic Ocean and the Indian Ocean — and she circumnavigated Britain. She also plans to attempt a Pacific Ocean crossing in 2017, something that has eluded her thus far.

Madsen's latest passions, coaching adapted rowing and running her two foundations — Row of Life and California Adapted Rowing Programs — are keeping her busy at the moment. She wants to promote rowing's versatility, she says: "It is the most all-inclusive sport there is. People can participate at any level."

More about CARP: [www.carplb.net](http://www.carplb.net)

### Bruise Mystery Marker

"Every superhero needs a suit." This is the mindset behind Bruise, a bruise detection suit created by engineering students at the Royal College of Art in London.

This unprecedented suit is made for athletes with spinal cord injuries who are unable to feel when they've hurt themselves below their level of injury. Everything from fractures to bruises can go undetected, but this suit helps these athletes know exactly where they're injured.

Bruise works by being a tight, flexible top and pant. In all of the high-risk areas of the body, disposable made-to-fit film inserts are located, which turn red when pressure is applied. The color density varies according to the pressure level applied.

These inserts are specifically located on the thorax, pelvis, femur, knees, fibulas and tibias on both legs. And with the suit revealing color right away, it may finally be possible for paralyzed athletes to get help sooner rather than later. To learn more about Team Bruise, visit: [designandviolence.moma.org/bruise-team-bruise](http://designandviolence.moma.org/bruise-team-bruise).



### The Alt Guide to Living with SCI

Finally, a fun and humorous guide to life after SCI is available to newbies and those looking for a refresher. Called *The Very Alternative Guide To Spinal Cord Injury*, this guide shares first-hand experience, "questionable humor" and time-saving pictures.

Order here: [veryalternativeguides.com/spinal-cord-injury](http://veryalternativeguides.com/spinal-cord-injury)

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# EAT WELL, LIVE WELL

## Eat Well and Get Fit!

We all know that eating well and working out are essential to good health — and this couldn't be more true for people with SCI. Numerous studies show that including certain nutrients in your diet and exercising regularly can help you along your journey to improve your strength and endurance, reduce pain and depression, and prevent the development of conditions such as cardiovascular disease and diabetes. Also, healthy diet and exercise can keep you looking good and feeling great, as well as enhance your independence and overall quality of life!

What are the physical activity guidelines for adults with SCI? Researchers recommend that healthy adults with SCI should participate in at least 20 minutes of moderate-vigorous aerobic activity two times per week, as well as strength training exercises two times per week. These are the first evidence-based guidelines to be developed specifically to support people with SCI in improving their physical fitness.

Here are some tips for what you should eat to fuel your body for aerobic exercise and strength-training:

- **Aerobic exercise:** The preferred energy source for any cardiovascular exercise is carbohydrates. To help prevent fatigue and replenish energy stores eat approximately 30 grams of complex carbohydrates one hour before exercising. If working out intensely, eat 50-70 grams of carbohydrates 30-60 minutes after working out. Healthy complex carbohydrates sources include oatmeal, whole grain bread, low-sugar energy bars and bran muffins.
- **Strength-training:** When doing strength training exercises, your body has greater



protein requirements in order to help build and repair muscle. Eat 20 to 30 grams of whey protein 30-60 minutes after working out. A whey protein smoothie is a fast, easy and delicious way to do this — one scoop of whey protein equals approximately 25 grams of protein.

Good fats and water are also critical to optimize both types of exercise.

**Good Fats:**

- increase delivery of oxygen and nutrients to muscles
- increase aerobic metabolism
- reduce inflammation in tissues/muscles, therefore helping to speed recovery time after weight training

Good fat sources include fish, avocados, nuts and seeds. Omega-3 fatty acid supplements are another great source.

**Water:**

- delivers required nutrients, oxygen and hormones to cells
- helps regulate body temperature
- reduces risk of dehydration

Drink at least six to eight cups of water or herbal teas a day.

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*Joanne Smith and Kylie James are co-authors of the book, Eat Well, Live Well with SCI and Other Neurological Conditions. For more information on nutrition for neurological injuries go to [www.eatwelllivewellwithsci.com](http://www.eatwelllivewellwithsci.com).*



By Joanne Smith and Kylie James



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# EVERYDAY ADVOCACY

## Historic Properties



By Michael Collins

**Q.** *My wife and I enjoy visiting a variety of parks, but last year we had a frustrating experience at a rustic park lodge. I use an electric scooter, so when making reservations for lodging I always ask questions about accessibility. We knew that this particular facility had been built early in the last century, but we really wanted to stay there.*

*There was limited accessibility in the main lodge, a log structure. Access was only provided to reach the restaurant and a restroom adjacent to it. There were no accessible guest rooms in the lodge. Our reserved room was located in a nearby cabin that was reached via a boardwalk that also led into the park. A leisurely "stroll" around the park was impossible, as there were stairs on the route. When asked why the entire facility was not accessible, the manager said that it was a historic property, so they didn't have to make such improvements.*

*Something similar happened a couple of months later at a history museum located in a former county courthouse. It was not possible to enter with my scooter — every entrance had steps. The volunteer at the information desk said the museum was exempt from the ADA because the courthouse was on a roster of historic buildings. Later, at home, I visited the National Park Service website and found the National Register of Historic Places. The park lodge was listed there, but the courthouse was not. Even if it had been, aren't there requirements that these historic properties be made accessible to people with disabilities? What more could I have done?*

— Locked out

**T**he status granted to historical facilities was not intended to be a blanket excuse to avoid provid-

ing necessary accessibility. Instead, historical properties are required to comply with the applicable accessibility guidelines to the maximum extent possible. If such improvements would threaten or destroy the fundamental historical significance of a property or cause undue financial hardship, the owners or operators must still find a way to provide alternate means of access for disabled visitors.

However, facilities listed on the National Register of Historic Places or similar state and local registries are allowed to use some alternative standards that may result in a reduced level of access, such as creating an accessible entrance somewhere other than the main entrance; using a steeper ramp than is normally allowed; requiring accessible routes only on the level of the accessible entrance; and getting by with only one accessible restroom. Alterations to the facility must also be accessible per the applicable architectural guidelines to the extent possible, even if the property is historical in nature.

When you are given the excuse that some place is exempt, it can be confirmed by checking with the State Historic Preservation Office, as those offices are responsible for approving applications that are submitted for inclusion on the national registry. If a property is not approved for the national registry, the state office may still have a record if it is on a local or state registry.

You took an important step by questioning the lack of access, and the reasoning for why those properties were not accessible. Once that is determined, it can be useful to have someone to

consult with regarding access requirements and possible violations of federal or state laws. There are ADA Technical Assistance Centers assigned to each region of the country; they can help determine what regulations cover a particular property, and whether potential violations have occurred.

If the facility does not comply with applicable laws, it may help to have someone knowledgeable to serve as a representative if you want to file an ADA complaint with the Department of Justice or a state civil rights agency (for violation of state laws). Each state or territory also has an assigned Protection & Advocacy agency to protect the rights of people with all types of disabilities. There is no charge for their services. And depending on the situation, private law firms may also be interested in handling such cases through the judicial system.

Thanks for your help in assuring that historical properties will be accessible for all of us when we want to visit.

### Resources

- National Register of Historic Places: [www.nps.gov/nr/research](http://www.nps.gov/nr/research)
- State Historic Preservation Offices: [www.nps.gov/nr/shpolist.htm](http://www.nps.gov/nr/shpolist.htm)
- ADA Standards for Accessible Design: [www.ada.gov/2010ADAstandards\\_index.htm](http://www.ada.gov/2010ADAstandards_index.htm)
- ADA Title II Primer: [www.ada.gov/regs2010/titleII\\_2010/title\\_ii\\_primer.html](http://www.ada.gov/regs2010/titleII_2010/title_ii_primer.html)
- ADA National Network (for technical assistance): [adata.org/national-network](http://adata.org/national-network)
- Protection & Advocacy agency network: [ndrn.org/en/about/paacap-network.html](http://ndrn.org/en/about/paacap-network.html)





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### Crossing the Border

By Lee Goldstein

It was 1950, and I had never been in trouble with the police until this year (except for when I was 9 and threw a clump of mud at a shiny black car which turned out to be a plain-clothes cop car). Yet in the next month or two, I would be fleeing from the California Highway Patrol with two ladies who were on the lam with me.

My dad had just read a *Life Magazine* story about an amazing university in California that was encouraging wheelchair-user enrollments, one of the first universities in the nation to do so. The article explained that there were curb ramps, classes which could be moved downstairs, and even elevators in some newer buildings on campus. UCLA's resolve to provide opportunity to wheelchair users, particularly vets who had

served in WWII, put it at the forefront of disability awareness. And Southern California had perfect weather for such an undertaking.

I was 18, a partial quadriplegic from a diving accident, and a new high school graduate from the small town of Winnetka, Ill. Suddenly the family, except my mom, was excited about sending me all the way to Los Angeles. The question was how the devil to get me to California with my chair, medical equipment, full body braces for exercise, and little knowledge or experience in how to drive over 2,000 miles in the new hand-controlled Oldsmobile Dad had bought me months before.

Well, my folks found an answer, such as it was. I had a gorgeous physical therapist, Helen Steinhour, who had become a close friend of our family after working on strengthening my arms for the last four years since my accident. Not only was my

family in love with her, even I had a terrible crush on this woman who had movie star looks and charm. And as it turned out, she needed a ride to California to visit ailing relatives there.

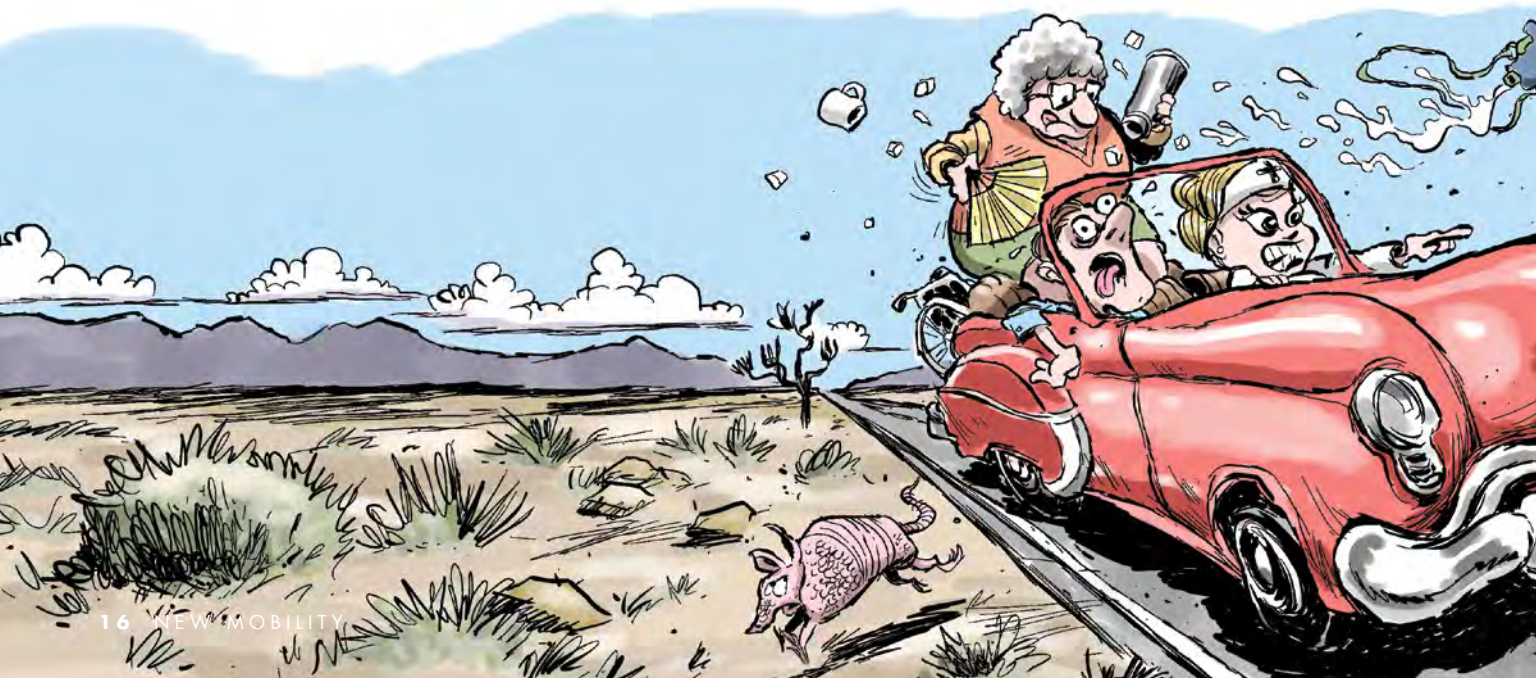
My mother volunteered to go if Helen would accompany us to help with my needs and do some of the driving. So it was settled. The three of us — Mother, who didn't know how to drive, but whose job on the trip was to dispense iced tea to keep me hydrated, and to read maps backward and constantly try to send us back to Illinois; Helen, whose duty was sharing driving with me and to continually remind me to shift off my tender behind, and who wiped my eyes when she saw me secretly crying from the torture of leaving behind my long-time high school sweetheart; and there I was, already suffering from a terrible case of homesickness and sadness of leaving friends and the only home I'd ever known. And the

trip had only just started!

But the most amazing time of that already eventful, sometimes hysterical trip happened the second-to-last day. It was my first incident of running from police. And it happened this way.

We were about to enter California's Mojave Desert in the middle of summer on historic Route 66, and it had grown uncomfortably hot. The car was not air-conditioned — it was long before that comfort was available in cars. Helen was driving as things got worse for me. Like many quadriplegics, I could not take heat, nor could I sweat to reduce body temperature. Mother kept wiping me with cool water from a thermos, and when she ran out of that, she began feverishly using a thermos of iced tea.

We raced toward a motel we had picked out in a guidebook. It was the only one shown for the next 100 miles. It was just inside Cali-



fornia. By the time we neared the California border, I was on the verge of passing out. I was unable to hold my head up and was fading in and out of consciousness. I thought I heard Helen yelling, "Lee, hold on ... it's only 10 more miles! It *will* be air-conditioned!" Sounded like she was trying to convince herself that it would be air-conditioned, since the book did not specify.

Then I faded again. Suddenly I was startled into semi-consciousness by Helen shouting, "I'm not going to stop! We don't have any damn fruits or vegetables!"



She had come to the California border vegetable inspection station, and a long line of cars was stopped in the sweltering heat as state police questioned drivers and inspected car trunks. Helen wheeled the car around the line and yelled at one of the men in uniforms, "I've got a sick person inside, can't stop!" And she shot past the wide-eyed trooper, gunning the engine and speeding away from the station.

"Hang on, Lee, we're almost there! Hang on!" The words faded in and out of my sick haze.

As they told it to me later, the motorcycle officer, siren screaming and red lights flashing, caught up with them as they were pushing the wheelchair with me slumped in it, over the rough gravel path of the motel driveway. The blonde lady from the office was helping them rush me toward an air-conditioned room. As Mom and Helen pushed the chair through the difficult gravel, the blonde clerk held me in the chair, until the state patrolman caught up with us and took over for her so she could open the room door.

I woke up to find myself lying on a bed in a strange, freezing cold room. A blonde lady in a tiny halter top and shorts was pulling off my clothes, while a trooper in full uniform and Smokey Bear hat sloshed a thermos of iced tea in my face.

Helen was there, yelling, "Wake up Lee, we're there! Wake up ... you'll be OK ... wake up!"

Mother was in the background, rocking from side

to side, clucking and mumbling, "Never again, oh, never again!" and holding her head with both hands.

I raised myself on my elbows to take in this apparition, and everyone suddenly hugged me, except the state trooper. He grabbed me by the shoulder and said in an official sounding voice, "Welcome to California!"

In a moment, my mother brought snacks and sandwiches from the car and fed everyone at the small round table in the room. The blonde lady wanted to know where Helen bought her slacks. The state trooper exchanged tuna fish recipes with Mom. Another lady from the office came in with dishes and a gallon of ice cream. She told the blonde lady she closed the office for the day and turned on the "no vacancy" sign.

The entire ensemble stayed through dinnertime and finally exchanged names and addresses and promises to visit one another when in town. The trooper and I watched *Guns-n-smoke* together on the small black-and-white television in the room. He left about 9 p.m. I was so exhausted that I don't

recollect Mom and Helen preparing me for bed.

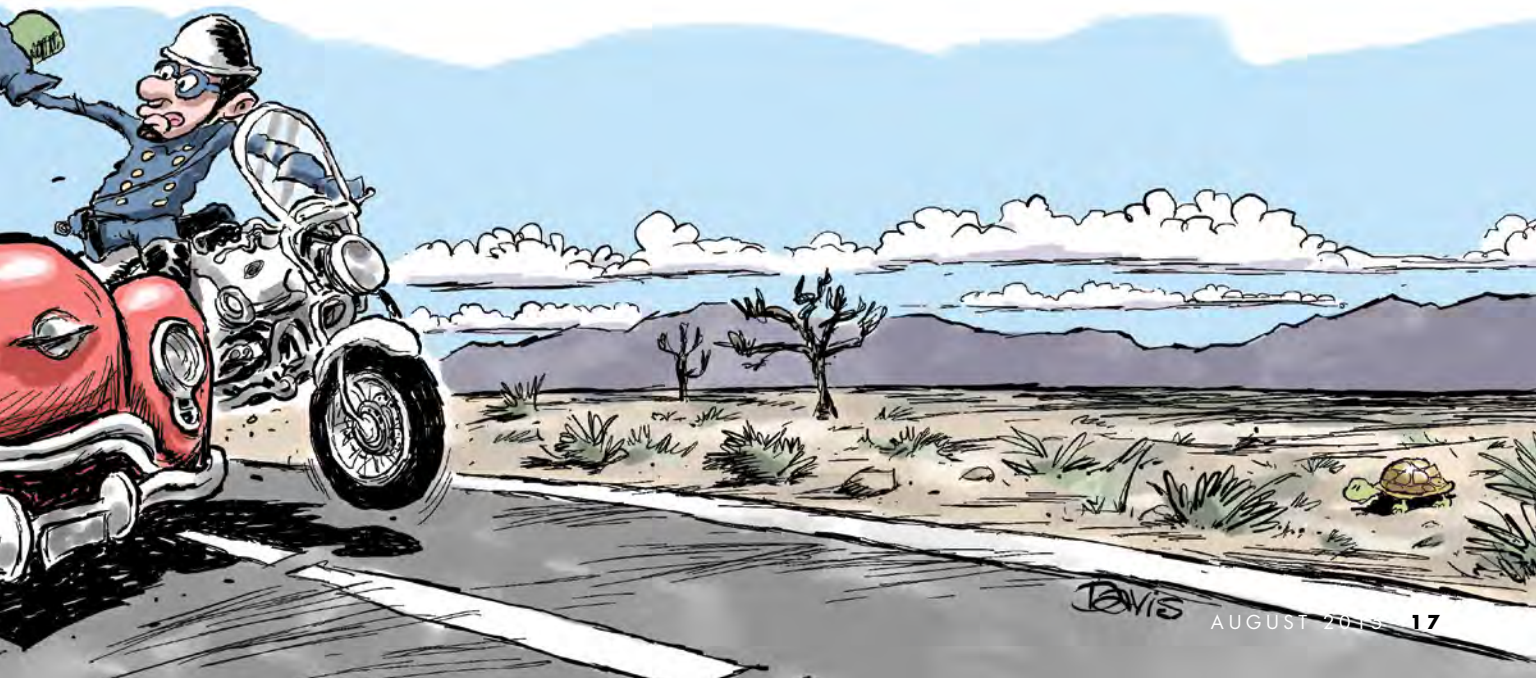
I only recall waking up in that room the next morning and wondering if what I was remembering of the previous day had been just a dream.

## Milepost 38

By Cheri A. Valle

It's July 24, 2014, a few miles outside of Ludlow, Calif., on I-40 eastbound, the "new" interstate that roughly parallels old U.S. Route 66, on what feels like the hottest day of the year, or maybe the century. I had left my brother's home in coastal southern California a few hours before and was on my way back to my home in Colorado. But first I have to drive my old van through the Mojave Desert. I am 61, have had a progressive neuromuscular condition since birth and use a power wheelchair. It is an incredibly hot 110 degrees, and the van is very unhappy about it.

The transmission overheats and begins slipping. No exit in sight. In fact, pretty much nothing in sight — just sand and rocks. A parched desert.



When the highway starts up a gentle grade, my van decides it is done. I get to the right shoulder, as far off the highway as possible, but the shoulder is quite narrow and traffic is charging past me a couple of feet from the car door.

OK, no problem. This is why I have a AAA membership. I call, the operator asks where I am. Somewhere in a 20-mile stretch of I-40 eastbound between Newberry Springs and Ludlow, I say. The operator can't seem to comprehend this. She wants a more specific location, a milepost or call box number. I explain that my wheelchair unloads out the driver's side, and I am *not* going to unload it onto I-40 with cars going by at 75 miles an hour just inches away. If a tow truck just starts driving east, they will find me. How many gold vans with Colorado disability

plates are likely to be stranded out there?

But the operator will not dispatch the tow truck, because I cannot pinpoint my location.

One hour and three calls to AAA later, I finally get an operator who suggests a way out of this dilemma. She tells me to call 911 and the California Highway Patrol will dispatch an officer to find me and tell AAA where I am. This seems like overkill to me — I need a tow truck, not the Highway Patrol! But it is *very* hot, so I swallow my reluctance and dial 911.

In fact, all it takes to get a tow truck is having the 911 operator make the call to AAA instead of me. The 911 operators apparently have AAA Roadside Assistance on speed dial, and they have rather more credibility than does the driver herself. So

she tells the AAA operator to have the tow truck driver just start going east on I-40 until he finds the gold van with the Colorado disability plates. This time, the AAA operator finally dispatches a tow truck.

While I wait, a pleasant young CHP officer shows up. Finally we know exactly where I am — milepost 38 — and we convey this information to AAA. The officer and I both get our workout for the day moving me out of my car and into his, where we sit in air-conditioned comfort for the hour it takes for the tow truck to appear. Even though the day, and perhaps my entire cross-country trip, is ruined, I feel guilty about monopolizing a CHP officer and car for such a long time when he could be out distributing speeding tickets and watching for drunk drivers.

The officer assures me that

in his eyes, by helping me he is doing exactly what he should be doing. We have a lovely conversation about the challenges of raising strong children in an atmosphere of gangs, drugs and violence.

When the tow truck driver arrives, he is also supremely helpful. He and the officer manage to get me into the very high cab of the tow truck. An hour later, we drop off my car at the nearest transmission repair shop in Barstow, just at closing time. There is, of course, no wheelchair-accessible taxi in Barstow, so the tow truck driver loads my power chair onto his flatbed and hauls it and me to a hotel. My lonely little power chair looks ridiculous shackled down on a flatbed meant for large cars as we drive down Main Street in Barstow. At the hotel, I slither out of the tow truck — getting down is

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so much easier than getting up! — and my chair and I are finally reunited.

I am reminded of two things that I already knew: It is often way harder than it should be for a wheelchair user to solve relatively simple problems; and, most people really will go out of their way to help, once they understand what the wheelchair user needs and how they can help.



My elderly gold van ended its days in Barstow. It wasn't worth the cost of repairing, so I donated it to an organization that serves homeless veterans — they could repair it more cheaply than I could. Hopefully my van can putter around a small town being useful and will never again have to brave the trek across

the Mojave Desert trying to get back to its former Colorado home.

The week and a half I spent relying on other people for transportation was not fun. *Really* not fun. But I have a new used van now, 13 years younger than my sad gold van. A platform lift for my wheelchair unloads out of the back, which means I can get my chair out just about anywhere. In an inaccessible parking space. In my brother's driveway. And yes, on the shoulder of a busy highway.

Someday I expect I will have to quit driving cross-country by myself. Just like my old gold van, I will have to limit myself to puttering around a small town. But for now I am home in Colorado, back in business, getting myself anywhere I want to go without needing to ask for help. Life is good. M



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# WHILL It or Whon't It?

BY IAN RUDER AND TIM GILMER, WITH BOB VOGEL

**M**inimalist. Attractive. Design forward. Pretty.

Those aren't words usually associated with power wheelchairs, but they keep popping up in conversation after conversation about the WHILL, a new "personal mobility device" designed and brought to market by a team of former auto industry designers. After five years of design and testing, a good degree of Internet fame and a successful funding campaign that resulted in \$11 million, the WHILL — pronounced like "will power," not "wheel" — is finally available to a nationwide market.

With a low-profile frame highlighted by two white arms emerging from just in front of the rear wheels, the WHILL resembles a wheelchair that was ripped off the set of a futuristic sci-fi movie more than it does any power chair currently on the market. It is sleek. It is eye-catching. As one user told me, "It's like the Apple of wheelchairs."

The current version, the Model A, does not have all the features that wheelchair users with higher level spinal cord injuries would need and is not intended for medical use (meaning it's not yet covered by insurance), but has more than a new

style to excite potential users about future versions. Atop the list is an all-directional four-wheel drive system built around novel casters that allow for pin-point turning and all-terrain use. Also of note is an app that allows users to control the chair via smart phone. It could be great for caregivers of users who can't control the chair on their own, or users who simply want to move the WHILL to a corner or summon it to bedside.

Still, you need look no further than the iBot to remember that it takes more than promise and potential to make it in the fickle world of wheelchairs. Whether

the WHILL is truly the white knight that changes the industry or just a passing whim will depend on more than its looks or tech. Among the many questions out there are: how service works (the company currently promises to fly technicians out to repair chairs where owners live, but knows that is not sustainable long-term); whether the business-side of WHILL is viable; and how and if they will adapt the chair for users with complex rehab needs.

Questions aside, it is easy to see why

the WHILL often provokes giddy reactions and reposts on Facebook and other social media. “This is an opportunity to see something challenge the power chair industry,” says Fernanda Castelo, a C5-6 incomplete quad who has been testing the chair for WHILL for the last two years. “I’m going on 20 years in a chair and I have not seen any different designs. People come up to me and want to talk to me about it. They’re excited about it, and that excites me.”



Check out that omni-directional front wheel — Whitley Hodges says it makes for a smoother ride than her manual chair.

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## What Users Are Saying

Whitley Hodges, injured in 2009 at T7, is 26 and lives in Elgin, Ill. She has gone to the Abilities Expo in Chicago every year since her SCI. As a young wheeler, she likes to show some style with her choice of manual wheelchair. That’s why she currently rides a Colours Saber. But at the Expo in June of 2015, she tried out a new WHILL power chair, drawn by its futuristic design.

“I’ve never seen a power wheelchair as compact as the WHILL. It’s very sleek and modern,” says Hodges. “Definitely appeals to me, especially the compactness. The footplate didn’t stick out as far, and it’s shorter in the back. The arm rests are a sleeker design, more aerodynamic, and a lot narrower. Even the joystick is sleeker, more like a rounded square.”

What about practicality? “I’ve never



ridden another power chair, but I have ridden power scooters,” she says. “With the WHILL I feel like you have more control with the wheels, how it turns on a dime. And it’s a lot smoother accelerating and stopping.” And rough terrain? “I didn’t get a chance to take it outside. It was a smooth ride on carpet, felt like I was gliding. Definitely smoother than wheeling in a manual chair.”

She would tweak a few things if she had one. “One of the things I would change is the cushion. I think my ROHO would fit in the WHILL. Right now it’s a firm foam on the WHILL, removable. Not the same skin protection as a ROHO. Even with the hard cushion, it felt OK, surprisingly. The seat was more bucketed, comfortable. But the seat was too long, touching the back of my knees.”

She says if she were seriously in the market to switch to power, the WHILL would definitely be in the running. But there’s a catch. “I don’t have an accessible vehicle with a lift,” she says. “Right now I disassemble my manual chair. Other than that the WHILL is a great chair. I drive a 2008 Nissan Rogue, a smaller SUV. I



The WHILL’s profile is thin and sleek compared to Reveca Torres’ everyday power chair. An incomplete quad with good trunk control, she says she felt secure and likes how she looks in it.

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would need a vehicle with a ramp or a lift.” Hodges is currently looking for employment and lives with her mother, who rents the main floor of a house, so money is hard to come by.

For now, at \$10,000 retail, the WHILL must wait.

“It would be something I would definitely save for,” she says. “Especially if they work on the design and move forward with new models.”

★ ★ ★

Reveca Torres, 33, a C6 quad since 1994, was also at the Chicago Expo. NEW MOBILITY readers know her as the founder of Backbones, a national peer support organization. She has owned power chairs since 1999. She liked her Invacare Arrow Storm (she had two) and now has a Quantum 4000. But she wants something “not so big and clunky,” and says she is disappointed at the options for power chairs in general these days. “There are a lot of cool types of manual chairs, but not a lot of options for power chairs.”

What does she think of the WHILL? “I was very impressed, actually, and haven’t

been able to stop thinking about it. I felt very stable in it. I’m an incomplete quad and have some pretty good control with my trunk. I do have weakness, but know my limits.” She was secured with a safety belt across her hips. “It feels like it has a little more suspension. I didn’t feel the bumps as much on my back.” She had no problem going up a ramp into a van and also into an MV-1.

What did she like most? “Visually I like that it fits my body better and is comfortable, and you can see more of me and there is less chair. Also the drive control works like a mouse and I picked that up quickly. I tried turning in small spaces. No problem at all.” And the sleek design? “It felt like it allowed more room to move, and the same with the back rest, smaller, and no handles, so I had more movement with my upper body.”

Lifestyle considerations? Torres likes the turning radius and 23-inch width for going through doorways and sees no problem with transferring to and from the WHILL. But she’d like a little less dump to sit more upright and wonders if the arm design would be good for driv-

ing. “I use the arm rest to lean into. I would need to move the WHILL arm rest because it would interfere with the hand-control accelerator. I use my present arm rest (on my Quantum) for stability when going into a turn.” She also wonders about flying. “I’m curious about how you would transport it on airlines. It might be a little more fragile.”

At the Expo, the WHILL had a one-time 50 percent off sale price of \$5,000. Torres was tempted at that price but would have to have cash. “The lack of FDA approval is a definite barrier,” she says. Even if it was approved, insurance companies might give people a hard time about getting it covered.”

★ ★ ★

At 62, Paul Knott, a complete C6 quad for 30 years, comes from a different demographic than Hodges or Torres. He lives with his wife, Linda, in Village Homes, a wheelers’ paradise in Davis, Calif. So when Bob Vogel, our pre-eminent wheelchair tester, proposed a dual WHILL try-out for himself and Knott, Knott jumped at the opportunity.

Chris Koyama, WHILL’s marketing director, drove to Knott’s home in Davis with a demo model. Knott works full-time with map management data for the California Department of Forestry and Fire Protection. He’s old school, having always owned a full-size van. He has also avoided power until just recently, when he bought a Spinerger ZX-1 power add-on for his Quickie GT manual chair. “I think it’s important to keep using my arms, but my shoulders have taken a beating recently. The ZX-1 works great for me.”

So why test a WHILL? “I like to stay up with the latest in mobility.” Although he didn’t say it, at his age he also knows that one day he may have to switch to a full-on power chair. But for now his ZX-1 unit gives him what he needs. “To work Charlie, my service dog, I need to have one hand to drive and one hand free to give commands and treats.”

He likes the WHILL’s wheels best. “Those omni-directional wheels are great. I think there’s a future for those. But the lack of push handles handicapped me. And the chair was too flashy for me.” Maybe it’s because he’s a man and a former firefighter, but he wants a useful chair that doesn’t draw a lot of attention.

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A C6 quad for 30 years, Paul Knott says the WHILL isn't for him. He'll stick with his manual chair with the push handles he can use for weight shifts for now. Also, he says he'll keep his eye on it in case they add features that would make the chair more practical for his type and level of injury.

• See Bob Vogel's test results, next page.

"If anything, I want the attention to go to my dog, not what I'm sitting in."

Why were the missing push handles a problem? "I depend on the handles for lateral support." Many quads like to hook their arms on the handles for stability, to compensate for paralyzed ab-

dominal muscles. "After 30 minutes in the chair, I just knew it wouldn't work for me," says Knott.

If WHILL offered a new model with more traditional design, would he be interested? "I'll keep my eye on it, but the main criterion for me is do I want to be in

power chair full-time? In my present chair, my wife and her girlfriend can lift me up a step or two. Can't do that with a heavy power chair." And the futuristic design? Not so desirable. "Maybe something in plain black. With super offroad capability and flexible seating and arm rests." **MM**



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# Test Driving the WHILL

BY BOB VOGEL

As a T10 complete para in my 30th year as a wheelchair user, my current preference is a rigid TiLite TR manual chair. However, my background includes test driving power chairs as both a manufacturer's rep and writer for *NEW MOBILITY*, so I was interested in the WHILL's unique design.

**Initial impressions:** Moving the control arms to the halfway point engages gas springs that smoothly raise them past vertical, which makes transfers a breeze. The adjustable-angle back provides good support, and controllers are located at a comfortable position to rest your hands. I found the mouse-like drive controller — located on one hand rest — easier and more intuitive to use than a joystick controller. The other hand rest has a slide switch for low, medium and high-speeds; also, forward and aft for moving the seat forward 9 inches for transfers and sitting at tables. My backpack fit nicely on a hanger built into the seat back.

**Terrain:** The four-wheel drive combined with 10-inch front wheels and suspension handled a bumpy, grassy field with ease and smoothly crossed a three-inch deep, sharply angled drainage ditch. I ascended a steep grassy section — a challenge for my aging shoulders in my manual chair — and the WHILL climbed it with ease. On concrete, I



headed down a sidewalk at max speed — 5.5 mph, a fair clip judging by the quick trot of my service dog, Killy.

**Mall Wheeling:** Next stop was cruising an outdoor shopping mall, including wheeling through the late lunch crowd at a restaurant, then over to a grocery store. Paul Knott was behind me, checking people's reactions to the WHILL. There weren't any, which I like, but Davis is a college town and wheelchair users are common.

**What's Best:** The coolest part of the WHILL is the all-directional design of the front wheels. With no caster forks, turning is enabled by very small wheels transversely mounted within and around the main wheel. This enabled me to wheel right next to display aisles and back up and go forward without catching a swiveling caster, and may also prevent "caster swivel wall damage."

**Problems:** On the outdoor sections there was a minor rattle, and electronics were intermittently acting up. I

experienced sluggish turning, slowing while in high speed mode, and seat movement instead of chair movement in low speed mode. More puzzling, when we got to the mall, the problems stopped and the chair ran smooth as can be. WHILL's Chris Koyoma called the next day and explained a technician found the gas spring that lifts the right arm had come loose and was resting on the wiring, which caused electronic glitches on bumpy surfaces.

**Service:** Right now WHILL is located in California with dealers signed up in Washington, Florida, and the tri-state region of New York. Koyoma says if a customer has a mechanical or electronic problem and lives outside a reasonable driving distance from a WHILL dealer, the company will send somebody to fix the chair within 48 hours.

**Overall:** I'm impressed with the WHILL's performance, especially the front wheels. But as an old school guy, I find the futuristic design too flashy for me. For now, I prefer to stay in my custom-fitted, ultralight chair, clip on a FreeWheel in front for outdoor use, and help out my aging shoulders with a Smart-Drive power assist. This way it is still easy to bump me up stairs and I can use standard cars rather than ramp vans.

That said, I'm stoked at the innovative design and look forward to seeing where WHILL goes from here.





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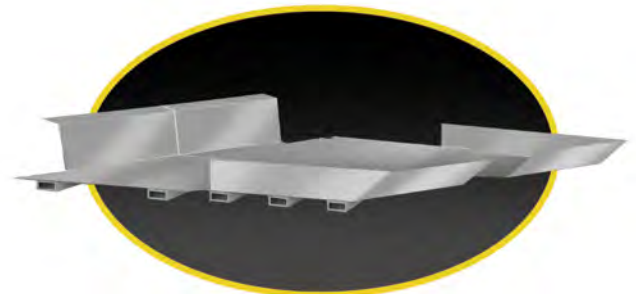
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# ▶ YouTube YOUR WAY

BY ROXANNE FURLONG

The minute I heard about YouTube in 2006 I jumped on board as a creator and started uploading videos. The first videos I uploaded were of my Dalmatian, Galloway. I filmed as my husband poured dog kibble out of a 40-pound bag like a waterfall and Galloway gulped as much food as he could while choking and spitting it onto the floor to eat later. The videos are a hilarious visual memory of our beloved dog.

In 2007, I created a new channel where I post crafting tutorials, haul videos and the occasional lifestyle “vlog” (video-blog). It’s hard to believe that I’ve since uploaded 800 videos with over 1.2 million views and 6,100 subscribers to my channel. While it may seem daunting at first, filming and posting on YouTube is easy to learn and fun.

## How to YouTube

YouTube offers something for everyone, touting 7 billion hours of video posted each month. I’ve made many purchase decisions — including my latest power chair — by viewing reviews and actual user tests. I’ve learned how to install a microwave door, figured out what caused a grinding noise in our Jeep, and learned how to make homemade soap.

A free alternative to cable, YouTube offers popular television show series, full-length movies and music concerts that even Netflix and other video services can’t offer. As a free subscriber, you can make playlists of favorite subjects or channels, or as a creator, become one of its many rising stars (comedian Zach Anner gained worldwide attention in just a few years). You can use it as a catapult for your own show, or as a means to launch a business.

With the exposure that my channel garnered, I parlayed it into an online,

worldwide craft network and a Facebook group for card-makers. As a YouTube Partner, I can monetize my videos to make a monthly income, enough to keep my paint and paper supplies stocked. Most

importantly, I have made friends from all over the world, many of whom I have had the chance to meet in person, and several I expect to know for a long time.

As interesting and fun as YouTube can

## ▶ VLOGGER BIO

**NAME/DISABILITY:** Jerry Diaz — SCI

**CHANNEL:** Jerry Diaz

**STARTED VLOGGING:** June 2010

**SUBSCRIBERS:** 2,280; **TOTAL VIEWS:** 771,300

**BEST VIDEO:** Out for a Run

**WHY I VLOG:** “I enjoy helping people and love that I can live my everyday life, film something I did and know that it might benefit someone. That’s my true reward.”

**CONTENT:** Diaz offers numerous wheeler instructional, wheelchair skating and views of his pit bull, gator, scorpion and tarantula.

**FAVORITE CHANNELS:** FailArmy; Ownage Pranks; Aaron Fotheringham; Blox Starz TV; Nitro Circus.



## ▶ VLOGGER BIO

**NAME/DISABILITY:** Nathan Sanders — Bilateral Amputee

**CHANNEL:** LookMom NoLegs

**VLOGGING SINCE:** April 2014

**SUBSCRIBERS:** 125; **TOTAL VIEWS:** 8,300

**VIDEO WITH HIGHEST VIEW:** Amputee Workout Video

**WHY I VLOG:** “Not only do I want to help someone out of the depressed ‘I can’t do anything’ phase of amputation, I want to show nondisableds to not count us out. Don’t avoid inviting us out because you think we can’t do something. Ask us if we can!”

**CONTENT:** Married with one daughter, Nathan began vlogging to find help to buy a new wheelchair to replace his dilapidated one after being fired. He is on his way to getting a new chair, thanks to generous viewers and T-shirt sales. Subsequent videos show him working out, bowling and doing other activities.

**FAVORITE CHANNELS:** AnimalBytes TV; Indian Trace; Josh Sundquist; Sports N’ Spokes; Steven Jacobo.





## VLOGGER BIO

**NAME/DISABILITY:** NAME: Ashleigh Marie — Multiple Sclerosis  
**CHANNEL:** Ashleigh Marie  
**VLOGGING SINCE:** July 2013  
**TOTAL VIEWS:** 29,600

**VIDEO WITH HIGHEST VIEW:** Slideboard Demo

**WHY I VLOG:** “Vlogging and watching videos gives you a sense of instant community. It became very difficult to deal with some of my MS symptoms. But to watch someone else’s story, going through the same thing, it gave me strength to keep vlogging.”

**CONTENT:** Young Christian wife and mother of one daughter vlogs about MS awareness and symptoms and includes a variety of fashion and makeup hauls and mommy moments.

**FAVORITE CHANNELS:** HillSongUnitedTV; SunshineRAE811; WhatsUpMoms; Our Family of Four; GabeBabe TV



## VLOGGER BIO

**NAME/DISABILITY:** Brian Kinney — SCI  
**CHANNEL:** Paralyzed Living  
**VLOGGING SINCE:** June 2011  
**SUBSCRIBERS:** 5,400; **TOTAL VIEWS:** 1,300,000

**VIDEO WITH HIGHEST VIEW:** Paraplegic Getting Dressed

**WHY I VLOG:** “My initial vlogs were showing how I did things that “normal” people do: driving, riding my motorcycle. Soon I realized there were many

daily activities that I was never taught in rehab — dressing, swimming, transfers — where I had figured out my own ways and thought it would help newly injured people.”

**CONTENT:** Married 34-year-old shows daily living skills as a para, including modifying a motorcycle and home.

**FAVORITE CHANNELS:** Jerry Diaz; MotorTrend Channel

be, if you decide to become a creator and start vlogging, just know that you may need a tough skin to handle the ubiquitous negative comments, trolls (people who post comments just to provoke your viewers), and stalkers that every YouTube creator gets; plus disability devotees, and other nuts that may surface. Though you certainly can disable comments and block unwanted users — leaving, receiving and replying to comments is the interactive part of YouTube that shouldn’t be missed.

As vlogger or viewer, you will learn that YouTube reflects the world we live in where people of all religions and races, from all walks of life, make up millions of small communities to offer something to fit everybody’s needs and desires.

To become a viewer, you can head right

over to YouTube and start searching and watching videos without setting up an account. But to save favorites, leave comments or upload videos, you must have a Google account to start your own channel.

We talked to several vlogger-wheelers to find out why they started vlogging, and asked them to share their experiences and tips to make this a positive, fun and inspiring part of your life.

## Why Vlog?

Jerry Diaz, Priscilla Hedlin and Nathan Sanders started their channels as an outlet. For John Buhler, Ashleigh Marie Looman and Brian Kinney, their vlogging grew more directly out of their disability experience.

Diaz, 28, expected his channel to be a way to share short videos having fun — some wild rides, like racing in his chair with his pit bull, maneuvering down 50-plus steps to the beach, and teeth-clenching chair skating.

Hedlin, 34, from Texas, uses her channel to add more personality to her blog. Sanders, 29, a bilateral amputee, at first used his channel to vent about being fired from his job due to disability.

For all but Hedlin, their channels morphed into more than what they expected as they changed and grew with new ideas and viewership. Their channels eventually became a platform to help others — and themselves — by sharing their experiences of being a wheelchair user.

“The first video I posted that really committed me to making videos was of me climbing into a buddy’s lifted truck,” Diaz says. “I got a lot of views with a lot of positive feedback and it turned a switch on in my head that people might enjoy watching the things I do.”

Then it became personal.

“To connect with the viewers, I started asking people what they wanted to see and thought about things to do that people may have a challenge with, to show them an easier way to do them,” Diaz adds.

Sanders, a North Carolinian with 29 years of being a double amputee, says he gets some of his vlogging ideas from visiting online forums for amputees. “For instance, if I see new amputees who are having difficulties getting into or out of a car,” Sanders says, “I will go make a video showing them how I do it. Or, I watch other wheelers and see how I can adapt what they are doing for amps.”

Buhler, who sustained an SCI and brain injury after falling three stories, not only wants to help others by sharing his experiences, he also says vlogging helps his memory by creating a visual record of what he does. The 43-year-old from Arizona came about vlogging in a “small world” kind of way. “While in rehab after my accident, my physical therapist filmed me while I worked on balance,” he says. “Later, when a buddy went to college for physical rehab in Arizona, he was blown away when his instructor showed one of my videos to his class. After he told me about it, I thought about how my video helped his classroom, and how I could share my experiences with other people.”



# Not All Roses and Rainbows

Unfortunately, there are people who think everything and anything goes, that manners and decorum are unnecessary on social media. Every YouTube creator or vlogger is exposed to rude or negative comments. Some have even dealt with stalkers, scammers and devotees. All agree that the best way to deal with these types is to ignore or block them.

“When I started my channel and website, I got a lot of devotees,” Sanders says. “They were mostly creepy males who would engage in innocent conversation and then suddenly switch to asking for pictures of my body. At first I shut down for a couple weeks, then decided not to let them ruin what I enjoy. Now I just ignore them.”

“I handle troll comments by simply deleting them, and if the person continues, I block them,” says Looman, 26, of Michigan. “I have a lot of amazing subscribers who have become like a virtual family to me, and I am very protective of my family.”

Kinney, 31, from Ohio, says his “Paraplegic Getting Dressed” video attracted several weirdo followers commenting on his “sexy feet.” Many times he deletes off-color comments or blocks users. “I realize that some comments are ignorance-based,” he says.

Something viewers should know is that most vloggers spend hours planning, filming and editing that uploaded video that took just eight minutes to watch. Then they spend more time replying to viewer comments or questions.

Buhler uploads exercise videos every other day, as well as some lifestyle videos. Most of Hedlin’s videos are spontaneous or by request and require little to no editing. Looman keeps meticulous records and plans of her vlogs and everyday life.

“I have to plan around times when I am feeling well enough to vlog,” Looman says. “Especially around my toddler’s needs. We are a planning type of family!”

Check out some of the vlogs listed in the vlogger bios, including favorite channels from our vloggers. If you are not hooked already, you will be before you know it.

## VLOGGER BIO

**NAME:** Priscilla Hedlin — SCI

**CHANNEL:** Priscillah81

**VLOGGING SINCE:** July 2009

**SUBSCRIBERS:** 524; **TOTAL VIEWS:** 151,150

**WHAT I GET OUT OF VLOGGING:** “I enjoy letting my blog readers see the real me, it’s not easy getting to know someone off screen.”

**CONTENT:** The Wheelchair Mommy is homeschool mom of three young boys, makes cocktails with a friend and talks about her day.



## VLOGGER BIO

**NAME/DISABILITY:** John Buhler — SCI, TBI

**CHANNEL:** d72466fly

**VLOGGING SINCE:** June 2011

**SUBSCRIBERS:** 2,075; **TOTAL VIEWS:** 864,012

**VLOGGER TIP:** “Stay true to who you are and don’t sacrifice your morals, your body or your self just to get more views.”

**CONTENT:** Buhler’s videos are of exercising, transferring in public and everyday life.

**FAVORITE CHANNELS:** ATHLEAN, Scooby1961, The Youngturks, Strength Camp, thegreat80s



## VLOGGER BIO

**NAME:** Roxanne Furlong — Muscular Dystrophy

**CHANNEL:** RoxyFur

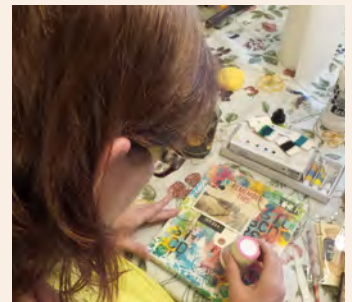
**VLOGGING SINCE:** June 2006

**SUBSCRIBERS:** 6,100; **TOTAL VIEWS:** 1,300,000

**VLOGGER TIP:** “What you might consider a mundane daily activity could actually inspire something in others. Don’t knock haul videos, reminiscent of ‘Show and Tell’ from grade school, they can be a fun way to engage viewers.”

**CONTENT:** Mixed media artist, card-maker, art tutorials, product hauls and lifestyle jaunts.

**FAVORITE CHANNELS:** CrazyRussianHacker, Maangchi, SacconeJolys, Vicky Papaioannou, K Werner Designs



And if you are so inclined, for about \$100, or with a good camera on your phone, you could be vlogging within minutes and on your way to changing your life and those of viewers around the world.

“YouTube is about sharing knowledge and helping people,” Kinney says. “This is a huge reason why YouTube is successful.”

“On YouTube, we all are a big community, we all share somewhat of the same ideas and feelings and care about other people,” Buhler adds. “That’s a beautiful thing and one reason why I like to watch

other people and their videos. We’re all trying to live together in harmony, and that’s what makes this world a beautiful place to be.”

YouTube is a great platform for stimulating change.

“I want my viewers to realize that nothing is impossible,” Diaz says. “And I hope I can help someone do something that they thought they couldn’t do. I want to show that independence is possible, you just have to put your heart and mind into it, and it will be possible.”

# ADAPTIVE OUTDOOR ADVENTURE SPORTS

BY BOB VOGEL

The popularity of outdoor adventure sports is massive and continues growing at a fast clip. As an outdoor adventure sport enthusiast myself, I believe this popularity stems from being in the beauty of nature, combined with heightened experiences — flying through jungle canopies, tapping into the power of waves or white water rivers, soaring in the air like an eagle or free-falling while suspended a mile above the earth. In addition to the immediate “WOW!” factor, these experiences create a very positive and profound effect — adrenaline flowing, senses heightened. Emotional baggage vanishes and you enter a Zen state of being fully in the moment — something that stays with you and gives you a new perspective.

Intrigued? Here is a look at certain outdoor adventure sports that are fully accessible, even with very limited arm movement. You can try them without purchasing any additional gear. And you don’t have to be a super-jock to do them. If they grab you, you can learn how to do them on your own.

## PARAGLIDING

Paragliding is a unique way to take to the sky, to soar in gentle breezes and share rising air currents with eagles and other raptors. It is also easily adaptable. The standard tandem harness supports the torso with straps fitting around the legs and waist, as well as over the shoulders and in front of the chest. It is helpful to add Velcro straps to secure the ankles of paralyzed legs to the instructor pilot so they don’t get tangled on landing.

This exciting sport can be done in all 50 states. A paraglider can take off and soar on the breeze of even a small hill. In flat lands you can launch behind a vehicle with a winch that pays out line. When the pilot has reached flying altitude, around 1,500 feet, the tow line is released and you glide down or catch thermals of rising air and stay aloft.

There are also several instructors offering adaptive lessons in a custom three-wheel chair designed for paragliding, both as a student and for flying solo. Chris Scantacroce, a tandem paraglider pilot from Sandy, Utah, gives adaptive tandem lessons — technically all tandem paraglider rides are considered instructional flights — on the adaptive chair and also offers paragliding lessons through Project Airtime [see resources]. In the United States there are already a handful of licensed paraglider pilots who are wheelchair users.

Kirk Williams, 27, in his fifth year as a C6-7 complete quad, went on a tandem flight last year in Jackson Hole, Wyo. He used a standard paragliding harness and started seated





Photo courtesy of Jackson Hole Paragliding

on the ground in front of his instructor. When they were ready, Matt, his instructor, gave a gentle tug on the controls and the paraglider gained shape and rose overhead in the gentle breeze. Two helpers lifted Williams while Matt took a few steps — and they were airborne.

“We quickly rose above launch,” says Williams. “When we turned back we were looking down on the people and pilots at launch. I didn’t feel so much like I was going up, but rather that the earth was falling away. It was late September, and the fall colors were peaking. It seemed like there was wildlife every-

where. We circled next to birds, flew over deer and a bear. It was fantastic!”

Matt helped Williams put his hands through the “toggle” loops — lines that control the glider — and let him fly for 10 minutes. “I was doing tight turns and diving down, then climbing up like a roller coaster, which was great fun until I started to feel queasy.” After being airborne for about 20 minutes, Matt had Williams put his hands under his knees and pull himself into a fetal position while Matt brought the paraglider in for landing. “Matt took two steps, then sat back with me in his lap. It was fantastic! I

look forward to doing it again.”

Approximate cost of a tandem flight: \$200.

## SAILPLANE FLYING

Sailplane flying is another accessible aviation option that is available in all 50 states. For a ride, no adaptation is needed. It is a good idea to sit on your own cushion for skin protection — better yet, wear a Vicair AllRounder cushion [see resources]. To try piloting, a joystick mounted in between the legs controls pitch and roll, but adaptive gliders have an additional joystick mounted to the left so you can control the rudder with your left hand — something that is ordinarily operated with the feet.

The sailplane is towed by a power plane to become airborne. At altitude the pilot pulls a knob to release the towrope. In the morning the air is still and a ride is smooth and relaxing. For more excitement and for those with a strong stomach, sign up for an aerobatic ride, pulling Gs, doing loops, rolls and spins. An afternoon ride in a sky filled with puffy clouds offers the opportunity — if you want — to find thermals, some of which can take you straight up at 2,000 feet per minute.

Ruth Aragon, 23, from Allentown, Pa., went for a ride with Freedom’s Wings — a nonprofit organization that offers free sailplane rides and deep discounts for instruction for people with disabilities. “It was a great experience!” says Aragon. “So much fun it was unforgettable. It completely changed my outlook and now I’ve become very interested in planes.”

Wayne Welker, a C5-6 complete quad, then 38, went for a sailplane ride in 2000 at Sky Sailing in Warner Springs, Calif. “I vividly remember that flight. I felt like I was floating on air — it was incredible,” he says. “Right there I knew I wanted to learn to fly.” However, work and commitments didn’t allow him time until 2007. Welker got his license in 2008 and now spends his time going cross country, riding thermals to stay aloft. His longest flight to date is 200 miles!

Ride costs start around \$145.

## HANG GLIDING

Another form of easily adaptable silent flight that is available in all 50 states is hang gliding. For teaching and tandem

Top: Ruth Aragon went on a sailplane ride with Freedom’s Wings and has been flying ever since. Below: Sailplaning is like floating on air, says Wayne Welker. He loved it so much he got his license in 2008.



Photo courtesy of Freedom’s Wings International

Photo courtesy of Sky Sailing

We were sitting at the open door, a mile over the drop zone, when suddenly my reptilian brain kicked in, saying, 'What are you doing?!'

rides, the hang glider is commonly towed up by an ultralight aircraft — much the same as a sailplane is towed aloft.

Andy Torrington of Kitty Hawk Kites in Nags Head, N.C., explains that on a tandem ride the passenger wears a harness that supports the body, including legs and feet, and the student hangs above the pilot. The glider has wheels on it, so it rolls on launch and landing. No arm movement is required, just the ability to hold up your head. However, to learn to fly solo, arm and hand movement are required.

Like paragliders, hang gliders fly at similar speeds to raptors, and it is not unusual to be joined by an eagle or hawk during flight. Under the right conditions, pilots have been known to hover a few feet behind hawks! Whether flying near your home town or on vacation, it is an amazing way to get a unique perspective of the world.

Rates start at \$159 for a 2,000 foot high tow, which gives a 10-15 minute flight, and go up to a mile-high tow.

## SKYDIVING

For the ultimate rush and bragging rights, nothing beats skydiving. Despite its daredevil image, skydiving is a well-controlled and professional activity, says Topher Downham, 46, from Boulder, Colo., in his 20th year as a C6-7 complete quad.

Downham went tandem skydiving last year with Mile High Skydiving out of Longmont, Colo. "They are very tuned in to working with wheelchair users. They have adaptive tandem harnesses that strap your legs to the instructor's legs,

and when it comes time to land, the instructor pulls a cord that lifts your legs up before landing," he says. Last year they were working with a woman wheelchair user who was going solo.

"The whole day I felt relaxed," recalls Downham. "That is right up to the point when we were sitting at the open door, a mile over the drop zone, when suddenly my reptilian brain kicked in, saying, 'What are you doing?!' Before I knew it we were out the door, free falling, and it was great! Like stepping off into nothingness. What a rush! The free fall was one part. Then when the parachute opens, it is an entirely different sensation, like flying." The landing went perfectly [see

video link in resources]. Downham's instructor pulled his legs up and gently touched down, on the mark — in soft gravel — setting down on his butt, with Downham on top of him.

A word of caution for those considering skydiving. Be sure the instructor you are jumping with has experience with someone who has your same disability. There are horror stories of wheelers going on tandem jumps without using the proper equipment that have resulted in broken femurs from a leg flopping down when the parachute opens.

Approximate cost: \$200.

## SURFING

Although adaptive surfing has been around for well over a decade, it is truly a world-wide phenomenon that is about to explode, says Cara Short, Executive Director of AccessSurf in Honolulu, Hawaii. It has been recognized by the International Surfing Association, the world governing body of surfing, and the first world adaptive surfing championship is going to be held this September in La Jolla, Calif.

Adaptive surfboards come in two styles: prone, where a surfer rides lying on his or her stomach; and seated — also called a wave ski — where a surfer sits on the board and paddles with a kayak paddle, says Jimmy Collins, 63, of Waipahu, Hawaii, in his

Here, Topher Downham enjoys the ultimate rush — falling out of a plane and hurtling toward the earth. His legs are strapped to his instructors for safety.





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FAVE



WHILL

Design your own road

Jimmy Collins still remembers flying across the face of the first wave he ever surfed for a nice long ride from an adaptive board — it was enough to get him hooked.



Photo by Jason Rose/Access Surf

44th year as a T5 incomplete para.

Adaptive surfboards are designed with more rocker (the rise in the front portion of the board) so the board doesn't pearl (nose in) when catching a wave.

Prone boards have foam pads to hold a surfer's legs on the board, a foam pad under the chest to keep the head up and handles to enable weight shifts for turning. Wave skis have a padded seat indent,

and come in varying widths for stability. Both types come in tandem versions to enable a student to go for a ride.

"I first tried tandem surfing with an instructor at a learn-to-surf day in Santa Cruz, Calif., when I was living on the mainland," says Collins. "I still remember that first wave, paddling as hard as I could, then all of a sudden there was a rush of acceleration and I felt the wave's energy, and we were flying across the face of the wave for a nice long ride. Right there I was convinced I had to learn to surf."

Rene Arellano, 34, from Oahu, Hawaii, is a C6-7 quad who has been surfing with AccessSurf for four years. "My first time tandem surfing was four years ago, shortly after I got out of rehab," he recalls. "I was a bit nervous going tandem my first time, but that vanished on my first wave. Surfing makes me feel free, and I have gone on all of their beach surf days ever since and hope to learn to surf on my own."

Collins was so enamored with surfing last fall that he and his wife moved to Oahu. After several surf sessions with AccessSurf, Collins had a custom board

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AccessSurf offers free tandem surf lessons once a month and private lessons and surf clinics with advance notice. There are surf spots and adaptive surf clinics in various places wherever there is coastline around the continental United States. See resources to find one near you.

Adaptive surf clinics are generally free. Approximate cost for private lessons is \$75-\$100.

## WHITEWATER RIVER RAFTING

River rafting is arguably the best way to get into deep, otherwise inaccessible wilderness. I have fond memories of a raft

trip through a rain forest in Costa Rica, watching tropical birds and howler monkeys on stretches of calm water between sections of class IV rapids on a raft trip down the Pacuare River.

River rafts are very adaptable. If an accessible seat isn't available, moving the thwarts (round inflatable seats) closer together provides support for your back, and the other thwart supports your legs

When asked why she tried river rafting for the first time, Mary Taloff says, “My friend talked me into it.” She loved it and goes back to the river every year.



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Mary Taloff, 29, of Davis, Calif., has cerebral palsy and is a power chair user who has gone rafting with Environmental Traveling Companions on the South Fork of the American River not far from Sacramento. “I was terrified starting my first ETC raft trip,” recalls Taloff. “My friend talked me into it.” She says the guides were really helpful, explained what was going to happen and asked what they could do to make her feel more comfortable going through rapids with names like Satan’s Cesspool and Troublemaker. “In the end I loved it and have gone every year for the past six years.”

ETC sets Taloff up in an oar raft paddled by a guide. An adaptive seat — made out of a plastic lawn chair with the feet cut off — strapped to the thwart provides a stable seating platform. A small inflatable thwart supports her feet, and an assistant guide and her attendant sit on each side to hold her in place in the bigger rapids.

“I’ve gone rafting with ETC on single-day and two-day trips,” says Taloff. “We bring a manual chair in the raft in case we stop for lunch, and they drive my power chair to the awesome accessible campground that we spend the night at.”

Lauren Steinberg, 29, from Berkeley, Calif., has arthrogryposis and also rafts in an oar boat. “I’ve been going rafting with ETC since middle school,” she recalls. “I still remember my first trip with them. It was exhilarating and it shifted my perspective on life because it was the first time I was fully immersed in nature.”

ETC raft prices start at \$70 per person per day, and scholarships are available.

## ZIP LINE

Zip lining is another popular and easily adaptable adventure. There are approximately 250 zip lines that are accessible for people with disabilities in the United States, says Don Rogers, a professor at Indiana State University who works with accredited zip line course vendors to make their courses accessible. And Misty Mountain Harness Company makes a line of adaptive zip line harnesses.

Many zip lines are naturally accessible via chair lift, or trail, where you can wheel to the start, get harnessed up to the zip line, and have your chair sent

“Going over the edge of the first 80-foot tower was jaw dropping, like flying through the rain forest canopy. Some of the zip lines flew over huge ravines and near waterfalls. It was amazing.”



Above: Kirk Williams and a friend enjoy zip lining in Costa Rica near the Arenal Volcano. Below: Some of those zip lining towers are 80 feet tall, so guides hoisted Williams up to the platform using rigged ropes and pulley systems.



Photos courtesy of Kirk Williams

to the finish. At Flying Eagle zip line in Park City, Utah, accessible by a chairlift ride, the zip line sends you flying above the ski runs, down the mountain at 45 miles per hour. Better yet, a wheelchair at the mid-mountain chairlift station goes from the chairlift to the zip line, so your chair will be waiting for you at the bottom. They say upper body strength to transfer from wheelchair to the zip line chair is required — they use a chair with shoulder harnesses.

Other zip lines require a bit of adaptation. The zip line at the New Zoo Adventure Park in Green Bay, Wisc., starts at the top of a 64-stair, 50-foot tower. On a busy day the ride can accommodate 60 people an hour. One day a month the park hooks up an adaptive rope-and-pulley system to hoist wheelchair users up the tower, which takes about 15 minutes per person. Dale Metoxin, 30, of Green Bay, who has CP and uses a manual chair, tried it for his first time this summer. “It was great,” he says, “It is something I will definitely try again. I like the speed and sensation of flying.”

Kirk Williams and Daewon Rojas-

Mikelson, a T12 para, experienced the ultimate in adaptation when they went on a zip line canopy tour in Costa Rica, near the Arenal Volcano, with a company called Sky Adventures.

Usually the company has eight people and two guides. They changed the ratio to eight guides to set up for Williams and Rojas-Mikelson. “At times we needed all eight guides,” recalls Williams. The tour consisted of 11 zip lines. “They kept us in

our chairs with a full climbing harness, as well as a harness around the chair because there were sections of one-half mile of inaccessible hikes in between zip lines,” says Williams.

In addition, there were a couple of 80-foot towers with steps going to the top and the guides rigged ropes and pulleys to get them up. The guides were totally accommodating and figured out how to adapt each section. “Going over the edge

Once a month the New Zoo Adventure Park in Green Bay, Wisc., hooks up an adaptive pulley-and-rope system so wheelchair users like Dale Metoxin can fly between towers.



Photos by Lisa Vogel



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# ABLE OUTDOORS

As we were putting together this cover package on outdoor recreation, we caught wind of a new magazine covering hunting, fishing, camping, outdoor adventure and travel. *Able Outdoors* printed its first issue in July and co-editor Chad Waligura says the cross-disability title plans to publish three times a year.

"The goal is to reach as many people as we can and show them what's possible," says Waligura. "I want to get people out and going and doing. People helped me do it, so I want to pay it forward."

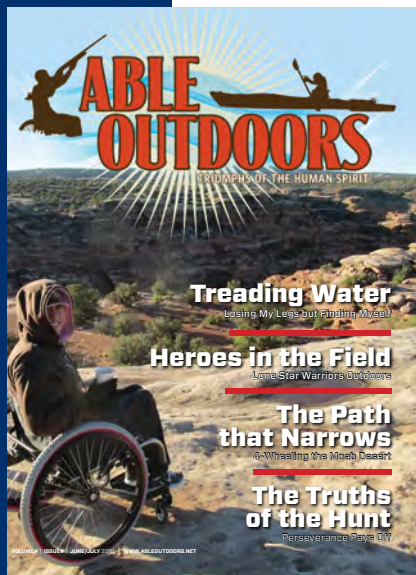
After becoming a C7 quad in 1986, Waligura spent a lot of time traveling the country, trying group hunts with various organizations. "The more people I met, the more amazing stories I heard," he says. "People need to hear these stories because they don't know what can be done."

Waligura built adaptive hunting equipment with his friends and family, launched his own hunting organization and started writing about his adventures. He found success publishing articles in several magazines and then began sharing his experience on his own websites. All of this has culminated in *Able Outdoors*, which he runs with co-editor Dawn Ziegler, an outdoor recreation enthusiast and C5-6 quad.

Although hunting is clearly an important focus for the magazine, Waligura says it is just one of six or seven major topics. The first issue's cover story is on camping and, in general, veterans' organizations and adventure travel will be prominent as well. "Dawn tries to rein me in on the hunting side of it," he says, laughing. "She's more interested in the recreation side."

Striking that balance is the key to helping the most people, he adds. "There are rehabs that when they have guys asking about getting outside, they call me. I'm their outdoor sensei."

Learn more and subscribe at [ableoutdoors.net](http://ableoutdoors.net).



of the first 80-foot tower was jaw dropping, like flying through the rain forest canopy," says Williams. "Some of the zip lines flew over huge ravines and near waterfalls. It was amazing."

Prices average about \$20-\$40 — more for a canopy tour.

## RESOURCES

- Adaptive Cushion—Comfort Company, Vicair AllRounder, 800/564-9248; [www.comfortcompany.com/product/Comfort%20Rehab/Accessories/All-Rounder](http://www.comfortcompany.com/product/Comfort%20Rehab/Accessories/All-Rounder)
- FreeWheel, 208/571-2051; [www.gofreewheel.com](http://www.gofreewheel.com)

### Hang Gliding

- Kitty Hawk Kites, 877/FLY-THIS; [www.kittyhawk.com/hang-gliding/](http://www.kittyhawk.com/hang-gliding/)
- Wallaby Ranch Hang Gliding, 800/WALLABY; [www.wallaby.com](http://www.wallaby.com)
- U.S. Hang Gliding and Paragliding Association, 800/616-6888; [www.usHPA.aero](http://www.usHPA.aero)

### Paragliding

- Adaptive Paragliding Super Fly Paragliding, 801/255-9595; [superflyinc.com](http://superflyinc.com)
- Jackson Hole Paragliding, 224/558-3083; [www.jhparagliding.com](http://www.jhparagliding.com)
- Project Airtime, 801/706-6076; [www.projectairtime.org](http://www.projectairtime.org)
- The Flying Chair Project video, [www.rode.com/myrodereel/watch/entry/1012](http://www.rode.com/myrodereel/watch/entry/1012)
- U.S. Hang Gliding and Paragliding Association, 800/616-6888; [www.usHPA.aero](http://www.usHPA.aero)

### Rafting

- Crested Butte Adaptive Sports Center, 866/349-2296; [www.adaptivesports.org](http://www.adaptivesports.org)
- Environmental Travel Companions, 415/474-7662; [www.etctrips.org](http://www.etctrips.org)
- Tahoe White-water Tours, 530/587-5777; [www.gowhitewater.com](http://www.gowhitewater.com)

### Sailplane

- "Discover Glid-

ing," NEW MOBILITY, [www.newmobility.com/2011/11/discover-gliding/](http://www.newmobility.com/2011/11/discover-gliding/)

- Freedom's Wings Canada, 519/884-4242; [www.freedomswings.ca](http://www.freedomswings.ca)
- Freedom's Wings International, 717/335-0458; [www.freedomswings.org](http://www.freedomswings.org)
- Sky Sailing, 760/782-0404; [www.skysailing.com](http://www.skysailing.com)
- Soaring Society of America, 575/392-1177; [www.ssa.org](http://www.ssa.org)

### Skydiving

- Instructional Video for Paraplegic Skydiving, [www.youtube.com/watch?v=YTx0GG28aM](http://www.youtube.com/watch?v=YTx0GG28aM)
- "Jarrett Martin: King of the Sky," NEW MOBILITY, [www.newmobility.com/2014/12/jarrett-martin/](http://www.newmobility.com/2014/12/jarrett-martin/)
- Mile-Hi Skydiving Center, 303/759-3483; [www.mile-hi-skydiving.com](http://www.mile-hi-skydiving.com)
- U.S. Skydiving Organizations, [www.usairnet.com/skydiving/organizations/](http://www.usairnet.com/skydiving/organizations/)
- U.S. Parachute Association, 540/604-9740; [www.uspa.org](http://www.uspa.org)
- YouTube video of Topher Downham: [www.youtube.com/watch?v=7HWmCO7jZ4&feature=youtu.be](http://www.youtube.com/watch?v=7HWmCO7jZ4&feature=youtu.be)

### Surfing

- Access Surf, [www.accesssurf.org](http://www.accesssurf.org)
- "Dancing in The Sea," NEW MOBILITY, [www.newmobility.com/2012/08/dancing-sea-adaptive-surfing/](http://www.newmobility.com/2012/08/dancing-sea-adaptive-surfing/)
- Infinity Surfboards, 949/661-6699; [www.infinitysurf.com/waveski/waveski-for-the-disabled/](http://www.infinitysurf.com/waveski/waveski-for-the-disabled/)
- International Surfing Association, 858/551-8580; [www.isasurf.org](http://www.isasurf.org). Type Adaptive Surfing into "search site".
- Kauai Ocean Recreation Experience, 808/651-6416; [korekauai.com](http://korekauai.com)
- Life Rolls On, 424/272-1992; [www.liferollson.org](http://www.liferollson.org)

### Zip Line

- Costa Rica Zip Line Operator, 844/GOTOSKY; [www.skyadventures.travel/skytrek/](http://www.skyadventures.travel/skytrek/)
- Misty Mountain, Adaptive Zip Line Harness, 866/647-8955; [mistymountain.com/program-gear/adaptive-gear.html](http://mistymountain.com/program-gear/adaptive-gear.html)
- New Zoo Adventure Park, 920/434-7841; [newzoo.org/adventure-park/](http://newzoo.org/adventure-park/)
- Park City Flying Eagle Zip Line, 435/649-8111; [www.parkcitymountain.com/site/summer/activities/zip-lines](http://www.parkcitymountain.com/site/summer/activities/zip-lines)
- World Wide Zip Line Locations, [www.ziplinerider.com/Zipline\\_Locations.html](http://www.ziplinerider.com/Zipline_Locations.html)



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## MY TAKE

Nestled in the Puget Sound with panoramic views of the Olympic Mountains to the west and the Cascades to the east, Seattle's diverse landscape offers outdoorsmen like myself plenty of opportunities to get out and enjoy nature. There is a wide array of organizations working to get people with disabilities outdoors with adaptive equipment for sports of all kinds.



In the winter, the incredible volunteer staff with Outdoors for All straps me in to one of their adaptive skis for an exhilarating day on the slopes at Snoqualmie

Pass. And when the summer gets hot, you'll find me out on Green Lake or the Interurban Trail, pulling my girlfriend on her longboard with my power chair as my service dog, Hank, trots happily alongside.

Even when the weather takes a turn towards the long rainy season, there are still plenty of opportunities to connect and have

## SKINNY ON THE CITY

Seattle is the largest city in Washington and the cultural epicenter of the Pacific Northwest. With an ever-expanding public transit system and a whole slew of accessible parks, trails and concert venues, there's no secret why the Emerald City is consistently named one of the most livable cities in the country for people living with disabilities.



fun indoors. Whether it's wheelchair basketball, quad rugby, or just catching a movie in IMAX at the Seattle

Science Center, there really is no excuse for your event calendar to ever be empty. — KENNY SALVINI

Learn about the Washington Chapter on next page

## GETTING AROUND

Living a mere eight minutes by wheelchair from the heart of Seattle, I find wheeling is often the easiest way for me to venture into the busy downtown area. This way I don't have to worry about finding accessible parking, especially with our highly abused disabled parking placard system — fraudulent use of placards was reported to be at 60

percent in 2013. Some hills can be dicey, but not problematic for power chairs. Although known for frequent rainfall, Seattle's is typically just drizzle. Still, that can be enough to require taking our accessible ferry, bus, and light-rail systems at times. There's also Access, a system of small buses that are especially equipped to handle only persons with disabilities. But be prepared for a potentially

frustrating trip. Wait times can be hellish! Despite its shortcomings, Access is still handy in a pinch, especially if paired with our other public transportation systems.

## HEALTH CARE

The University of Washington and Harborview rehab clinics are two functionally separate clinics that were recently consolidated under UW — the same attending physiatrist oversees a person's care. My experience as someone who went through both inpatient and outpatient rehab there has been overwhelmingly positive. With a number of other rehab clinics within the Seattle area, the availability of quality SCI medicine here is excellent. Also notable is the UW-based SCI Forum, attended by students of SCI medicine as well as injured persons and their supporters. In the monthly forums, experts and panelists present on issues of living with SCI and related topics, like breakthroughs in SCI medicine and demonstrations of new assistive technology. The Forum has been an essential part of my recovery from SCI. — KOTI HU

## MUST SEE, MUST DO

**Venue:** For a unique picnic spot, check out Kubota Gardens in South Seattle. Blending Japanese landscaping with Northwest horticulture, the city's deep Pacific Rim influences are on full display in the 20 acres of beautifully sculpted terrain. The garden's mix of paved and gravel trails can be a little difficult to navigate at times, but you'll be glad you got your wheels dirty once you get a glimpse of the breathtaking scenery.

**Sports:** CenturyLink Field is notorious for the Seahawks and the 12th man, but the weather during football season can be a little harsh. Get tickets for the Sounders in the spring or summer and you'll be transported to a raucous European soccer stadium in an instant. The ample accessible seating gives you just enough separation from the fray of rabid fans with their crazy outfits and organized chants. It's an experience unlike any other!

— Koti Hu



## Washington Chapter: Ramping Up Advocacy and Connection

As one of Washington state's most renowned trial lawyers and only the second woman in the state to be named a Top 10 Super Lawyer, Karen Koehler long ago proved herself in the courtroom. But in 2010 she found herself looking for a way to give back to the community outside the courtroom. A case with a quadriplegic client opened her eyes to some of the harsh realities facing the SCI community and she identified a need and the opportunity to make a difference. "I was really discouraged in trying to help him access resources. I figured I'd just go to the spinal cord injury association of Washington and there was none. So that started the process of starting the Spinal Cord Injury Association of Washington."

Since its inception, SCIAW has partnered with the Christopher and Dana Reeve Foundation, launched a peer mentoring program and built up a hugely successful annual Walk and Roll event that drew almost 350 people last fall while raising \$35,000 to support the

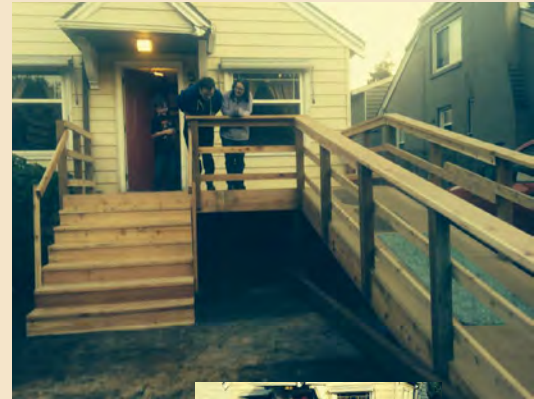
association's mission. The fifth annual Walk & Roll is scheduled for Oct. 4.

Last year, SCIAW signed on as a chapter of United Spinal with hopes of tapping into the organization's background in advocacy. "We've looked into some advocacy locally and we're not stopping it, we're just not mobilized to do anything yet. We're very, very excited," says Koehler.

One area the association has mobilized in is ramp construction. Two years ago SCIAW launched its Build-A-Ramp program, aiming to help people with SCI get the ramps they need to live in their homes. SCIAW members work with therapists and discharge workers to identify individuals in need and then figure out the best way to ensure that individual gets a ramp.

"It's almost always for people who are recently discharged from the hospital and have no idea how they are going to get back into the house," says Koehler.

Over the last two years the association has



In the past two years, the Washington chapter's Build-A-Ramp program provided nine ramps.



aided in the construction or securing of nine ramps. From lengthy, twisting ramps with handrails, to suitcase ramps, they've seen it all. Whether someone has secured the funding for a ramp but can't find anyone to build it, or they have the builder but no materials, or they simply have no idea where to turn, the Build-A-Ramp program is there to help. Koehler has enlisted the help of clients with construction backgrounds for the bigger projects and often gets materials donated from local businesses. Washington's rugged terrain creates a lot of need for the program, but sometimes proves too big an obstacle to overcome. "We live in the Pacific Northwest and there is not much flat land here," she says. "Sometimes we have to turn people down because we can't build ramps for what they want."

Accessing and socializing with other paralyzed individuals can be equally, if not more important than accessing your home after an injury. To help paralyzed individuals do just that, SCIAW member Kenny Salvini, a quad, launched the Here and Now Project. The Project hosted two big get-togethers in 2014, including the after-party for the SCIAW's Walk and Roll, and is looking to expand in its second year. "We find that people really want to get together so that's what The Here and Now Project is focusing on, trying to pull people get together."

To find out more about SCIAW, visit [www.sciaw.org](http://www.sciaw.org) or [www.facebook.com/sciawashington](http://www.facebook.com/sciawashington).



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## Rolling for Rights: 4th Annual Roll on Capitol Hill

On June 9, on a beautiful Tuesday morning, traffic in downtown Washington, D.C., came to a halt. The brief respite in the capital’s incessant hubbub wasn’t precipitated by the usual police or VIP escort, but by something much more unique: a flock of wheelchairs. Lobbyists trying to make their way down K Street and cabs rushing down Massachusetts Ave. all stopped for a minute to watch as over 50 wheelchair users and many more advocates made their way to the Capitol as part of United Spinal 4th Annual Roll on Capitol Hill.

Roll on Capitol Hill is United Spinal’s signature policy event that highlights key advocacy priorities for its membership and the broader disability community to ensure that legislators include wheelchair users and all people with disabilities in policy debates on Capitol Hill.

This year’s event was held at the Marriott Marquis in downtown Washington from June 6-10 and brought together over 100 advocates from 29 states and Washington, D.C. A Sunday night welcoming party and an all-day schedule of educational presentations and panels Monday prepared attendees for over



**More than 50 wheelchair users participated in this year’s Roll on Capitol Hill event.**

200 congressional office visits Tuesday. The busy day on the Hill wrapped up with an awards ceremony and reception during which United Spinal honored Senator Patty Murray (D-WA), Congressman Rob Wittman (R-VA) and Congresswoman Tammy Duckworth (D-IL) for their dedication to serving people with disabilities and veterans.

“Every year this event keeps growing and getting better,” says James Weisman, United Spinal’s executive director. “It has been a pleasure to watch our mix of new and old advocates really come together and represent this community in a way that no one else can. They speak about the issues so eloquently that their representatives have to listen and that’s often the first and biggest step to affecting change.”

Advocates learned about and then hammered home the importance of a number of issues critical to the spinal cord injury community, including Complex Rehab Technology, safe and accessible transportation and adequate funding for Medicaid.



**NEW MOBILITY’s senior editor, Ian Ruder, meets with his elected representative’s staff.**

First time attendee Andrea Dalzell found being surrounded by so many like-minded advocates to be empowering. “Learning about the different bills and legislation was great, but the highlight for me was seeing so many advocates come together and share their passion to get these bills passed,” she says. “There is a big wall to climb to get the change we want, but after an event like this you see things from a different light and it adds to your confidence that we can do it.”

Returning attendees say they can see progress being made, even if it doesn’t always manifest in change as quickly as they would like. “The wheels of progress turn slowly,” says Willis Washington, an Oklahoma member who has attended three of the four Rolls. “It takes time, you’re not going to always hit a home run the first time you step up to the plate. I hope that we continue to build our relationships with our legislators and I hope in turn that we as advocates take it upon ourselves to be more involved and make change.”



**United Spinal’s Alexandra Bennewith, Jim Weisman and Illinois member Steven Burns met with Illinois U.S. Rep. Tammy Duckworth.**



The post-50-year set

## Historic Gathering of 40- and 50-year SCI Survivors

By James Krause

**O**n June 7, the spinal cord injury research team from the Medical University of South Carolina held a historic celebration of the Longevity After Injury Project in Minneapolis, Minn. The celebration brought together study participants and guests, including 10 SCI survivors who are more than 50 years post-injury. The people with SCI in attendance averaged 41.8 years post-injury and only a handful were less than 30 years post-injury. The event commemorated and celebrated 40 years of research for this study, which was initiated by Dr. Nancy Crewe, at the University of Minnesota in 1973. The celebration was held in Nicollet Island Pavilion on the Mississippi River in downtown Minneapolis.

Former president of the National SCI Association, John Schatzlein, received the Career Contributions Award, much to the delight of the attendees, many of whom he had known for nearly 50 years and for whom he has served as a peer mentor. Barbara Armour was presented with the Longevity after Injury Award, having reached 58 years since the



Don Bania talks with 54-year survivor, Don David Taylor.

onset of her SCI. Other awards included: Community Contributor Award to Margo Imdieke Cross, who has spent countless hours advocating for accessible environments in Minnesota; Staff Lifetime Contributor Award presented posthumously to Sarah Lottes, who had a tireless commitment to SCI and who literally worked with the research team until the day she died in February at age 72. Laurel Cibick accepted a plaque of appreciation on behalf of her mother, Dr. Nancy Crewe, who initiated the study.

The collective accomplishments of the participants are amazing. There have been over 2,200 participants since the study's inception in 1973 and they have collectively worked for over 12,500 years, logging more than 22 million hours of gainful employment.

Several current and former participants were recognized for their outstanding individual accomplishments, including Dr. David Gray, who was one of the true pioneers of disability rights and a leader in SCI research, both as an investigator and presidential appointee as director of the National Institute for

Disability and Rehabilitation Research. Dr. Gray also passed away in February, and he had been the first individual to plan on attending the event, saying "I will be there." He was there in spirit, as were so many others.

The event was a reminder of the magnitude of accomplishments by so many people with SCI. Dr. James Boen wrote the book *The World's Oldest Living Quadriplegic* prior to his death after 56 years with SCI, a total eclipsed by two current participants. Larry Kegan was a boyhood friend of Bob Dylan and played on stage with him. Other individuals have written books, including Robert Peters (*A Dive Too Deep*) and Mike Patrick (*I Still Believe in Tomorrow*).

When the study was initiated in 1973, living 40 years with SCI was viewed as unattainable, yet there were 26 people at the event to have lived more than 40 years with SCI. Those attending were proud that knowledge gained from their participation has helped improve understanding of SCI and the changes that occur as people age with SCI.

This was a truly inspiring event, even for



Barb Armour, a 58-year survivor, accepts the Longevity Award from principal investigator, Jim Krause, who is himself 43 years post-injury.



Two 40-plus-year survivors, John Schatzlein and Bruce Gryting, share some memories

## Tennessee Member Jessica Harthcock: Determined to Help Others

Jessica Harthcock and her husband, Adam, had been working without a salary for over a year to develop an application that would match people with neurological disabilities with the facilities best suited to their needs when they just about decided to give up. Harthcock had been developing the idea since she had to navigate the overwhelming maze of options after she was paralyzed in 2004. Thanks to her family's help, she managed to find the right facilities and studies that would eventually help her walk again (see "The High Costs of Walking," March 2014). Knowing others were not as fortunate as she had been and didn't know where to turn, she had persevered through college and graduate school to get the skills to build her dream business and help them. Then, in 2012, everything came to a halt.

"It all fell apart at the 11th hour," she recalls. The challenge of launching a business reminded her of her battle to walk again. "You take two steps forward, then you take 10 steps back. And you don't know what's going to happen the next day or if you're going to make it to the next milestone."

Just as she had refused to give up when doctors told her she wouldn't walk again, once again Harthcock soldiered on. "We actually thought about throwing in the towel and moving on and then someone reminded us what we were trying to do," she says. "I felt very compelled to be able to build something that truly matters that can help people. That's what kept us going."

Over the next three years, Harthcock and company would take part in a business accelerator program, a global health challenge, a start-up challenge and a head-to-toe



**Adam and Jessica Harthcock, along with the whole Utilize Health team, want to make it as easy as possible for people with disabilities to access quality health care resources.**

rebranding effort. They didn't win any of the big competitions, but gained valuable feedback. Seeing so many startups up-close and personal helped Harthcock better appreciate what set Utilize Health apart and what made it so important. "I think a lot of companies know what they're going to do and how they're going to do it but we started with the why, which is I think a little more unique. We've always known our why and every day we go back to doing this because patients need help and facilities need help finding patients."

This spring, Harthcock's determination paid off when she officially launched Utilize Health, the matching application she had always dreamed of. At its most basic, Utilize Health is a quick and easy Web-based matching service that asks users questions to determine which medical facilities offer the best match for their needs. The user's location, disability, payment options and health are among the numerous factors its algorithms take into account as they whittle down the hundreds of medical facilities in the database. Right now the site is intended

for people with SCI, brain injury, stroke, multiple sclerosis, muscular dystrophy and cerebral palsy, but Harthcock hopes to expand it.

Harthcock's original vision was simply to match clients, but as the service has evolved she realized many clients needed more than a list of places that would best suit them. "They were like, 'I want to be matched but after you help me find those resources, I literally need you to help me get to those resources by calling my doctors, by helping me write an insurance appeal, by finding me transportation.' ... It was fascinating because it was outside of our scope at

the time, but we took it as a cool customer development opportunity." Those needs led to the birth of Utilize Health's patent advocacy program.

Matt and Jill Wheeler are two of the early beneficiaries of that program. The Tennessee couple was among hundreds of people nationwide who reached out to Utilize Health following an article on Harthcock's efforts in *USA Today* in November 2013. Since the Web application wasn't ready, Harthcock and her team had matched Matt to find therapeutic options for his type 2 spinocerebellar ataxia. "Jessica was wonderful in helping open our eyes to some things we were not aware of and things most doctors don't consider because they are outside of the box," says Jill. Through Utilize Health's advocacy help, the Wheelers got their insurance to cover an extensive amount of therapy which the couple say has greatly improved their lives. "I was pretty depressed after the diagnosis," says Matt. "Utilize Health gave me a newfound life and drive."

those of us who have lived for decades with SCI. The study participants have faced many unique challenges, but despite that, have worked tirelessly to make this world a better place for all of us with SCI. Together, we have worked to facilitate accessible environments, promote employment, and advocate for policies that create opportunities. We look forward to the next generation of people with

SCI building upon these accomplishments and with hope for anyone with SCI that they have the opportunity to live long, healthy and fulfilling lives.

- The Longevity After Injury Project, Medical University of South Carolina, 843/792-2300; [www.longevityafterinjury.com](http://www.longevityafterinjury.com). Also look for the project on Facebook and LinkedIn.

*Dr. James Krause is a professor and associate dean for research in the College of Health Professions at the Medical University of South Carolina and serves as director of the Center for Rehabilitation Research with Neurologic Conditions and scientific director of the state of South Carolina Spinal Cord Injury Research Fund. He was paralyzed at the C4 level in a diving accident in 1971 at the age of 16.*

## Mission

United Spinal Association's mission is to improve the quality of life of all Americans living with spinal cord injuries and disorders (SCI/D). Membership in United Spinal is open to anyone with an interest in SCI/D. For more information on the benefits of joining, visit [www.unitedspinal.org](http://www.unitedspinal.org) or call 800/404-2898.

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# KENNEDY NGANGA:

## Painting So Others Can Live

BY MARK BOATMAN



Sustaining a spinal cord injury can turn anybody's life upside down. Now imagine dealing with an SCI in a country with limited medical care, no government assistance and rare access to even a basic manual wheelchair. When Kennedy Nganga became a C3-4 incomplete quad after a diving mishap in 1992, he spent over two years in an orthopedic hospital ward before coming home. In the years after his accident, he would go on to become an accomplished painter. But his true calling may be his philanthropic work through the Momma Kennedy Mission, which empowers, educates, and helps Kenyans with disabilities find mobility equipment, food and clothing.

Nganga's story began near the coastal metropolis of Mombasa, Kenya's second largest city. He grew up near the beach and quickly developed a passion for swim-

ming that would carry him to becoming a decorated high school swimming champion. But a diving accident when preparing for a swim meet left him in critical need of immediate care. "In our country we still only have one hospital that takes care of spinal cord injuries," he says, "and it's in Nairobi, 600 kilometers from here." He was sent instead to a nearby orthopedic ward.

In the hospital, Nganga developed severe pressure wounds that went down to the bone. His health was in significant decline until his mother, Sethi, stepped in and learned how to care for her son. "When I came home she was there for me 24/7," he says.

Nganga was able to be mobile in his wheelchair until 1998, when he moved with his mother to a small house with an earthen floor. He's rarely been out of bed since because there is very little room to maneuver



Thanks to Nganga's philanthropic endeavors, these school children are learning art at a rescue center.



Nganga's Momma Kennedy and Friends Fund provides disabled Kenyans with goats and other goods.

his wheelchair and there are two large steps to reach the outside. When he needs to leave his home, it takes three strong men to carry him and his wheelchair outside. This limitation has done little to stop him from pursuing a fulfilling life that has given much to many people around him.

His introduction to painting came during his hospital stay when a missionary brought him a magazine article about Joni Eareckson Tada, the noted Christian author and disability advocate. "Joni had a diving accident just like me and she was painting and helping other people," he says. "I said if she can paint using her mouth, why couldn't I paint with my hands?"

He experimented with various paints and colored pencils but had trouble holding the brush. In time he

managed to develop a technique holding the brush between his right index and middle fingers. It wasn't long before he was turning out many works of art. Sketching was an outlet for Nganga's considerable stress after the accident. It was a form of therapy that grew into a way of living, he says. He began painting the landscapes of Mombasa and various types of African wildlife.

## Scarce Resources, Abundant Vision

In 2002, Nganga wrote a letter to Hubert Seifert, the director of Kenya's Association for Persons Living with Disabilities, requesting assistance for an art teacher to visit his home. Seifert himself visited and encouraged him with his art. Later an art teacher began teaching him seven lessons on the basic elements of art. "That was the foundation for my art, and from there I've never looked back," he says.

He developed into a skilled artist and soon had a growing Facebook following with his vibrant and colorful paintings. The income generated from selling his paintings on Facebook is Nganga's main source of earnings. Proceeds also help fund his philanthropic efforts. And this was just the beginning. "Because of my customers, I had to keep on learning," he says. "People bring me everything that they want me to paint from — pets, dogs, cats, their houses and portraits of their loved ones, everything."

Candace Cable was one of his Facebook followers. Cable, 61, purchased a sea turtle painting from Nganga but became more deeply connected to him through his compassionate spirit. His wide smile and willingness to always forge ahead spoke to her. "He's very committed to giving back, and he also helps to look after others with disabilities and provide for them when he has so little," she says. That commitment is something few Americans can grasp. "It's unimaginable, I think, to those of us living here in our 'bubble' to comprehend what it takes to live with SCI where he lives," she says.

Cable has unique insight into Nganga's trials. Left a paraplegic by a car accident in 1975 at the age of 21, her life became a depressing purgatory. "I thought my life was over, and I felt isolated," she says. Rehabilitation did little to ease her isolation. Nothing changed until she received counseling and enrolled in California State University Long Beach.

Also, Cable is an accredited representative to the United Nations for the Christopher and Dana Reeve Foundation. Her role is to focus on sustainable global developmental goals, so she understands the plight of people with disabilities in poorer countries. She says 80 percent of children with disabilities don't attend school. "They don't go to school because they can't get to school and their parents don't know they can go to school," she says. Children with disabilities are often told they are worthless or undesirable. "That is what Kennedy is dealing with there, and my limited understanding of that feeling of isolation is magnified a hundredfold for him," she says.

His work relieves the isolation for people in Bamba, a



poor, marginalized area where the need for help is dire. Cakes are an expensive commodity in Kenya, but Nganga has arranged to buy the leftover crumbs cheaply from a major bakery. Cable is amazed at how much his handing out of cake crumbs means to the residents. “He lives in a society where there’s such scarcity, but there’s abundance in his vision that everything counts,” she says.

### Birth of the Momma Kennedy Mission

In June 2011, Nganga’s life came crashing down when his mother passed away. As she was both mother and sole caregiver, Sethi’s death was a crushing blow to his spirit and future. “I thought it was the end of me,” he says. “The biggest problem was how to heal.” Luckily, one of his younger brothers abandoned working and stepped into the role of caregiver.

After a traditional 40-day period of mourning, Nganga wanted to remember his mother, but he only had a small amount of money left from her burial. He told his Facebook friends that he wanted to help his brothers and sisters with disabilities living in Bamba.

The money raised for the destitute village marked the beginning of the Momma Kennedy Mission. Nganga coordinated a drive to collect clothes, shoes, bedding, books, school bags and kitchen utensils. Many disabled people in the village were hidden away by their families, but that changed when they came out to register for assistance.

Initially, the Momma Kennedy Mission gave away a goat and chicken to 10 families living in Bamba. Goats are valuable assets for the village. “The goats provide nourishing milk, and goat’s milk is regarded as medicinal here,” he says. “Once you give someone a goat, the goat will reproduce and you’ll be getting milk.” The chicken eggs are an excellent source of protein, and chickens require much less maintenance. “Chickens here just roam and you don’t have to feed them,” he says. To date, the mission has given away over 400 goats and chickens.

The response from the citizens of Bamba during the first year was so great that Nganga decided to start a Mbazizo community-based organization that now assists about 750 members with varying disabilities.

Four years ago, Nganga’s attention was brought to three blind girls living in Bamba. Nuru, Amina and Kwekwe weren’t doing well and needed help desperately. Facebook followers once again came to the rescue, helping to place the girls in a quality boarding school.

Nuru and Amina were not only blind, they were also born with albinism — lack of pigment in the eyes, skin, hair, and nail cuticles. The girls had lived a tough life and never had access to something as simple as sunblock. “I thought the best way is to move them from the village, bring them to town, where they joined a special boarding school where they get lotions, food and education,” he says. “Now they are in a very good school, they are doing very well and they are the best in their classes.”

The non-albino girl, Kwekwe, dropped out of school

for three years because she couldn’t pay the school fees. Nganga made sure she got back to school. She’s supposed to be in high school but is in grade six. That isn’t stopping Kwekwe from achieving her goals. “She’s very confident and her dream is to become a teacher,” he says. “She wants to prove to our community and to our family that blind people are ordinary people and can achieve more than other people.”

Helping the girls puts a huge smile on Nganga’s face. “It makes me feel excellent,” he says. “It gives me a purpose to live.” The support of his Facebook family for the girls has been amazing. “I don’t call them my girls, I call them *our* girls on Facebook because they belong to many people,” he says.

### Growth and Gratefulness

Nganga’s artistic talent has evolved considerably during the past three years, thanks to his friendship with artist and missionary Michael Lang’at. A member of the Kalenjin tribe from Nakuru, Lang’at began teaching Nganga art daily for two hours, but it was difficult



Proceeds from Nganga’s paintings support his charity work.



One way Nganga honors his mother is by helping others, such as this villager.



Nganga takes special joy in ensuring these three sisters receive an education.

**“He’s very committed to giving back, and he also helps to look after others with disabilities and provide for them when he has so little. It’s unimaginable to those of us living in America to comprehend what it takes to live with SCI where he lives.”**

because Nganga had a weak grip and low confidence in his ability. However, over time, his ability soared, and he only needed lessons twice a week. According to Lang’at, it has been a fun challenge for the both of them. “We have come a long way,” he says. “It’s fun because he is not a boring person to be with, he’s really outgoing and down to earth.”

When they began their partnership, Lang’at admits he pitied Nganga and wasn’t hoping for great achievement. But Nganga surprised his new friend. “Little did I know the potential he had in him,” he says. “He went on to challenge me a great deal. He humbled me tremendously.” He also loved that Nganga thinks big and isn’t afraid of looking beyond his own community.

As Nganga’s art flourished, Lang’at became active in the work of the Momma Kennedy Mission. Almost every day, Lang’at hops the ferry for the three-hour trip to the other side of the island where Nganga lives.

By networking with people on Facebook, Nganga discovers many children and adults with disabilities who are in dire need of assistance. They may need financial help, clothing, food or basic mobility devices like crutches and wheelchairs. Since Nganga often can’t get out of bed, Lang’at travels to carry out missionary work on his friend’s behalf. “He would send me to go check on the situation and then bring feedback to him if there is a need,” he says.

One of Nganga’s many accomplishments includes getting a small health clinic built for the poor living in Bamba. He received vital help with the project through his friends at the Love and Light Ministry in Singapore. These efforts astound Lang’at. “The greatest miracle of all is that he does all this from his bed,” he

says. “It’s unbelievable.”

Lang’at has greatly enjoyed watching his friend succeed. “His talent has really grown and it’s the main part of his life,” he says. “I don’t think he would enjoy life without it.”

The Momma Kennedy Mission has achieved much, but Nganga’s proudest accomplishment is the disability awareness that he has been able to foster. “In that area, most families keep their disabled persons hidden in houses, and they don’t expose them to outsiders,” he says. “We managed to make them bring the disabled persons outside.”

Last August, the Rotary Club of Mombasa North Coast partnered with Nganga by setting up a large medical camp in Bamba. Rotary has provided tremendous assistance with the medical needs of the village. They also made Nganga an honorary member of the organization.

Meanwhile, his painting skills continue to improve. “I’ve gotten better, and I keep on getting better,” he says. The vibrant paints that he uses lend more realism in every painting he does. Once the canvas is prepared by his brother, it doesn’t take long for him to complete a painting. The more complicated paintings with intricate details can take over a week to complete.

He estimates he has completed nearly 150 paintings. He encourages people to contact him via Facebook to commission a painting. He sells his work directly to clients through his PayPal account. A portion of each painting benefits the Momma Kennedy Mission.

Kenya is a poor country, and Nganga hopes to soon improve his living conditions. Currently, he lives in a small house with inadequate wheelchair access. He’s hoping to move into a wheelchair-friendly home, which has been under construction for nearly three years, financed mostly by his art sales and a few friends. The new accommodations will boast electricity, running water, a studio and art gallery and small boardroom where he can meet with people. “It will also be a mission center where people can bring stuff, and I’ll be finding where to take it for the needy people,” he says.

Twenty-three years after his accident, Nganga says he’s still adjusting to life with a spinal cord injury. The hardest part of his life is that the Kenyan government gives no assistance to people with disabilities. Wheelchairs are extremely rare. “We have people who have never accessed a wheelchair in their life,” he says. “To access a mobility aide sometimes is a miracle, and it’s taken as a luxury.”

Life for Kennedy Nganga has been a series of small and large miracles. Helping others is more than a physical act to Nganga, who says he has so many people to thank for making his life fulfilling. “First is to thank God — and to thank each and every individual who has stood by me, my Facebook family and friends,” he says. “They have made me who I am.”

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# OUTDOOR TRACKS



Nakoda

By Kary Wright

It is a beautiful spring day, the sun is shining, the grass is green and we are enjoying father-daughter time out at the farm. We are hunting a common prairie pest, the gopher. These little creatures are much like a ground squirrel, but their burrows are dangerous to horses and cattle, so we keep their numbers down. My daughter has walked over the hill, and I sit back at the wheelchair accessible portions of the field with our trusty yellow lab, Nakoda.

"Now you stay back here with me, I'm going to be shooting so you can't go out in front of me," I say to Nakoda. She looks into my eyes, walks calmly back and lies down right beside me with an exaggerated sigh. I move forward to position myself for the shot and feel my wheel drop into a rut. Uh-oh, I try to back out, only to spin down deeper.

"Dang," I mutter as I realize I am stuck. "Can you go and get Shania?"

Nakoda trains her eyes on mine and her ears perk up as if to ask me to repeat the question.

"I got stuck, my wheelchair won't move, will you go get Shania, she is just over the hill over there," I say, gesturing and looking to where I want her to go. She looks that direction, and then stares back for verification. "That's right, that's where she is."

Nakoda springs to her feet and bolts off.

I calmly sit and wait, frustrated with myself that I got stuck in a tire rut once again, but glad that it is a nice day and my coffee



cup is full. A little while later my daughter walks up over the hill a couple of hundred yards away.

"Did you send the dog to look for me?" she calls. "She kept bouncing in front of me."

"Yes, I got stuck in a rut here."

Shania walks over, chuckling, once

again rescues me with a simple pull, and then refills the clip of my gun.

"Good girl!" We reward the dog with pats. She smiles back and wags her tail.

\*\*\*

We had come to realize as Nakoda grew older that we could speak to her like a human, and she seemed to understand what we were saying. We could send her to find people and she always seemed to go to the right person. We suspected that this would come in handy. On this day it proved that it was a very valuable game to play.

It is amazing how attached you can get to a dog. They are such constant and loyal companions. I recall going for runs with her leash tied to my chair. She had seemingly endless energy and would run without tiring as far as I wanted to go. I recall her sitting on the picnic table looking over my shoulder as I was writing emails while on camping trips, giving the odd lick of encouragement to the back of my neck.

She loved to be in water, so we would head out to the farm and all I could do was

tell her to swim since I could not throw anything for her to retrieve. She would swim in circles in front of me, and if I wheeled down the shoreline, she would follow. I could always safely take her with me when I was alone and could count on her to always be by my side even though I could not put a leash on her. I fondly recall her tireless frolicking in the waves on the Texas Gulf Coast.

I think of the many





hours she spent lying on her bed under my desk while I worked. She was so patient and would wait until I would ask if she wanted to go for a walk or a swim, then she would perk up and bounce by the door, ready to go! There were all the miles of running she did while retrieving countless tennis balls thrown by anybody who would come by and play.

\*\*\*

As the years went by, walks were getting shorter and shorter, her eyes started getting cloudy, and we wondered if her hearing was diminishing.

A few weeks ago we took a trip to the West Coast and rented a place on the shore. During our trip her breathing became labored. She made it to the shore of the ocean a few times, but showed no interest in going in to the water. She just slowly turned around and sauntered back to us. My wife and I commented that we aren't going to get many more trips with her.

"Come on, old girl! We'll get a short walk in and then you can sleep!" I said to Nakoda one morning. She plodded along, slightly behind me, and showed a noticeable smile. We were planning to take in the last practice routine of the Canadian Air Force Snowbirds aerobatic team. Nakoda would stay at the cabin and relax while we were gone for a few hours. She slowly followed me back to lie down on the porch. We could tell that she wasn't feeling well; she was not her bubbly self. As we were explaining to the owner of the cabin about our concern for her, Nakoda

got a funny look on her face. My wife was familiar with that look and right away knew that a seizure was about to happen. They held her through the seizure, and we rushed to the nearest veterinarian, only to find that there was no hope for our great friend and family member.

"I want you there waiting for me when I get there," I said, gazing into her eyes. She stared back into mine as if to let me know that she had gotten the message. Then she took her last breath and was gone.

If there are no dogs in Heaven, I want to go where the dogs went.



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# RAISING A RUCKUS

The archetypical disability cheater should be living it up on those felonious checks, hanging out by his infinity pool and drinking Crown Royal.



By Allen Rucker

## The New Welfare Queens

If you've been keeping up with the news lately, you know that potshots aimed at the disabled are back in favor. This is not the first time our entire demographic has been slandered — for too much ADA regulation, too many government handouts, or just a pain in the libertarian back end. Given that there are 14 people running for the Republican nomination for President, including Donald Trump's hair, and 90 percent of them are small-government believers, we of the disabled class might find ourselves in the crosshairs for a while. We may even come in for some mild rebuke from Hillary Clinton, but since she has yet to make a policy speech or let a reporter ask her a question more serious than *How do you like our Iowa pork?* — it's hard to know.

Leave it to Rand Paul, the one candidate who seems to speak his mind, whether you like it or not, and in general, doesn't like the government giving people money, full stop. Campaigning in New Hampshire last week, he laid it on the line when it came to "safety net programs": "Everyone in this room knows someone who is gaming the system. Over half of the people on disability are either anxious or their back hurts. Join the club. Who doesn't get a little anxious for work every day?"

Note: these comments came from video shot by a Democratic opposition research group. "Fifty percent of people on disability are cheating dogs"

may become this year's "47 percent of Americans are deadbeats."

Whether Rand's statistics are true or not, the strategy here is clear. Anyone in the audience might have walked away, saying, "Gosh darn it, that's where my tax money is going — to a bunch of conniving crybabies in wheelchairs! Boy, that burns my bonnet!"

This is burgeoning stereotype — the disability cheater. Who is he or she? What's the most egregious crime these scofflaws have committed? A penny ante scheme of making a few grand a year in a government shakedown? Hey, man, Bernie Madoff has got nothing on you.

The first thing that comes to mind are those local news reports with grainy video showing some guy collecting disability for his debilitating lumbago as he's bowling in a league championship. That's stupid to get caught like that, but it's not going to anger millions. If you were around in the early 1970s, you might remember the dreaded "welfare queen." Ronald Reagan often alluded to the real-life example of one woman from the South Side of Chicago who had 12 social security cards and was drawing veteran's benefits from four patriotic but nonexistent dead husbands. The implication was that this super-queen was not unique, just one of millions of such ghetto gamers. (They were always black and always women.) Someone else came up with the image of a welfare queen driving her brand

new Cadillac down to the welfare office to collect her 12 checks, and that's what really stuck in the minds, and craws, of Middle America. It became the stuff of a thousand political cartoons.

They haven't come up with that kind of deeply resonating image of the disability cheat yet, but I bet someone's working on it. The fat guy with the trick knee loading up 90-pound bags of Quikrete at Home Depot is a start, but it needs something like a Cadillac El Dorado or gold jewelry to really sell it. It's got to be more upbeat, more aspirational. The archetypical disability cheater should be living it up on those felonious checks, hanging out by his infinity pool, drinking Crown Royal, fending off buxom beauties while having a faux sword fight with his crutches. Something like that would make millions envious *and* angry.

While we await our moment as the welfare queens of the future, just know that Rand Paul is not alone in working this angle. Pundit Anne Coulter recently opined that people in wheelchairs should be barred from entering the United States and applying for citizenship. That's all we need, she snarled. More low-lives gorging at the Federal trough, and they don't even speak our language!

Bottom line: These hardballers are picking on an entire class of people who often have severe needs — and virtually no political voice. Now that really burns my bonnet.



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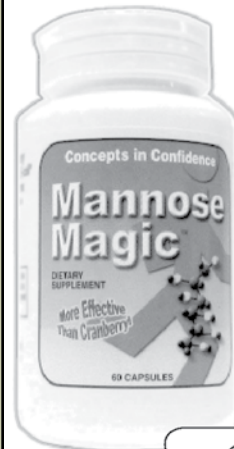
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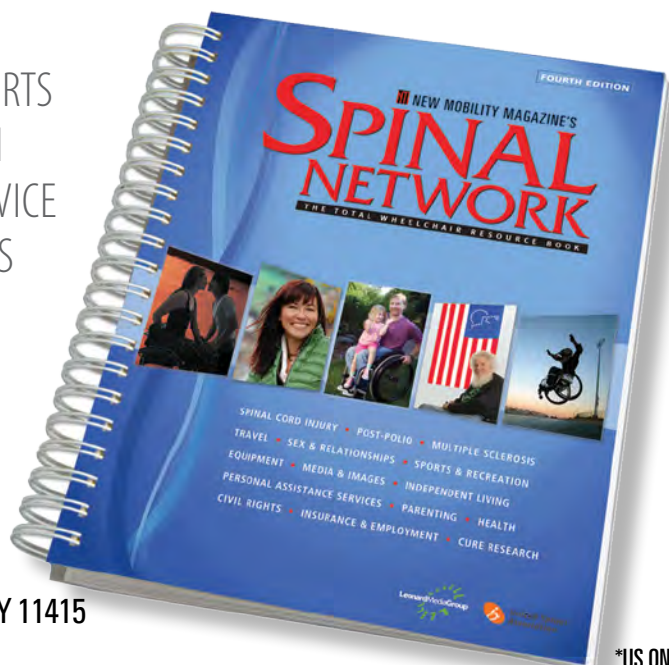
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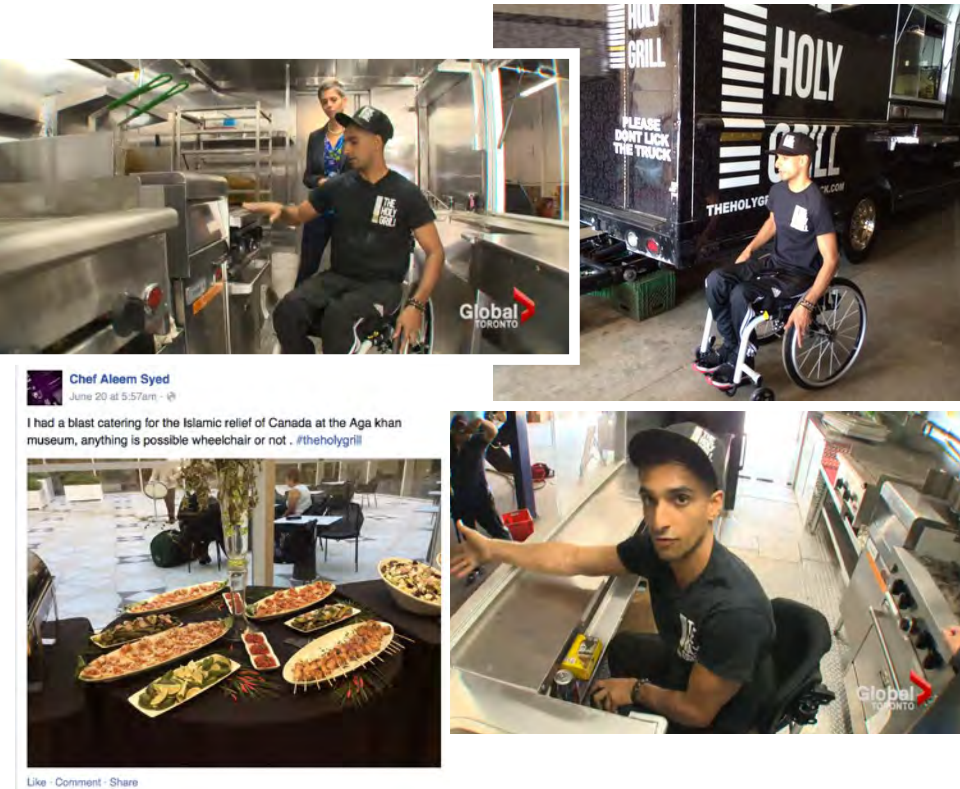
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While ADAPT activists in Austin are protesting food trucks for lack of access, wheelchair-using entrepreneur and chef Aleem Syed owns and operates a fully accessible food truck in Toronto. “I didn’t understand how I could make it work,” confessed the halal chef to Global News in December. But then French chef Pascal Ribreau, who is also a paraplegic, showed Syed his own accessible kitchen.

Soon Syed was working with designer Kashif Tejani and in less than a year The Holy Grill was ready to hit the road. “It was definitely quite challenging,” said Tejani, about getting accessibility features such as a custom ramp into a vehicle that has to hold an industrial kitchen.

Syed plans to bring his truck to the United States so he can be closer to a Project Walk facility.

Read more at [globalnews.ca/news/2023403/chef-breaks-barriers-with-custom-wheelchair-accessible-food-truck](http://globalnews.ca/news/2023403/chef-breaks-barriers-with-custom-wheelchair-accessible-food-truck).

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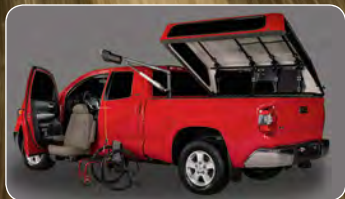
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