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Special thanks to Kimia & Matt Othick and the entire team at San Diego’s Crust Pizzeria on Carmel Mountain Road.
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Transportation network companies like Uber and Lyft are revolutionizing the way we get around, but are they leaving riders with disabilities at the curb? JOSIE BYZEK checks in all around the United States to see how the revolution is affecting our community and the different ways people are adapting to the new reality.

ALL ABOUT UBER  22

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The days of renting a wheelchair accessible minivan with hand controls from an adaptive van dealer are all but over. Too bad.

I love minivans. In 1984 I bought the first available minivan, a Plymouth Voyager. Then I purchased a 1988 Grand Caravan with the more powerful engine, followed by a used 1993 model. Now I own a 2001 Town and Country with 163,000 miles on it. I’m fortunate to be a low para with decent arm and shoulder strength. I use a tall wheelchair, so I can transfer with no need for a lowered floor. I take out one back seat, get in on the passenger’s side, pull my chair in with the wheels on, slide over to the driver’s seat (no console) and go.

I have rented dozens of minivans with hand controls from airport rental companies. I did that throughout the 1990s up until about 2012, renting in California, Florida, New York, Arizona, Hawaii — wherever business or pleasure took me. Then the airport rental companies stopped putting hand controls on their minivans.

Today if you try to rent a lowered floor minivan with hand controls from an adaptive van dealer, with rare exceptions, you will not succeed. You can rent one for someone else to drive — a nondisabled friend, spouse, or aide, but if you want a hand-controlled minivan to drive yourself, forget it.

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The largest wheelchair accessible van dealer in the United States, Mobility Works, advertises wheelchair accessible minivans for rent. With 57 stores, they are one of the fastest growing companies in the United States. I called three Chicago area Mobility Works stores, looking to rent. The first store said they had one minivan with hand controls, but it was out, rented for one year. What? One year? The second store said the only hand-controlled minivan they had was out for two years. At $79 per day, that’s $59,250! Huh? The third store said Mobility Works has no hand-controlled minivans for rent in all of Illinois. Hmmm.

I called three other Mobility Works stores in different states but never found a single minivan available with hand controls. A smaller dealer (not Mobility Works) told me: “Ninety percent of people who want to rent a minivan are (nondisabled people) who need to pick up Grandma at the airport. It’s too much hassle putting hand controls on and taking them off.

Besides, it’s not a problem for those who need hand controls if they plan ahead.”

Really? Not a problem for the single mom who’s a para and wants to drive her children on vacation? Not a problem for the businessman wheeler who flies frequently by himself and must have a ramp van? Not a problem for me when I wanted to visit my nephew who was dying in a hospital in a distant location 200 miles from the nearest airport?

I tried contacting the president/CEO of Mobility Works multiple times to clarify the company’s rental policy and have a discussion about the ADA, but ... no response.

Have you had a similar experience? Let me know.

— Tim Gilmer
Joanne Smith sustained a spinal cord injury at 19, then went on to earn a psychology degree and become a certified nutritional practitioner. Dedicating her career to raising awareness of disability issues, she has hosted and produced two national award-winning television programs that focused on telling in-depth stories about Canadians with disabilities. She also runs her own successful nutrition company in Toronto, working with clients with neurological injuries. As if that isn’t enough, she models and is an experienced public speaker. She lives with her husband and loves to handcycle at every possible opportunity.

Since his C5-7 spinal cord injury in 1988, Michael Collins has been bringing information about disability and accessibility to the mainstream and disability communities. Mike began writing for New Mobility in 1991 and is currently the author of two NM columns — Everyday Advocacy and Motorvation (as “Uncle Mike”). Besides writing, Collins has served as executive director of both the California State Independent Living Council and the National Council on Disability. He attributes much of his success to an ability to convert frustration into actions necessary to achieve change, and he strives to share that information in his writing.

Bill Mancini is an elementary school special education teacher and president of the Spinal Cord Injury Association of Connecticut. He has a sixth year degree in educational leadership and has been active in disability advocacy for the past 10-plus years. Mancini is an active peer visitor, lives independently with a spinal cord injury and does motivational speaking, where he focuses on “not making excuses” and problem resolutions. His involvement with the SCI community focuses on the Connecticut Chapter’s mission of representing member’s rights and promoting healthy living.

As vice president of government relations for United Spinal Association, Alexandra Bennewith directs advocacy strategy for legislation and regulations regarding federal and state health and disability policy. She is also a steering committee co-chair and member of multiple coalitions and committees, including the American Spinal Injury Association and the Multiple Sclerosis Coalition. Bennewith has more than 17 years experience in government and public affairs. She lives in Fairfax, Virginia, with her husband, David. In her spare time she and David enjoy cycling and eating. “The more we eat, the more we need to cycle,” she jokes.
Thanks to Portlight

Portlight Strategies and all of its partners are working to prevent the kinds of chaos that disabled people experienced during Katrina and Sandy [“Training the Red Cross,” March 2016]. I can testify firsthand that Portlight made a real, tangible difference in my home community of Coney Island in the aftermath of Superstorm Sandy and has continued to provide relevant support and resources.

Leslie Freeman
via newmobility.com

Money and Planning

When storms hit, people in the path of those storms suffer tremendous economic pain [“Training the Red Cross”]. But people with disabilities whose incomes are marginal at best don’t have the monetary means to relocate, nor are facilities and equipment readily available. When streets are riddled with debris, it is impossible for people with mobility issues to even move to a place of safety. Wheelchairs don’t roll over tree limbs. Power wheelchairs require electricity, as do breathing machines. Medications often require refrigeration. Disasters wreak havoc on most people but can be deadly for people with disabilities. It’s imperative that FEMA and area emergency management agencies have plans that include places where disabled people live. They need to be aware of medical requirements and whether a safe place should be either a shelter or a hospital. The only way solutions are going to be found is by including disabled people in the planning stages.

Danny Neff
Lavaca, Arkansas

Climate Change Disasters

The job I worked at assisting people with disabilities started disaster prep a few years ago in case of an environmental emergency, which included random simulations of what to do and extensive quarterly training [“The End of the World As We Know It,” March 2016]. But this started only a few years ago. You would think all agencies would do this, but ours was a pioneer. I agree that the minority group of people with disabilities is often left out, which is incredibly disheartening, but a lot of it is just ignorance by the majority, not intolerance. Thank you for spreading the word about this and the incredibly scary reality of our current climate state.

Shantra Perez
Eugene, Oregon

More Chairs, Lower Cost

Many years ago, my husband took my daughter’s old manual wheelchair, bought the big EZ tires and welded a system to connect the two (“Beach Wheelchairs — More Available Than Ever,” March 2016). She has used this for years, allowing a completely different beach experience for the whole family. It even floats so she can “jump” waves. People come up to us every trip asking where we got it. I’m glad to see so many other options now, and I hope as their popularity grows, the price on these remarkable chairs will become more affordable for every beach town to have plenty for all who need them.

Christie Smith Hilliard
via newmobility

WD-40 to the Rescue

I would like to recommend that Kary Wright add a can of WD-40 to his tool arsenal (“The Dead Chair Game,” Outdoor Tracks, March 2016). WD-40 (the WD stands for “water displacement”) is great for drying out wet electronics. It has saved my life a few times.

Paul Vaughan
via newmobility.com

Other Side of the Desk

Allen Rucker writes an interesting column about Texas Governor Greg Abbott and his cynical abandonment of the disabled community [“The Strange Case of Fightin’ Greg Abbott,” Raising a Ruckus, March 2016]. What he did not mention is that Abbott sued when he became a paralyzed law student and as of 2013 had collected $6 million, and ultimately could be $9 million. Rucker is right. Abbott was probably as empty of compassion before his paralysis as he has been after. A multi-million dollar settlement has sure enabled him to be even more disgracefully insensitive. Without all those dollars, Abbott would have been on the other side of the desk alongside ADAPT in the governor’s office, not snubbing them.

Nicholas Fowler
Elizabeth, Maine

Reaction Formation

I appreciated the column on Greg Abbott. His injury clearly didn’t make him more empathic. In fact, in people like him, the tendency is to get worse in regards to empathy. Speaking as a psychologist and a quad, it is what is called a reaction formation. Put simply, the feelings that you have for yourself are unacceptable, so you go in the opposite direction. This made me think about whether Abbott might have been more empathic had he become a quad. I used to work on a spinal cord injury unit (one of the top ones in the country) and had a guy as a patient who became a quad when he was 18–20. I found out much later that he became a judge in a mid-California county and was known for his insensitivity to the needs of poor and disabled people. He seemed to have forgotten that he was a recipient of Medi-Cal and other state-funded services.

Dan Mayclin, Ph. D.
via newmobility.com
“Since I have been using iLevel, it has been a lot easier for me throughout my day. Whether I am in school or attending a concert or ceremony, I can now see what is going on in front of me. My friends had to look down at me in my other chair. iLevel works a lot better for me because I can now talk to my friends and drive my chair at the same time at eye level.”

Zoe Hernandez
United Spinal and NYC Reach Curb Cut Settlement

On April 7, 2016, United Spinal Association and New York City agreed to expand a groundbreaking 2002 settlement in a class action lawsuit that requires the city to install and upgrade wheelchair curb cuts at all of its street corners.

“Now that the great majority of curb ramps have been installed, we felt it was time to revise our agreement. We are glad the city agreed to work with us,” said James Weisman, United Spinal’s CEO.

Under the new agreement, NYC will continue to spend $20 million per year and another $87.6 million through fiscal Year 2017 to finish installing and upgrading curb ramps citywide — all in addition to the $243 million that it has spent under the 2002 settlement to ramp 97 percent of its 158,738 corners, as required by the Americans with Disabilities Act.

The 2016 settlement arose out of disputes between United Spinal Association and the city over implementation of the 2002 settlement concerning installation of curb ramps at 3 percent of corners in the city remaining to be ramped, and the need to upgrade curb ramps that complied with the ADA when they were installed but are no longer ADA-compliant.

To resolve those disputes, the 2016 settlement requires the city to continue to spend $20 million per year to install curb ramps, augment those expenditures with $37.6 million in FY 2016 and $37.6 million in FY 2017 to upgrade existing curb ramps and provide $11.5 million in FY 2016 to upgrade existing ramps in high-construction and/or high density areas.

As 97 percent of NYC street corners are now ramped, the city will no longer use neighborhood-by-neighborhood "blitz construction" to install ramps, but will install and upgrade curb ramps, as needed, on corners adjacent to streets that are being resurfaced.

People in the News: Cody Unser Diving into the Record Books

She is the granddaughter and daughter of NASCAR greats Al Unser and Al Unser Jr., but instead of breaking records behind the wheel, Cody Unser is making history beneath the waves. On Saturday April 2, the 29-year-old scuba diver extraordinaire became the first paralyzed woman to be inducted into the Women Divers Hall of Fame at the Beneath the Sea awards banquet in Secaucus, New Jersey.

“It was such a huge honor,” says Unser. “What makes this so special to me is the fact that I am the first woman with a disability to be inducted. It’s been interesting for me to see the dive industry embrace the disability community.”

Paralyzed from a sudden onset of transverse myelitis at the age of 12, Unser started scuba diving the following year. “After becoming paralyzed, everything I did or thought about included the broken body I was now living in,” she says. “Scuba diving took all the doubts away.”

She started the Cody Unser First Step Foundation to raise awareness for transverse myelitis. Her foundation has focused on the therapeutic potential scuba diving has for those with disabilities for over a decade. Through her programs, Cody’s Great SCUBA Adventures and Operation Deep Down, Unser has been able to help those with disabilities experience scuba diving for the first time and even become certified.

“Scuba diving is pure freedom from the gravity I feel in my wheelchair everyday. Working with adults, veterans, and kids with disabilities … and watching their excitement from getting out of their wheelchairs and into the freedom of the water is so inspiring.”

On April 18 Unser will conquer yet another milestone when she heads to Key Largo, Florida, with a group of kids with spina bifida and cerebral palsy as part of her “Changing Lives One Dive at a Time” adaptive scuba program. Although they have trained in pools and aquariums, this will be the first group that Unser takes into the open ocean.

For more information on Cody Unser and her foundation visit www.cufsf.org.
Wheelchair Accessible Gondola Rides Debut in Venice

They are used to singing “That’s Amore” as they navigate the picturesque canals of Venice, and now veteran gondoliers Enrico Greifenberg and Alessandro Dalla Pieta are showing that love to the wheelchair community. The two are the founders of the public-private campaign Gondolas4all, and on Friday, March 11, they unveiled the first ever access point for wheelchair users to board Venice’s iconic black gondolas.

A large crowd gathered in Piazzale Roma Square to watch 7-year-old Nicholas Pistolato and a few other wheelchair users take their exciting maiden voyage on the classic Italian boat.

A dream of theirs for more than two decades, Greifenberg and Pieta started a crowd funding page in 2012 after witnessing countless wheelchair users miss out on a quintessential Venetian experience. “Enrico and I decided to start this project four years ago,” Pieta said. “We have been gondoliers for more than 20 years and would see people in wheelchairs who wanted to get in the gondola. They would look at us like we were the last bit of water in the desert.”

Garnering support from The Tourism Department of Veneto Region and many other contributors, they raised enough money for the accessible infrastructure, which consists of a special jetty complete with an automatic lift that allows wheelchair users to comfortably embark and disembark the boat without exiting their wheelchairs.
Q. Some local advocates have made a proposal to our county council to adopt a new version of the symbol that appears in all of the accessible parking spaces in our community. I feel that this change will be a distraction from the very limited progress we have made in trying to get the ADA accepted and implemented. Am I wrong to think that this change is unnecessary and may even be illegal?

When I read through the many documents referring to the ADA, I see photos and illustrations that refer to the figure in the wheelchair as the International Symbol of Accessibility. If this is truly an international symbol, and a part of our laws, why would changing it locally be acceptable? There is currently little, if any, enforcement of our parking regulations, even though signs displaying the ISA are in place at the head of parking spaces and painted on the ground. There is much more ADA enforcement needed before we start changing any signs.

— Still Seeking More Parking

Those pushing for this change are introducing the new symbol through businesses and at lower levels of government — states, cities and counties. One of the problems with that approach is that the ISA is not just a local symbol. It actually originated in Europe prior to passage of the ADA, where it was adopted by the International Organization for Standardization and made a part of the International Building Code. The American National Standards Institute followed that code and so did those who developed accessibility regulations for the ADA. Those codes do not allow even a slight variation in the symbol. The ISA has since been made a part of the law in more than 140 countries that have adopted the recommendations of the International Convention on the Rights of Persons with Disabilities.

Parking regulations, building codes and a variety of laws at all levels of government refer to the ISA, and making changes to the symbol’s design without updating all of these laws would likely make them unenforceable and subject to abuse by those who already ignore accessible parking requirements and the ADA Accessibility Guidelines. It is important to remember that even disability parking placards that are effective in other states have a common design element that includes the current ISA. Unless there is a universal change to the law, it is possible that other jurisdictions would not recognize the legality of parking placards displaying the proposed symbol for accessibility.

The ISA and other mandated signage has been extensively tested for its ability to be recognized by people with all types of disabilities, including visual and cognitive disabilities. The Access Board has weighed in on this issue already, warning that any proposed changes require testing before they can be considered equivalent to what is currently in place. The Federal Highway Administration also issued an opinion that replacement of the ISA with a new symbol prior to testing and approval by the Access Board would be illegal, even if approved locally or by states.

Also, the proposed symbol resembles an active manual wheelchair user in the act of racing. Some wheelchair users who lack that ability have pointed out that the new symbol is a disrespectful representation that marginalizes their disabilities. Before any changes occur, some explanation as to why they are necessary needs to be discussed with all affected. The ISA is not only for identifying accessible parking spaces; it also identifies accessible routes and features used by people with various disabilities, not just wheelchair users.

Even at a local level, some governing body needs to approve such a change. If there are objections to a proposal, it is important for those who disagree to speak up early through letters, email or testimony at a public hearing. For those advocates who seek these changes, a study about changing the ISA should be completed by a reputable research body. After that step, it could be presented to the Access Board for consideration. If the Access Board approves a change, it would then be forwarded to Congress for inclusion in periodic updates to the ADA.

Until then, the federal law takes precedence over whatever changes have been approved locally or at the state level. Failing to address the inter-jurisdictional, national and international implications of making changes to the ISA, even at the local level, disrespects those who worked so hard to draft, lobby for, and who still seek widespread enforcement of, this important disability civil rights law.
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A wayward moose on a late-night Alberta, Canada, road in November 2013 may have been the cause of Kiesha Mastrodimos’ C6-7 quadriplegia, but where she has taken her life since then is a much more worthy story. Despite being only 17 at the time, she embarked on her journey fearlessly and continues to persevere. “My accident happened when I was in my senior year of high school,” she says. “Afterward, I did all my schoolwork in the hospital so I could graduate with my friends and receive my diploma. I also taught myself how to use a computer and write again.” Most recently, Mastrodimos has been accepted into college and has her eyes on a journalism degree.

But academics weren’t the only area she put impressive effort into post-injury. She also worked her butt off in therapy and wanted to share her progress with family and friends; hence, the birth of her YouTube channel as well as “Kiesha’s Road to Recovery,” a Facebook group that spreads the word.

“I started making videos because when I was in the accident that’s how my mom and I found other people, and it gave us motivation to keep striving, so I hope to do the same,” she says. So far she has made nearly 50 videos sharing her struggles and joys since her injury, ranging from “Wheeling a Tilt-in-Space Wheelchair” to the lighter side — “My Talent: Downing a Full Glass of Water in Seconds.”

Motivational speaking is also one of her goals. By the time you read this, she will have given her first speech at the center where she did her rehab. Resilient to the core, she seems certain to make an impact (and we cannot wait for her next video update).

Type Mastrodimos’ name into YouTube and enjoy her videos.

**Danes Take On Sport Chairs**

Every country has its own premiere wheelchair manufacturer. When wheelers from Denmark want the finest quality wheelchair around, they turn to Wolturnus, a company named after a WWI steamship that sank on its way from London to Copenhagen carrying crutches for the British Navy.

What makes Wolturnus unique is its vast selection of wheelchairs manufactured for a variety of adapted sports, all made from 7020 aluminum alloy (the strongest aluminum alloy you can weld). The company makes rigid wheelchairs and Comfort Wheelchairs (narrow, easy-to-push wheelchairs for kids and adults), but its sport chairs and handcycles are where it’s at.

Wolturnus makes highly maneuverable models for basketball, quad rugby and tennis, but it’s the E-hockey power chair, with a singular front wheel, and the dance chair, with a tight center of gravity and three casters, that are ultra-cool: They make you want to try the sports out yourself.

Visit www.wolturnus.dk/en/products/sports-wheelchairs/

**More Than a Pillow**

For quadriplegics who use automatic beds, traveling can be stressful without the ability to sit up in bed independently. In comes the 10-in-1 Flip Pillow. With the ability to transform into 10 different positions, including a backrest to help you sit up, this pillow could be a game changer for many. Cost: $49.99

Check it out at www.sharperimage.com/si/view/product/10-in-1-Flip-Pillow/202035?trai=1
Keep It Simple

People often assume that eating well is complicated and time consuming. It’s actually quite the opposite. Sticking to basic, whole fresh foods is an easy, healthy and flavorful way to eat. On a recent trip to Greece, I absolutely loved the simplicity of the diet — which studies have repeatedly demonstrated is one of the healthiest in the world. Fresh fish, hearty legumes, savory feta cheese, plump tomatoes, olive oil and creamy yogurt are some of culinary staples, and the last item in particular has multiple health benefits for those of us with spinal cord injury.

Good health starts with a healthy digestive system. A spinal cord injury, however, significantly compromises digestive and bowel function, leading to issues such as chronic bloating, gas and constipation. An easy, enjoyable and highly effective way to support your gut health and help prevent these issues from occurring is to simply incorporate yogurt into your diet several times a week. Yogurt contains probiotics (good bacteria) that actually enhance the digestion of nutrients and support peristalsis (the involuntary muscular contraction that propels matter through the intestines). These good bacteria also help produce B and K vitamins and boost the immune system (which is compromised after SCI).

Healthy bacteria consume the nutrients that would otherwise feed unhealthy microorganisms and block receptor sites that harmful bacteria latch onto to cause an infection. However, the main reason that probiotics protect us is that they produce substances such as lactic acid and hydrogen peroxide, which stop harmful bacteria from growing in the first place. They are so effective at enhancing our immune system that they are sometimes referred to as nature’s antibiotics (probiotics can also be found in fermented foods such as sauerkraut and a fermented drink growing in popularity called kombucha).

I indulged in these natural antibiotics twice a day for my entire trip to Greece — every morning for breakfast with fresh fruit and every afternoon as a dip with vegetables. The yogurt recipe below can be enjoyed as a dip with fresh vegetables or whole grain pita, or as a salad dressing or sauce for grilled chicken. Not only is it healthy food, it is simply delicious!

Homemade Tzatziki

2 cups plain Greek yogurt
2 tbsp fresh chopped dill
¼ cucumber, shredded
½ garlic clove, crushed

First, shred cucumber and squeeze out excess water. Next, combine shredded cucumber, yogurt, dill and garlic in medium bowl and let it sit in the refrigerator for at least one hour to combine flavors. Leftovers can be refrigerated for up to a week. Enjoy anytime.
Kerri Morgan, a C6 incomplete quad from Birmingham, Alabama, has been playing wheelchair rugby on and off for 13 years and tried out for the U.S national team in 2008. She wants to raise awareness that the sport isn’t just for men. “We were all excited when the movie Murderball came out,” she says. “But if you watch that movie, they never show a woman playing. When you watch that film, you get a sense of testosterone and that this is a men’s sport, and very male.”
tered players are women. It’s worth noting that approximately 80 percent of spinal cord injuries reported to the National Spinal Cord Injury Database happen to men.

De Leve is the only woman on her team and the only woman playing in the area, and Entz was the only female on her team when she started playing — a common reality for female players.

Aimee Bruder, 41, has been playing with her local Alabama team for nine years and has only had one female teammate during that time. During one of her first practices, her teammates got into an argument. “I heard one of them say, ‘You can’t hit a girl!’” she says. “And I was like, ‘Come on, just hit me!’ One hit and then we were fine.”

Jessica Kruger, a C5-7 quad from Vancouver, British Columbia, says her male cohorts have been relatively well behaved. “On the court you obviously get trash talking in general. And because I happen to be the only female, I think it is a little sex-specific, like ‘Oh, I wasn’t even trying anyways. I’m just being nice.’ But it’s definitely not a significant part of the sport, I would say.”

Richard says only one of the 25 women she has talked with had an “extremely negative” experience, and the vast majority claimed to be having fun. “Some of them would tell me that it’s really stressful or that it’s annoying having to listen to their teammates’ sexist comments. Or they told me that ‘Oh, I took two seasons off because I just couldn’t handle dealing with the team.’ So I guess they pick their battles, and sometimes whether they love rugby or not, just the atmosphere removes them from the sport.”

Richard has focused her studies on how the women articulate their identity in the sometimes overwhelmingly masculine culture. “There are some that just embrace the culture and just kind of become ‘one of the boys,’” she says. “They are just OK with hearing the guys talk about sex, cathing, Viagra — whatever. But there are others who are disgusted by it and either will distance themselves from their team, or they set boundaries between their team and they tell them, ‘Hey, this isn’t OK. Don’t speak about that around me.’”

Bruder, who has CP, tried to ease her teammates concerns about her violating the space they had created around rugby. “When you’re a quad, rugby just isn’t about the sport. You talk about anything and everything. Out in the open. At first, they were kind of like trying to shield me and be quiet about it. I’m like, ‘Guys, I had a brother. It’s OK.’”

The adjustment period took a little time for de Leve, who had never played team sports before, but supportive teammates made it easier than she had expected.

“There is a super masculine culture to it,” says de Leve. “And that can be off-putting to some women. But I think it ultimately depends on the culture of the local team. If you have a really supportive team around you, and those are the people you’re
seeing week to week, then you’re going to have a good experience. If your team is very hyper-masculine, overly macho, maybe prone to making distasteful jokes, it’s gonna be a little harder to feel like a real member of the team.”

MORE THAN A WORKOUT

Being a part of the team has become one of the sport’s biggest draws for Kruger. In addition to being the only female, when she started playing eight years ago she was only 15, by far the youngest participant in her region. She was drawn by the competition, but stayed for the camaraderie.

“It’s so much about the community of people,” she says. “Especially after I had my accident, having those people that just sort of get it … I mean now these are all my friends. They’re not just my teammates. I have that place where people understand, and I have that friendship with them. That’s a pretty huge part of it for me.”

Like Kruger, Kathryn Mahoney, a C6 quad from the Chicago suburbs, has been surprised by how valuable the social side of the sport has been. “It’s a great way to meet people, especially people who have been injured for several years. I’ve learned a lot from being around them and traveling with them. A lot of these guys are quads who do everything themselves and are completely independent. For someone who’s newly coming off of an injury, that’s really important to see.”

Still, many women commented on the added difficulty of being the sole female on their respective teams. “Sometimes it’s a little lonely, because when I go to practice, I’d like to talk to some girls,” says Bruder. “So it’s a little lonely in that respect. But it’s not like I dread it.”

Bruder and others say they look forward to catching up with other female players at tournaments. Entz has split hotel rooms with opposing women on the road to save money and says the experiences have been positive.

Entz is no longer the only woman on her team and says having a female teammate has changed her perspective. Her teammate commented on how it was not that difficult being a woman in a male-dominated sport, leading Entz to point out that she had never been to a practice where she was the only woman. When Entz missed a practice a couple of months later, she got a text message from her friend saying, “You are never allowed to miss a practice again!”

“We love the guys,” she says, “but sometimes that male-focused atmosphere can be a lot to take.”

GROWING THE SISTERHOOD

Many of the women say they have no long term goals as far as quad rugby, other than to keep improving and having fun, but Kruger, 23, has set her sights on making the Canadian National Team. In what is possibly a sign of how quad rugby is changing, she even has a role model for her pursuit — current national team member Miranda Biletski. “We’re actually good friends,” says Kruger. “To see where she started and how far she’s come is a huge inspiration to me. Just the fact that I know some of the politics around being a woman on the national team that she’s
faced, and the fact that she’s been able to navigate around them and still sort of be in that position is reassuring to me.”

All of the women in this story said they would encourage a woman with a new spinal cord injury or disorder to at least explore quad rugby. “Go into it with a fighting spirit, that you’re gonna do the very best you can. If it intrigues you, don’t let your gender stop you,” says Bruder. “Because this league is male and female and that’s just what it is. So if you want to do it, do it.”

De Leve had perhaps the simplest rationale: “It’s no different playing as a woman in rugby than it is playing as a guy. Once you’re on the court, nothing else matters.”

Kruger credits the sport with being nothing short of life changing. “I honestly think that rugby was a huge part of the reason that I am where I am today after having my accident, which is being in a place where I wouldn’t necessarily take back what happened to me,” she says. “I definitely went through a period where I was struggling with coming to terms with what had happened, but rugby just gave me that outlet that reminded me that I wasn’t really giving up the things I had in my previous life, but finding a new way to embrace them in this new life.”

With all the potential benefits — physical, emotional and social — and the fact that so many women came to love the sport unexpectedly after simply giving it a try, the question for many is how to expose more women to the game.

In Canada, Entz and others are working to organize a casual all-women’s team, not so much for tournaments, but more for bonding and camaraderie. She found the glowing coverage of quad rugby in last year’s Parapan Am games mostly encouraging and is optimistic that the trend of increased coverage and media attention will continue with this year’s Paralympic Games in Rio de Janeiro.

When Richard asked interviewees how they would reach out to more female players, respondents repeatedly suggested a women’s-only clinic “where it’s a really safe environment for the women.” At the time Richard started her interviews such a clinic was only a dream, but months later it is a reality. Adaptive Athletics at the University of Houston has scheduled a women-only wheelchair rugby camp for July 7-10 at the University of Houston Recreation and Wellness Center. “We’re really excited that it is actually happening, and we’re just working to rally more people to attend,” says Richard.

If you are a coach or a female wheelchair rugby player and would like to attend, contact lramirez22@uh.edu.
With flexible seating, ample headroom, and enough floor space to execute a full 360° turn, VMI vans offer enough room for the entire family, and allow even the largest power wheelchairs to maneuver with comfort and ease.
As a child, Monica Goulette contracted a viral infection, since diagnosed as Lyme disease, which doctors believe lay dormant for a few years. She started showing symptoms when her body went through puberty. One of the consequences was her right leg became completely paralyzed, except for her hip flexors. At 16, Goulette began using a knee/ankle/foot/orthotic. While being fitted for a replacement KAFO, Goulette’s orthotist told her about a new product — the Ottobock C-Brace. Now, says the 21-year-old from Los Altos, California, “I love it. It has opened up a lot of doors I didn’t even know were closed.”

The C-Brace Goulette gushes over can be a game changer for people with incomplete SCIs, stroke, post-polio or other neurologic conditions causing partial paralysis. At first glance the custom molded, carbon fiber device, which extends from high on the hip down to a foot plate, can easily be mistaken for a powered device designed to assist the user to walk, primarily due to the large knee joint unit, which bulges out just above the knee. That unit houses both the brains and the brawn of the system. The brains consist of a microprocessor that monitors the user’s gait pattern at the knee and ankle joints throughout the entire gait cycle. The brawn consists of a hydraulic piston designed to provide resistance at the knee to ensure the user’s knee joint won’t buckle and result in a fall. Power needed to walk comes from the user.

The C-Brace monitors the knee joint every .02 seconds, or 50 times a second, and adjusts the resistance in those joints as needed — in anticipation of the user’s next move. As a result, the brace can respond to changes in terrain, direction and speed. That continual monitoring and near instantaneous response helps prevent falls by providing resistance to uncontrolled knee flexion when sensors read a moment of instability, giving the user the necessary time to recover.

The brace helps normalize the gait through controlled dampening — slowing down knee flexion and extension — which allows a more normalized and efficient ambulation pattern. A strain gauge runs from ankle to knee, which tells the microprocessor where the user’s body weight is in the foot. That information, along with the angle of the knee, determines the amount of hydraulic resistance.

Everyday life is obviously easier with the ability to walk on uneven ground, descend stairs...
“I can go anywhere and not worry about being able to get into a house or a building because of steps or whatever.”

Monica Goulette hikes for miles with the brace.

and ramps, and tackle the slopes of sidewalks. The unit’s microprocessor monitors and responds to those obstacles while reducing wear and tear on the sound side.

A conventional KAFO works for people because it locks and stays locked, giving the user confidence that her knee won’t buckle. The downside of those KAFOs is the pronounced “hip hike” necessary to propel the leg forward for the step. The C-Brace’s constant monitoring of joint angles provides support by automatically adjusting resistance while anticipating the next phase of the step. That resistance with the knee or ankle bent is key when going from sitting to standing or climbing a flight of stairs. This real-time monitoring and response allows users to walk with greater ease and less concentration while normalizing the gait pattern and eliminating the hip hike.

The brace can impact a user’s life quite profoundly. For Chris Bridgman, a T10 incomplete para, the brace has eased his transition back to work full time as a loan officer. “I love being able to look people in the eye, standing 6 feet tall. I can go anywhere and not worry about being able to get into a house or a building because of steps or whatever,” says Bridgman.

Bridgman, 38, was injured in 2010 and used a KAFO brace in rehab, but found it impractical. He happened across the C-Brace much the same way as Goulette, by stopping in at his local orthotics shop. Training at Craig Hospital for five weeks with a physical therapist helped him make good progress with both strength and endurance, though he still needed crutches or someone’s hand to hold for stability while walking. He has good quadriceps and hamstring strength in his left leg, but little strength in his right. He continues to use both crutches and says “losing even one seems like a long ways away.”

The C-Brace has also helped Goulette in her job as a kindergarten aide. She says it’s comfortable to wear and allows her to squat, get down on her hands and knees and even walk quite fast without having to worry about falls or trips. “I can go to the gym and work out, ride a bike or the elliptical, or use the treadmill,” she says. “This winter I want to go snowboarding. I’m confident more doors will open as technology improves. Now I have the ease of mind to live a normal 21-year-old life.

“I can go hiking for miles without having to worry about screwing up my spinal alignment and being in pain. The brace gives me a normal gait and prevents misalignment and long-term consequences, both structurally to the spine and possible medical issues as well. I’m not as concerned about the distances I walk because I know my spine is properly aligned, or about falling because the brace gives me the time and support to recover. With the locking KAFO I was falling down five or six times a day and seeing a chiropractor very regularly, but no more since the C-Brace,” Goulette explains.

Not Without Challenges

Both Goulette and Bridgman say to expect a learning curve when adjusting to the C-Brace. “It’s much more challenging to use on a daily basis than a chair. It’s really tough to carry stuff, open doors or use the bathroom,” Bridgman says. “I was surprised by how hard it’s been to master, even though the person who fitted me said it could take months or years to master.” He was dead right. “It feels like a high wire act every time I stand,” he says. The brace forces people to use different, infrequently-used muscle groups, so fatigue is often a big problem, even for people like Bridgman, who rows four times a week and lifts weights as well.

Goulette says she has adjusted over two years of using the C-Brace. “I was used to walking with the locked KAFO, so I got the hang of it quickly and felt comfortable using the brace after about a month,” she says. “The hardest to learn were stairs or curbs. After using a locked brace for three and a half years, using one that never fully locks and trusting the brace to catch me was terrifying.

“The falling has been completely eliminated. If I stumble, the brace senses I’m off-balance and provides more resistance. My walking is much more fluid going up curbs and stairs, and I no longer have to constantly be on guard about being pushed or bumped into.”

Simply putting the bulky brace on also took some getting used to. “Clothing has been a challenge due to the bulkiness of the hydraulic unit,” Goulette says. “Getting used to having something so large strapped to me took time. I occasionally still walk into corners and walls.” Many users alter pants and jeans with a slit to accommodate the hydraulic unit, which requires skin tight contact with the user’s leg.

Bridgman says it takes him about 10 minutes to get the brace on, a testament to its form-fitting nature. “I feel like I’m going into battle or getting ready to do motocross,” he says.

A Life Changer, at a Cost

“Seeing Chris standing and walking for the first time was a ‘take your breath away’ moment,” says Bridgman’s wife,
Jennifer. “I stopped seeing Chris’ wheelchair years ago, though I’d forgotten how tall he is or how satisfying it is to walk down the street side-by-side.”

“To me, the C-Brace is a milestone in our ongoing recovery. Now, with Chris being able to choose between the chair and the brace, we’ll be able to attend sporting events as a family and concerts as a couple, bypassing the quick-to-sell-out accessible sections and moving on to previously inaccessible locations. Perhaps most important are the added health benefits, such as cardiovascular strengthening and decreased wear and tear on the shoulders. This brace can potentially change our daily life as we know it. We feel very fortunate.”

If you’ve heard enough, the next question is: Are you ready to fork over $75K? That is not a misprint.

The MSRP of the C-Brace for self-payers is the price of an exoskeleton. Ottobock couldn’t provide a definite price because the device lacks insurance coding. Lu Aadland, a Denver orthotist with Hanger Prosthetics, says coding and rate agreements vary from funder to funder (presently Worker’s Comp or VA). Each brace is custom molded to the user’s leg, making it a specialty item. On the bright side, the price includes training and necessary mechanical adjustments to the device. Most third party payers will reimburse PT sessions.

“I stopped seeing Chris’ wheelchair years ago, though I’d forgotten how tall he is or how satisfying it is to walk down the street side-by-side.”

If the price seems steep, Aadland says, she’s yet to hear any complaints from users, “because they say you can’t put a price on the independence of walking.” She has done several evaluations and explains that the process begins with an orthotist doing an evaluation to determine suitability for the brace. Candidates are initially fitted to a trial unit, which adjusts to accommodate most people. Once fitted, candidates take the unit for a test drive. If the evaluation is positive and the candidate wishes to proceed, her leg is then measured and casted in plaster — a very intricate casting technique — and then fitted with a diagnostic brace to verify the finished carbon fiber brace will fit like a glove and the knee center joint is properly and accurately located. The tight fit ensures that all the sensors function accurately. Units are then hand made in Utah, making each one unique.

“The C-Brace isn’t something I fit and say ‘good luck,’” says Aadland. “People need to be able to reciprocate. They must have some glute and/or hip extensors, as well as good proprioception. Strong motivation is vital. They need to be committed to learning how to use the brace, which involves 20 to 30 therapy sessions, so they can be walking full or nearly full time.”

When asked to sum up his feelings about the brace, Bridgman offered this: “Knowing what I know now, there is no doubt in my mind that I would still buy it.”

More Info
The thing you’ve got to understand about transportation network companies like Uber and Lyft is, they’re so damn convenient. You download an app on your smartphone, enter your credit card info, and then whenever you need a ride somewhere, just push the button on your phone. Usually within 10 to 15 minutes a driver who uses her own personal car, possibly your neighbor, whisks you off to your destination.

And this new way of getting around is gaining popularity worldwide. In 2012 Uber Technologies went global, and as of April 2016 riders can submit ride requests in 60 countries and 404 cities worldwide — including all major cities in the U.S.

There’s only one problem, and in this post-ADA, disability-enlightened era, it’s a maddening problem: It was not designed to include people who use powered mobility devices.

Whoops.

Don’t worry, says TNC giant Uber, they’re working on it. “We are constantly refining and renovating our products and technology to provide even more options for consumers,” says Uber, in a statement emailed to New Mobility for this story. “For example, we are piloting several different models nationwide to determine which solutions best meet the needs of our riders and drivers. These pilots run the gamut from licensing our technology to WAV [wheelchair accessible vehicle] taxi drivers to providing our own WAV options through partnerships with commercial providers.”

To see how they’re doing, we spoke with wheelchair users and advocates from around the nation about how well Uber is working in their region. We focused on Uber, since right now Uber is the most responsive TNC to our community.

**PHILADELPHIA: THE COOLEST THING EVER**

College student Shayna Pulley is an enthusiastic Uber rider. “I just use the regular UberX and we break down my rigid Quickie Q7 — pop the wheels off, fold down the back, and then it either goes in the trunk or the driver puts it on the front seat,” says Pulley, 25. “I’ve never had any issue, all of the drivers have been really respectful.”

Sometimes she’ll get a driver who asks if they can break down her chair themselves. “There’s a video Uber put out on how to break down a rigid wheelchair, and a lot of them have watched the video. If they haven’t, it’s still a teaching moment and they’re always so excited, they think it’s the coolest thing ever. I explain how the back folds down on mine, but that it may be different on another chair, so they’ll be educated the next time they come across a manual chair.”

Pulley, who lives outside of Philadelphia, has a cocktail of neurological conditions, including syringomyelia at C5-6, and depending on the day will use her manual chair, forearm crutches or her rollator. The first time she used Uber she was in a jam. “We share cars in our family and all the cars were gone. My mom left her cell phone home, so when I called her, I heard it ring in the house. Then I thought of Uber. Luckily a few months ago I had downloaded the app and entered my credit card.”
And that, she says, brings her to another point about how awesome Uber is. “In a cab you’re fumbling for your wallet and when you use a wheelchair, your hands are busy all the time, so this way, when you reach your destination, you’re ready to get out of the car as quickly as possible and get on your way.” Since your credit card info is in Uber’s system and Uber drivers do not accept tips, no money changes hands.

Another advantage to the Uber app is that it is GPS-based. It tells the driver where you called from, so the driver doesn’t need you to give your address. “So when the driver says ‘where are you,’ they mean ‘are you next to the flag, at the curb cut or at the door.’ I’ve used it in residential settings, urban settings, everywhere.” She tells them to look for the wheelchair with the hot pink wheels.

Pulley says Uber cars tend to be cleaner than cabs. “In a recent trip to Washington, D.C., I used a cab once and Uber four times. The Uber car was so clean and the drivers were so respectful. When I used the cab, the driver had no idea how to handle my wheelchair, and he was sick, and his car was very dirty. I was concerned because my immune system doesn’t work properly.”

And in her hometown Philadelphia, good luck catching an accessible bus. “They will pass you right by,” she says. And once, when using Amtrak to attend her classes at Philadelphia Community College, she fell asleep and passed up her stop. “I would have missed class if I hadn’t called Uber. With Uber I’ve never had a driver say, ‘oh, sorry, I can’t deal with a wheelchair.’”

Uber also employs wheelchair-accessible vehicles in the Philadelphia area via its WAV program. Pulley has only used that system once. “It costs more, but I usually go with UberX because I don’t need an accessible vehicle.”

**THE FARE ISN’T FAIR**

In Philadelphia, according to Uberestimate.com, Uber has a few options for its riders, ranging from the most affordable, UberX, with a base fare of $1.25 to the most expensive, Uber SUV plus Carseat, with a base fare of $24. Most, like Pulley, use UberX, which in addition to the base fare of $1.25, also charges 18 cents a minute, $1 per mile, a service charge of $1.25, and a minimum fare of $5.

But UberWAV in Philadelphia — the only option possible for power wheelchair — charges significantly more. The base fare is $7, then add on 25 cents a minute, $2 a mile, a service charge of $1.25, and the minimum fare is $7.25. This is the same pricing for an inaccessible SUV, for sure, but nondisabled passengers can choose whether or not they would like an SUV. Power chair users in Philadelphia don’t have that luxury and, because of their disability, cannot choose the lower rate.

They can in some parts of the country, such as Portland, Oregon, where a 25 cent surcharge is added to all TNC rides to subsidize the WAV rides.

But back to Philly. Turns out, not all wheelchair users in the City of Brotherly Love are as enamored with Uber as Pulley. Dissatisfied users and advocates took to the streets on Feb. 11, along with cab and limo drivers, to protest both Uber and Lyft. The cab drivers are pissed at the competition and claim Uber is creating anarchy in the city and ought to be taxed more. Plus, say the cabbies with a straight face, they were protesting for public safety and wheelchair accessibility.

Yeah, right.

No one in their right mind would or could ever believe that the cab companies in Philadelphia give a damn about people with disabilities. After all, the only reason that dozens of shiny new taxi WAVs hit the street in 2015 is because disability advocates won a lawsuit in 2011. And the best the industry says it can do is have 8 percent of its fleet accessible by 2021.

But wait … alongside of the cabbies are … can it be? My goodness, yes! Disability rights activists, including many wheelchair users.

“Seeing wheelmen and wheelchair users united was a curious sight, given that less than a year ago, the taxi industry was fighting accessibility advocates over a Philadelphia Parking Authority proposal requiring all new taxis to be wheelchair accessible vehicles,” noted an article by Jim Saksas on PlanPhilly.com. Yet just a few months before that, disability rights...
advocates praised Uber for launching UberWAV.

And this unlikely alliance between wheelchair users and the taxi industry isn’t just happening in Philadelphia, but in New York City, also. Or should we say, especially in New York City, which is, after all, home of the original Taxis For All campaign and the city that won an agreement for 50 percent of its taxi fleet to become accessible by 2020.

NEW YORK CITY: THE ONLY ONES LOSING SOMETHING

New York City is the only city that is losing existing accessible transportation because of Uber. “New York is different than any other city because we have a mandate for 50 percent accessible taxis, and Uber is cutting into that,” says United Spinal Association CEO James Weisman. “Uber operates over 30,000 vehicles in New York City, and not one is accessible. They have an UberF on their app, which gets you a taxi, and in there is another tab, UberWAV, and that will call you an accessible cab that advocates worked two decades to get, and Uber is putting them out of business.”

Although cabs are owned by their companies, to drive a cab in New York City, you need to purchase a medallion. Because of the advocacy of groups like United Spinal and the Taxis For All campaign, for a brief shining period about four years ago, cab drivers slavered after medallions for accessible cabs, and it looked like the golden dream of a power wheelchair user being able to actually hail a cab was coming true.

Then came TNCs, including Uber, “and now in 2016 no accessible medallions have been sold and there are no plans to sell them,” says Weisman. “There are no buys, they’re worthless.”

And the city is just letting it happen. “The city fought us for years on accessible cabs and the Taxis For All campaign is 19 years old now,” says Weisman. “And now they let Uber just take over. They could have protected the Yellow Cabs and regulated Uber by treating it like a taxi company, but they would not do that.”

So in a twist of fate, Weisman has thrown in — for now — with the cab companies. “We are not your average disabled population that has nothing,” says Weisman. “We had 50 percent taxi access. If Uber doesn’t do something like that, or that is as effective, our population loses. We can’t just walk away from that.” Half of the city’s cabs will still have to be accessible, but the fleet will have significantly shrunked.

United Spinal has vigorously campaigned against Uber, including running anti-Uber ads, in hopes of saving the taxi industry and, by extension, saving the deal for a dramatic increase in accessible cabs. Without the taxi companies, after all, the deal for 50 percent of all cabs to be accessible is worthless. And then UberWAV is worthless, too, since there won’t be enough WAVs for UberWAV to connect with in the city.

Still, there are ways that Uber’s business model could benefit all people with disabilities, says Weisman. Think about all the types of transportation that exist just to serve our community. “You have Medicaid ambulettes, Voc Rehab types of transportation, paratransit, VA medical center transportation … in New York City hundreds of millions of dollars are spent getting wheelchair users to the doctor,” and think of how much money and time could be saved using a platform like Uber’s that connects people directly to a WAV driver. Still, says Weisman, “They should not receive government money if they’re going to keep their for-hire business inaccessible.”

That’s for the future. Right now, advocates are grappling with a brand-new system that works beautifully for everyone but those who use power chairs or scooters. “People don’t notice when wheelchair users are not included,” says Weisman. “A whole transportation mode has been created without wheelchair accessibility.”

PHOENIX: IT’S IN OUR COMMUNITY’S INTEREST TO HELP UBER

When Uber announced it would begin providing UberWAV service in Phoenix, wheelchair users were excited … followed quickly by disappointment. “We started pressing the button for a ride and only got ‘check back later’ from the app,” says New Mobility community partner Loren Worthington, the communications and marketing manager for Ability360. “We reached out to Uber through the front door and all we got was, ‘we’re working on it.’”

At this point, Ability360 had a choice. The organization publishes the quarterly LivAbility magazine and considered publishing a story on the lack of accessible service, but instead decided to try to work with the company. “Our opinion is that it’s going to take some time, but in the long term it’s in the best interest of our community to try to help Uber develop successful programs to serve our community,” says Worthington, a C5-6 quad.

The problem is that transportation network companies such as Uber are profitable because their app-based software connects private drivers directly to riders.
“We were able to connect with a person at Uber responsible for making their program work in our city,” says Worthington. “He told us their challenge was finding drivers with accessible vehicles. He told us ‘we thought we’d get accessible drivers, and they didn’t materialize.’”

Worthington says of an evening program held at the local Uber headquarters to recruit WAV drivers: “They had drinks and some snacks, and anyone interested could come in and discuss the program with Uber.” But only a few came.

Uber will be running an ad seeking drivers in an upcoming edition of Livability Magazine, and Worthington thinks that may help. “I am optimistic that Uber can find drivers and that its model will find success in Phoenix,” he says.

But in the meantime, Uber is not working for people who don’t transfer independently. The City of Phoenix is trying to entice TNCs to provide access with an ordinance that would allow them to fully operate at Sky Harbor International Airport on the condition that equitable wheelchair accessible vehicles be available within 30 minutes. Currently, TNCs can drop off but not pick up at Sky Harbor International Airport. Being able to fully operate at the airport is coveted by the TNCs and their partners.

**PORTLAND: UBER CREATES ANOTHER OPTION**

Portland, Oregon, is another city in which the local government cultivates community-wide accessibility, and so it’s probably no surprise that in Portlandia, when you push the UberWAV button, you are given an actual time of arrival. It’s not perfect. When our senior editor Ian Ruder attempted to use it one Saturday night, the wait was over an hour.

What’d you do? “I had my attendant come get me in my van,” says Ruder, a C5 quad who doesn’t drive. He checked the app randomly for this story and the wait was a reasonable 25 minutes — but that was on a weekday.

Portland’s Disability Program Coordinator, Nickole Cheron, a power wheelchair user, has had better luck than Ruder. “The few times that I have endeavored to call, Uber has gotten to me within 10 to 15 minutes,” says Cheron, who has spinal muscular atrophy. She says cabs are more often,” says Lipp, an incomplete T4 para. “But while getting that built up, I didn’t think they should be doing nothing — and they were doing nothing — and they agreed. There was no argument or long discussion.”

Soon, Lipp was helping to develop UberASSIST — the program that trains drivers about disability — and also Uber ACCESS, which pilots programs that partner with taxi or paratransit companies that have WAVs. His trainings are cross-disability and he, as well as Uber, are proud of the progress made in ensuring the app works with screen reading programs for people who are blind or have visual impairments, and signaling software for drivers who are deaf. For assisting wheelchair users, the trainings focus on disability etiquette as well as how to properly remove the wheels, fold and stow manual wheelchairs.

“With Uber they’re a bunch of young kids who really care about this stuff,” says Lipp. “We need to help them, and there’s a willingness among them, and a willingness among the drivers, too. We’re getting there.”
iffy in Portland. Even if you call a day ahead, they may still be an hour late, and so far Uber’s outperforming the taxis. “With Uber, if there’s a ride available, I can see their progress on the app, that they’re coming.”

As of press time, Uber Portland had between 15 and 25 peer-to-peer operated WAVs — privately-owned wheelchair accessible vans — and they are trying to recruit more so it can continue to meet the city’s 24-hour service requirement. “Uber is meeting this, Lyft is falling short,” says Cheron.

The city estimates a WAV ride can cost $30-40, and so has instituted a 25-cent surcharge on every TNC ride. “We’ll figure out a way to reimburse the drivers of the vehicles or the companies since we recognize WAVs cost more,” says Cheron. “We want WAV rides to be competitive.”

In Portland, a wait for an UberWAV cannot be more than twice the time of UberX. “Whatever the status of the regular service is at any given point, say around 10 to 12 minutes, the wheelchair accessible service can’t be outside the range of 20 to 25 minutes,” says Cheron. “So if wheelchair users are getting consistently longer wait times, they can make a complaint.”

Cheron says UberWAV is still not equal, “but it’s equitable, and it’s an option that we’ve not really had. So many people who rely on paratransit wait up to two hours, so I feel like anything that makes more options available to folks, it’s a good thing.”

For more than 30 years United Spinal Association has led the fight for affordable, accessible transportation, and today this includes holding Uber accountable to provide rides to all wheelchair users.

Thanks to a lawsuit filed by United Spinal CEO James Weisman in 1979 and settled in 1984 — years before the law he helped to draft, the Americans with Disabilities Act, became law — New York City became one of the first cities in the United States to require buses have lifts.

In 1988, United Spinal negotiated a settlement to make Philadelphia’s bus and commuter rail system accessible and to establish paratransit.

Then, 20 years ago, United Spinal teamed up with the Taxis For All campaign to get more accessible cabs on the roads in New York and other cities as well. That fight seemed to draw to a close with a landmark settlement in 2013 requiring 50 percent of all taxis in New York to be accessible by 2020.

Weisman says at this point in our history all transportation options should be developed to serve everyone. “There should be universal design and let’s stop this nonsense. We said all buses should be accessible, and people with disabilities did that, made that happen. That wasn’t government, that was advocates.”

And now advocates must band together to make a whole new mode of transportation accessible for everyone, including wheelchair users, as it seems transportation network companies such as Uber and Lyft didn’t think about how to serve our population when developing their products. How did this happen? “The truth is no one cares about disability stuff, it’s not offensive enough,” says Weisman, who notes if any other community had been left out, there would have been hell to pay. “It is offensive to us, though. It is to us.”

But the biggest obstacle in this contemporary transportation battle is that the TNC model isn’t based on a fleet, but rather on drivers of private cars, who are considered independent contractors, not employees. “So where does the money come from to buy accessible cars? Uber could afford to do it themselves,” says Weisman. “A legislator could say, ‘look, we don’t care how you do it, but one in so many cars will be accessible.’ But government doesn’t have the nerve to do that. They could say, ‘You figure out how to make it happen and we’ll pay in Medicare/Medicaid payments,’ and let Uber take over those calls. There are ways to make it happen, and if you forced Uber to do it, it would work. They’d figure it out.”

After all, bus companies figured out how to operate lifts, and taxi companies figured out how to run accessible cabs. TNCs like Uber and Lyft can figure out how to provide rides to all passengers, including power wheelchair users, as well.
Help is Just a Click Away!

When faced with the challenges of living with a spinal cord injury or disease (SCI/D), the right resources and support can make a world of difference.

United Spinal Association’s Affiliate Service Providers provide the full spectrum of clinical care, products and services, with an emphasis on SCI/D. Search our valuable online directory at http://providers.spinalcord.org/ to discover service providers near you that specialize in optimizing the health, independence and quality of life of people with SCI/D.

Visit our directory at http://providers.spinalcord.org/

If you have any questions, contact our Resource Center staff at http://www.spinalcord.org/ask-us/ or call (800) 962-9629.

Quickly connect with top providers specializing in:
• vehicle & hand controls • therapeutic & bathroom equipment • urological supplies • scooters • wheelchairs • ramps • assistive devices, and many other disability-related products and services.
The unemployment rate for people with disabilities has barely changed since the ADA was passed in 1990, and financial independence is still far out of reach for many wheelchair users. But some find if they have a nice car and hand controls, they can make money driving for transportation network companies like Uber. Below are three wheelchair users who are making the Uber platform work for them.

**FROM VENICE TO UBER**

Born in Venice, Italy, Luigi Girotto, 54, moved to Rye, New York, where he now lives with his family. “I was 40 years old and I had a career crisis,” Girotto said. “Nothing was challenging me enough.”

Then came a skiing accident in Austria 10 years ago that resulted in quadriplegia, after which he was upset because he didn’t think he’d ever be able to drive again. “A friend of mine, also a quadriplegic, said if I could touch my nose, I could drive,” says Girotto. And he could touch his nose. Four years after his injury, he was once more driving independently.

A jewelry consultant who commutes five days a week to Manhattan, Girotto first learned about Uber from his son, a student at the University of Miami who uses Uber to get around the city. He was intrigued with the platform and in 2014 signed up to be a part-time UberX driver serving the Greenwich and Stamford communities in nearby Connecticut.

If he’s not in Manhattan or driving UberX, chances are you’ll find Girotto talking with people who’ve recently sustained a spinal cord injury at the local Burke Hospital. Or, on the slopes somewhere, as skiing — presumably adaptive skiing — is still his favorite sport.

**MARINE VET SAYS UBER CAN BREAK DOWN BARRIERS**

A few years ago, Bob [name withheld] and his wife sat in their Ohio home watching the snow pile up against the front door. They decided enough was enough and moved south to Charlotte, North Carolina. He needed a fresh break, since hearing loss meant he could no longer continue in his job as a 911 dispatcher, and he wasn’t sure how he would make ends meet.

But Bob, a wheelchair user since 1970 due to injuries sustained while serving with the Marines during the Vietnam War, is nothing if not resilient.

Job opportunities were sparse in Charlotte, but after speaking with an Uber operations manager about his modified Dodge Caravan in 2014, he decided to drive for Uber and has driven for them since, enjoying the social interaction.

“Uber is a way for a lot of vets to get out — especially disabled vets — who are stuck at home trying to find something to do,” says Bob. “It’s a good way to try to break down the barriers that are still left for people with disabilities.” He is part of Uber’s UberMILITARY initiative, which actively recruits veterans, reservists and military spouses to drive on the Uber platform.

**JACK OF ALL TRADES**

Gabriel Garcia says he’s pretty much a jack of all trades. “I really don’t do one thing, I do as much as I can, and Uber driving is one of them,” says Garcia. Although he has a full-time job as a bookkeeper for a national student housing company, Garcia has driven for Uber SELECT in Austin, Texas, since 2014 to supplement his income and keep him busy. “I really enjoy what Uber has been able to do in allowing me to get out there and to work, make a profession and interact with so many people.”

A low quad who uses a manual chair, Garcia didn’t want to stop driving SUVs after sustaining his injury 10 years ago, and thought, “Why not go for the biggest vehicle possible to modify?” He found a company that could customize his full-size Cadillac Escalade. The driver’s seat swings out and drops down so he can transfer into it. Then a lift pulls his wheelchair into the back seat area and stows it.

Garcia’s Escalade is so nice that he qualifies to be a driver for UberSELECT, a product designed as a mid-tier option for frequent riders who want a little luxury in their lives. So far he has given over 1,000 rides since partnering with Uber.
Back in 2012, Jennifer Mendoza was walking through San Francisco and noticed a bunch of cars with pink mustaches. “I Googled, found out what Lyft was, and said, ‘I have got to be a part of that.’”

At the time she and her husband, Peter, didn’t own a vehicle because public transit served them well. The very next year they moved from Berkeley to Marin, purchased an accessible ramp van that could accommodate Peter’s power wheelchair, and Jennifer became a Lyft driver.

“We talked about Lyft a lot and eventually I went to work for Lyft briefly, as a consultant on accessibility,” says Peter, a 35-year-long activist for accessible transportation who has cerebral palsy. “I, too, wanted to change the world. Unfortunately, Lyft decided not to move forward on accessibility. Today, if you go on Lyft’s app, you get a link to paratransit and other transportation resources.”

Why? Not enough owners of wheelchair accessible vehicles are signing up as drivers for either Lyft or Uber. The Mendozas note that when the California Public Utilities Commission voted to regulate Lyft and Uber in California, they required the companies to develop strategies and offer incentives for drivers of accessible vehicles.

“I don’t think people have come forward because there has not been enough outreach,” says Peter. “We really need the community of people with disabilities to come together and be a part of the conversation with Lyft and Uber.”

“It appears Lyft and Uber have yet to develop a strategy that will encourage drivers of accessible vehicles to operate on their platforms,” says Jennifer, who drove for UberWAV — Uber’s wheelchair accessible option.

Unfortunately, Jennifer received word in late March that she could no longer drive for UberWAV, as Uber has decided all van conversions must have been done by a NMEDA-certified technician. The Mendoza van, fairly new, meets all federal requirements, but is not NMEDA certified.

But it was good while it lasted, and Jennifer was the only Uber driver of a privately-owned WAV that she’s aware of, working about 30 hours a week. Usually drivers do not work set hours, but rather sign in to the app when they are ready and available to pick up a ride. But Jennifer committed to a set amount of hours so UberWAV would work for people with disabilities in her community.

Now, say the Mendozas, it’s hard to get San Francisco Uber to commit to a beefier WAV program because they say the demand isn’t there. From the Mendozas’ perspective, that’s because of the barriers the TNC is putting up to drivers. Fix that problem, and the riders will follow.

“These barriers come from a lack of understanding about accessible transportation, and it’s only going to work if there’s a better understanding of what accessibility is, and what it can be,” says Peter. “One of the things that needs to happen, too, is all the people working on accessibility for Uber need to get on the same page. You might find one thing in one market and another in another market.”

“So we’ve made ourselves available to Uber and Lyft to find drivers to talk about incentives and clear up myths,” continues Jennifer. “One myth that Lyft believed was that most personally-owned vans are not compatible with most wheelchairs, and so it’s not possible for a peer-to-peer model to work. Maybe they’re thinking EZ Lock, but most on a peer-to-peer platform would generally use the four securements and a seat belt. But they think it’s complicated and inconsistent.”

The California Public Utility Commission ought to step in and define what a wheelchair accessible vehicle is, say the Mendozas, who would like to get them started with this: a vehicle that can accommodate a power wheelchair, with a ramp or a lift installed; a conversion completed by a recognized mobility vehicle conversion company, consisting of four floor securement/tie down devices in the passenger seating area, and a lap/shoulder seat belt large enough to accommodate a standard size power chair; and that all adaptations meet/maintain Federal Motor Vehicle Safety Standards.

So with all of these problems, the couple must be pretty down on TNCs, right? Wrong. “We’re super pro-Uber and Lyft being accessible,” say the Mendozas. “We support the platform because it can increase options for people with disabilities. We wouldn’t support them if we didn’t believe there was a path to accessibility.”
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MY TAKE

Visitors come from all over the world every fall to take in the majestic fall foliage. Driving tours are the norm, and Route 8 is an easy and great place to start. But if you want to get out of your vehicle and explore, the River Trail at Falls Village, Connecticut, offers one of the better accessible trails. The accessible portion is just under a mile long, following the Housatonic River through one of its flatter portions. This is one of only a handful of fully accessible sections of the Appalachian Trail.

If one mile doesn’t sound like enough of an adventure, you might want to try Connecticut’s extensive rail-trail system. The Farmington Canal Heritage Trail and Farmington River Trail both offer long, accessible paths that are perfect for a casual stroll or a handcycling outing. Just make sure the area you plan to tackle is suited for wheelchairs.

PLACES TO GO

Located just about midway between Boston and New York on the Long Island Sound, Mystic, Connecticut, has plenty to offer, whether you’re looking for a traditional tourist trip, a romantic getaway or just a day-long excursion. The Mystic Seaport is the largest maritime museum in the world, the Mystic Aquarium is one of the best in New England, and don’t forget Mystic Pizza, made famous in the eponymous 1988 Julia Roberts movie.

In addition to the expected ships and boats, Mystic boasts a 19th-century seafaring village with over 60 historical buildings that have been preserved. Only about a third of the Seaport buildings have accessible entrances and many others have accessible entrances but limited interior access. Make sure to check the thorough access guide at www.mysticseaport.org/visit/plan-your-visit/accessibility/physical-access before plotting your trip. If you’re tired of a landlubber’s perspective, Argia Cruises offers a two-and-a-half-hour harbor tour that is scenic as well as informative.

GETTING AROUND

Accessible transportation in Connecticut has greatly improved over the last few years. All CT Transit buses are equipped with either lifts or ramps, and service covers most all areas. Reduced fares are also available for seniors and people with disabilities. Both Metro and Yellow Taxi, two of the state’s largest cab companies, now have a bounty of accessible vehicles. Between these two services alone, visitors now have options that used to be lacking.

AVAILABLE HEALTH CARE

Connecticut isn’t right on the cutting edge of health care, but when it comes to SCI-related options, it has a surprising number of offerings. The two main rehab facilities our United Spinal chapter interacts with are Gaylord Specialty Healthcare in Wallingford, Connecticut, and Hospital for Special Care in New Britain, Connecticut. In addition to traditional rehab options, Gaylord has an Ekso exoskeleton and the Hospital for Special Care offers rehab using a ReWalk model. Our chapter maintains support groups and peer assistance programs at both facilities. Both facilities do admirable jobs of partnering with local SCI/D nonprofits to supplement their offerings, as does Mount Sinai Rehabilitation Hospital in Hartford. Mount Sinai collaborates on a great adaptive rowing program on the Connecticut River, while Gaylord also has an excellent adaptive sports program.

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life in a wheelchair can be costly, and unexpected expenses are even more unpleasant when you are already haggling with Medicare and Medicaid and trying to keep on top of all the day-to-day costs associated with life after SCI/D. To help alleviate some of that hassle, the Connecticut Chapter of United Spinal Association offers $500 Quality of Life grants to help members find the extra bucks to pay for wheelchair repairs, home modifications, vehicle accommodations, or almost anything SCI/D related.

“It’s not a huge amount of money,” says Bill Mancini, the president of the Connecticut chapter, “but at least it can get people out of a hole.”

Mancini says the number of grants varies with demand, but that some months the chapter will award five or more recipients. That adds up quickly. Luckily, the chapter has gotten pretty good at raising money in the 43 years since it was founded in 1973.

The chapter’s largest fundraiser is its annual Twilight Gala, a formal dinner, dance and auction, now in its seventh year. This year’s gala was March 12 at the Aqua Turf Club in Plantsville, Connecticut. Over 300 attendees showed up and helped raise over $30,000 to support the chapter. Boyd Melson, a professional boxer who donates all the profits from his matches to SCI research, gave a keynote address and attendees enjoyed a lively auction.

“This year’s event was very successful and hopefully we’ll continue building on that success,” says Mancini.

The funds raised will go to support the Quality of Life grants and the many other programs the chapter offers, including its three monthly support groups, its peer mentoring program, its Think First Prevention program and adaptive sports offerings like rowing. The chapter also raises funds with an annual Walk & Roll at Quinnipiac University in Hamden, Connecticut.

Mancini says the chapter embraces a true grass roots work ethic when it comes to fundraising, even rolling door-to-door to find the funds needed to sustain its programs. Before the balloons from the Twilight Gala had come down, the chapter had already prepared the forms to court sponsors for next year’s event. “We’re a small state and we’re limited to the number of groups we can get to, but we don’t use that as an excuse,” he says. “We want to expand our programs and see if we can offer bigger grants, and to do that we know we need more money.”

United Spinal Association’s Pathways to Employment Program

Would you like to return to work? After a spinal cord injury there is so much to think about. Everyone wants to participate in their lives as much as they can and regain their independence. But some of the challenges of living with SCI can seem insurmountable. This includes returning to work.

United Spinal Association’s Pathways to Employment Program is designed to support your pursuit of new job opportunities and a successful career. PTE, currently operating in New York, New Jersey and Pennsylvania, provides access to resources and information that you need. United Spinal’s PTE program will pair you with a trained peer mentor to work with. Your peer mentor is a person with SCI who is or was recently employed, and has experienced many of the things you will go through on your pathway to employment.

The PTE program will give you the opportunity to:

- Interact with someone who has successfully adjusted to working with a disability
- Gain practical information on resources, benefits, and work incentive programs
- Develop an employment plan
- Prepare for job interviews
- Learn self-advocacy skills
- Acquire reasonable accommodations

For more information or to sign up for the program, please visit www.spinalcord.org/pathways-to-employment and/or contact Barbara L. Kornblau, bkornblau@unitedspinal.org.
Building a Network of Peer Mentors

There is no greater support than that of your peers, which is exactly why United Spinal Association’s national Peer Mentoring Program is growing in leaps and bounds. Connecting newly injured or diagnosed individuals with others who not only understand their issues but how to overcome them is extremely valuable. It can change someone’s state of mind, provide a positive outlook and lead to new opportunities that were never even considered possible. It’s easy to see the power of peer mentoring working with individuals who credit just how empowering and life changing their own mentors once were.

The goal of the Peer Mentoring program is to ensure individuals across the country are connected to the very best resources to help people with SCI/D maintain independent and active lives. The peer-to-peer mentoring is also provided to caregivers and family members, and shares guidance on all facets of living with SCI/D, including: employment, affordable housing, transportation, health care and education.

The trainings are led by Lindsey Elliott, United Spinal’s director of member initiatives, and have had an immediate impact according to participating chapter members. “This set an immensely solid foundation for our marquee program, that we feel will set the tone for our young organization,” said Richard Bagby, deputy director for United Spinal Association of Virginia.

To date United Spinal has conducted trainings all over the country, including: Houston; Pittsburgh; Las Vegas; Boston; Oklahoma City; Madison, Wisconsin; Des Moines, Iowa; Rochester, New York; Minneapolis, Minnesota; Raleigh, North Carolina; Richmond, Virginia; and Nashville, Tennessee. A total of 169 mentors have been trained throughout this incredible network. The program has grown and flourished thanks to generous funding from Hollister, Inc. The 2016 goal is to continue to work with United Spinal’s chapter network and train at additional sites.

If you are interested in learning more about the Peer Mentoring Program, please contact Lindsey Elliott at lelliott@unitedspinal.org.
Ramping Up To The 5th Annual Roll on Capitol Hill

By Alex Bennewith, Vice President of Government Relations for United Spinal Association

It’s that time of year again! This June 26-29, we will celebrate our fifth year of Roll on Capitol Hill in Washington, DC. At the time of printing, we already know that members and advocates from 28 states plus the District of Columbia will be joining us this year, and I know there will be more states represented by the time June comes around.

We’ll kick things off with a welcoming and networking reception Sunday night and then dive right into a full day of speaker presentations and issue education on Monday. Advocates will be ready to spend all day Tuesday on Capitol Hill meeting with their legislators and making sure that our voices are heard on issues that matter to us. We’ll take care of scheduling the meetings and leave the fun part, the actual meetings, to you.

The day of legislative meetings will be capped off with an entertaining awards reception on Capitol Hill where we thank you, as well as our congressional champions, for all the support and leadership over the past year. This year, notably missing will be Finn Bullers, a strong advocate and friend to United Spinal. Finn was United Spinal’s inaugural Consumer Advocacy Award recipient in 2014 for his outstanding and persistent advocacy at the federal level and in his home state of Kansas on home and community services and complex rehab technology. Finn passed away too early at the age of 52 at the end of January. To honor his memory, United Spinal is renaming United Spinal’s Advocate of the Year Award the Finn Bullers Advocate of the Year Award.

The issues we will be focusing on at this year’s ROCH include ensuring access to the right medical equipment, prescription drugs, and medical supplies; safeguarding the provision of home and community-based services and supports so that individuals can live and participate in their communities; providing standards for vehicle modifications to guarantee safety and quality; expanding the pool of veterans entitled to home modification grants and tax credits; and ensuring that policymakers understand what SCI/D is.

If you know about these issues, great! If not, don’t worry. We will cover them extensively in our Monday sessions so you feel well-prepared for Tuesday’s meetings. Here are a few of the specific policies we will focus on:

- We are advocating for improved access to complex rehab technology. There are a number of bills on this issue, including Ensuring Access to Quality Complex Rehabilitation Technology Act, H.R. 1516/S. 1013 and H.R. 3229, S. 2425.

- We are opposing the expansion of a government program, called competitive bidding, to urologic, ostomy and prosthetic supplies as proposed in the president’s FY2017 budget. The program has the impact of restricting access to physician-prescribed products and services.

- Regarding community supports and services, the Disability Integration Act, S. 2427, states that individuals with disabilities have the right to receive supports and services in their communities as opposed to institutions.

- In the rehabilitation and medical research area, we will advocate for Enhancing the Stature and Visibility of Medical Rehabilitation Research at the National Institutes of Health Act, S. 800/H.R. 1631, which streamlines and expands rehabilitation and disability research at the National Institutes of Health. With the Advancing Research for Neurological Diseases Act, S. 849/H.R. 292, the Centers for Disease

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The United Spinal team is working hard to ensure that this year’s Roll on Capitol Hill is the most successful one yet.
Advocacy

control and Prevention is required to monitor and track neurologic diseases, including multiple sclerosis, Parkinson’s disease and other neurological diseases, and the National Institutes of Health is required to facilitate further research on neurologic diseases. Both CDC and NIH include SCI/D in their categorization of neurologic diseases and disorders.

The VetsFirst program will be advocating on the following: The Veterans Mobility Safety Act, H.R. 3971, establishing minimum standards of safety and quality for adaptive equipment at the VA; The Housing Assistance for Veterans Act/HAVEN Act, H.R. 385, support of funding of home modifications and adaptations for all categories of disabled veterans; Veterans Homebuyer Accessibility Act of 2015, H.R. 3975, advocating for funding, grants and tax credits for veteran homebuyers.

For those of you wanting to know more about all of the bills we will be addressing at Roll on Capitol Hill, visit United Spinal’s Roll on Capitol Hill page at www.unitedspinal.org/events/roll-on-capital-hill/.

JOIN US!

United Spinal Association knows that disability is a shared experience that affects you, your family, friends and communities. Fortunately, we are stronger together, and United Spinal brings decades of expertise to help: information, peer mentoring, advocacy and much more. Become a member today and Share the Journey.

800.404.2898 • unitedspinal.org
Handcycling is a popular sport for good reason. It provides a freedom akin to the feeling of gliding and allows for distant exploration, from neighborhood rides to on or off road trails. In addition, the combination of being outside, getting a cardiovascular workout and socializing with fellow cyclists, joggers and new friends you meet on a ride is a natural mood enhancer.

“Probably 70 percent of people buy recreational handcycles, partly because of affordability and also because they want to ride with family and friends and don’t want the stress of lying flat near the ground the way today’s racing handcycles are configured,” says Carlos Moleda, renowned handcyclist, triathlete and owner of High Performance, a wheelchair and handcycle racing website.

The advent of quad-friendly grip options for pedaling, shifting and braking has made handcycling more accessible for riders with more needs. When you add in power assist units, beginning riders and riders with limited muscle control can now keep pace with nondisabled cyclists.

“Things have improved a lot for quads since I first started riding 20 years ago,” says John Squires, 42, of Portage Lakes, Ohio, in his 28th year as a C5-6 quad. “Back then I had to have my hands duct-taped to the grips, and if I wanted to stop, I had to find a patch of grass to roll in. Now I can shift, brake, do it all, including remove my hands.”

Squires works for Bike-on.com, a company that sells a wide variety of handcycles and handcycling accessories, often at discount prices. His specialty is helping quad clients figure out just the right set-up. “It takes a quad to help figure out what is going to work for another quad,” says Squires.

Here is a look at popular handcycle options, directly from riders that own them.

**Top End Excelerator:**
“I tried a variety of different handcycles at an adaptive sports day before deciding on a Top End Excelerator,” says Jim Lunny, 59, of Marietta, South Carolina.

“I’ve always been into sports and athletics, and anything to get me outside is a big thing,” says Lunny, a T12 para as a result of transverse myelitis. “I like the Excelerator because it is the same height as my wheelchair, so it is easy to transfer into. I really like riding it because it is a great workout and is really social on the trails. It is more like I’m just one of the bike riders rather than a guy in a wheelchair.” Lunny’s favorite riding area is an 18-mile system of bike trails converted from old railroad beds that have been paved over for riding. A caution about riding the Excelerator — it has a higher center of gravity than recumbent bikes, so you need to slow down below 15 mph for cornering to avoid tipping.

Factoids: The Excelerator comes stock with 7-speed internal hub, “pedal backwards” coaster brake and many custom options, including quad grips, brakes and shifters. Junior version is also available. Suggested retail: $2,295; www.topendwheelchair.com.

**Rio Dragonfly:**
The Rio Dragonfly is an attachable handcycle-front-wheel-combination that quick connects to manual wheelchairs. Ed Barker, 73, has had a racing wheelchair, a recumbent handcycle, and even a hand crank bicycle in his 31 years as a T5-6 complete para. “All were great, but none as versatile as the Rio Dragonfly,” says the Carmel, California, native.
Barker purchased his first Dragonfly 10 years ago and he rarely leaves his apartment without it. “The increase in places I can easily go with the Dragonfly is incredible, and the speed with which I can get there is amazing,” says Barker. The highlight of his day is going for 10-mile rides along the ocean. “It’s great exercise, brightens my outlook on life and lowers my stress levels.”

A big plus for Barker is how the cranking motion preserves and balances the muscles in his shoulders, especially the pulling motion of the crank arms. “In terms of speed it does a really nice job of keeping up with most joggers and even some bicycles,” he says. Like other forms of upright handcycling, Barker cautions that high speed cornering and/or taking bumps at speed can cause the chair to tip.

He has used his Dragonfly to explore trails in many national parks, and it has come in handy in urban situations from easily traversing bumpy surfaces like cracked pavement, grass and gravel, to racing through airports to catch connecting flights and wheeling through long hotel hallways of hard-to-push-through carpet.

Factoids: The Dragonfly has eight gears, built-in coaster brake and is adjustable for adult and junior size chairs. Suggested retail: $1,990; www.riomobility.com/en/.

**BionX Power Assist:**
The BionX is a battery-operated wheel-assist that has changed the dynamics of handcycling, empowering many riders who might not have been able to use handcycles before. Simple to use, the BionX has a push-button screen mounted above the hand cranks that lets the user add 25 percent, 50 percent, 75 percent, or 100 percent power assist to their bike and has a maximum range of 80 miles under ideal conditions.

The power assist enables beginning riders who may not have strong handcycling muscles to climb steep hills and ride at speeds that keep up with friends and other cyclists on their first ride. Many riders report that over time they develop more muscle and use less BionX assist. The BionX is also great for riders who have limited muscle control.

Factoids: BionX power assist is offered as an option on many manufacturer’s handcycles and can be added to many current handcycles. Prices for handcycle versions start at: $1,799.00; www.ridebionx.com; also available at www.bike-on.com.

**Freedom Ryder FRH-1Q350X with BionX Power Assist:**
“I got hooked on the Freedom Ryder FRH-1Q350X when I tried one at an Abilities Expo,” says Jason Hall, 40, a C5-6 quad from Muskego, Wisconsin. “It is a recumbent handcycle specifically designed for quads, with quad grips, shifters, brakes, and a BionX power assist system.”

“When I found out it was designed for a quad and had the BionX system, I was sold,” he says. “Being able to dial in the amount of assistance I want made all the difference. I was able to join my wife and kids and keep up at their speed and distance on the first day, instead of taking years to build up to that fitness level. And the more I ride, the less assist

**For the Kids: HOC Zipper Kids Handcycle**
Like most kids, Hunter Pochop, 10, likes cycling. However, Pochop, who has spina bifida, wasn’t able to really get into handcycling because the handcycle he had didn’t fit him correctly. That changed last year when Pochop, who lives in Vista, California, went with his family to an Athletes Helping Athletes event in San Diego. The non-profit organization has an adaptive biking program for kids that provides grants for people 18 and under to purchase adaptive bikes, and had just received a bunch of new Zipper adjustable handcycles, designed for kids 3 feet tall and up, made by Hands on Concepts.

At the event Pochop hopped on a Zipper handcycle, had it properly fitted and adjusted and he was off. “He loved it — the adjustability on this bike is amazing, it fit him perfectly to a T, and it can be re-adjusted as he grows,” says Jacqueline, Pochops’s mom. The folks at Athletes Helping Athletes were so impressed with Pochop’s enthusiasm that they granted him the bike on the spot.

“I love riding it,” he says. “I ride around the neighborhood and on trails with my friends, and also ride at sports camp. My favorite thing about it is I can go really fast! Someday I want to get into racing.”

I need, so I’m getting a great workout and having a blast on every ride.”

“I’m fortunate that three blocks away from the house is a great bike trail system made by the power company,” says Hall. “Since they have to get from pole to pole to service them, they have created bike trails, either paved or hard gravel bike trails under the electric wires — a win/win for cyclists and for workers who service the system.”

In addition to exercise, Hall says being in a reclined position has loosened up the muscles in his hips and reduced his spasticity.


**NUKE OFF ROAD HANDCYCLE:**

James Watson of Winfield, Kansas, is in his 20th year as a C6-7 quad. Watson, 54, owns Quadgrips.com, which sells all types of adaptive grips, and rides a Force RX for road cycling but prefers riding his Nuke, upright-recumbent, rear-wheel drive, rear suspension handcycle made by Reactive Adaptations.

“When I’m riding with my friends or grandkids, I will ride the Nuke to be sitting in an upright position so I look around, see and talk with them,” says Watson.

“I like the Nuke because it enables a person with a higher-level injury to get out in tough terrain and wilderness,” says Watson. “The key is rear-wheel drive, which is where all the traction is needed in loose dirt and gravel. There are some great hiking trails along the river near my house, plus there is a local mountain biking park that I enjoy riding.” When Watson gets a chance, he goes on rides in places like the Tetons in Wyoming and the Colorado Rockies.

Quadgrips.com has grip set-ups that enable a quad to pedal, shift, and brake and can be added-on to a majority of handcycles. Most shifting is enabled by the back of the hand — you tap a lever that sits behind your hand, with the back of your hand. By applying pressure for one click it upshifts; putting more pressure to make two clicks makes a downshift; and pushing multiple clicks downshifts multiple gears. Braking works with different options. One type of brake has a pin above and below the wrist, and moving your wrist against the pin applies the brake. Another type has a single pin that stops with outward wrist pressure.


**TOP END FORCE 3:**

“I mainly do social riding, and for that, the Top End Force 3 is perfect,” says Sam Bridgman, 24, of Tampa, Florida.

“My previous handcycle was a recumbent three-wheeler that I pedaled with my feet, but my condition progressed, so I switched to the Force 3.”

The Force 3 is a recumbent handcycle with a seat back that can be adjusted in a more upright position for recreational riding or lower for a more aerodynamic position for racing, which makes it a great choice for both recreation and riders interested in taking a crack at the competitive aspect of the sport.

“I have my seat back adjusted low enough to be aerodynamic, but still upright enough to be social and talk with people while riding,” says Bridgman, who has Friedrich’s ataxia. “We have great bike trails right next to the water here in Tampa. I try and ride them right as the sun is coming up. It’s a great way to start the day. And if I get fast enough, I would love to try racing.”

Factoids: The Top End Force 3 features a 27-speed drive train and rapid fire shifter/brakes. Many options are available, including off-road knobby tires and BionX. Suggested retail: $2,995; www.topendwheelchair.com.

**TOP END FORCE RX QUAD ELITE:**

John Squires rides a Top End Force RX — a high performance recumbent bike designed with racing in mind — with Bike-on’s “Quad Elite package” that combines grips from Quadgrips.com.
and a Bike-On.com system for braking and shifting. “Our braking system enables you to apply the brake and back pedal. So, for instance, if you’re stuck on a steep section of a hill, you can brake, ratchet back to the power part of your stroke again and again to make it to an easier incline,” says Squires, who works for Bike-On.com.

Squires says many quads start out thinking they want to sit upright. He explains that without trunk support, a quad is going to be wobbly in an upright position, especially around corners, and without the use of triceps you aren’t going to be doing transfers, so don’t let that dictate the kind of bike you ride. Most of the Quad Elite bikes he sells are Force RXs and Force 3s because, as a quad, lying back provides better balance and support. “As a C5-6 quad I raise my seat back up a bit, rather than lying flat because with my level of injury I don’t have triceps muscles, and can’t push the crank between the nine o’clock position and up over the top,” says Squires. “By lying back — but not way back — my body is supported, doesn’t wobble, and I’m high enough to get the crank from nine o’clock up over the top using my biceps.”

The latest option on the Quad Elite package, which Squires now rides, is the pro-shift kit, an electronic shifter that is set up to automatically shift based on a choice of speed, cadence, or heart rate. “It’s great because it automatically shifts when needed,” says Squires. “All a rider has to do is pedal, steer and brake. The shift kit keeps the gearing in the sweet spot.”

Squires has created a YouTube video series showing braking, shifting and other options on the Quad Elite package as well as additional videos, including a converted Hoyer lift that fits into the receiver of a trailer hitch for easy chair-to-bike transfers. To view videos, go to YouTube.com and type in Bike-On Quad Elite.


RESOURCES:
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- Top End Force RX and Top End Force 3, Top End, www.topendwheelchair.com
- QuadGrips.com, 620/218-3133; www.quadgrips.com

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Golf is a lifelong sport played by people of all ages for fun, plus it also promotes improved stamina, flexibility, enhanced circulation, and social activity. Golfers are able to enjoy the surroundings in a relaxed atmosphere with family, friends and business acquaintances. Thanks to guidance from federal agencies and follow-up commentary from the Disability Rights Education and Defense Fund, many golf courses have started adding accessible golf carts to their rental cart fleets to comply with Title II (government-owned or operated facilities) and/or Title III (public facilities) of the Americans with Disabilities Act.

Some golf courses are accessible to all golfers, including those who must play from a sitting or standing position while in the accessible cart. The American Lake Veterans Golf Course in Lakewood, Washington — affiliated with the rehabilitation program at the local Veterans Administration hospital — has a number of accessible carts on hand, mostly ParaGolfer and SoloRider models. Also, all bunkers and traps have been designed without steep sides so that golf carts with wider tires can drive through them. Wide-tire models can also be driven on the greens.

Another course working to accommodate accessible golf is Haggin Oaks, a popular public golf course located in Sacramento, California. Morton Golf manages the Haggin Oaks golf course along with two other courses in the Sacramento area. The three facilities offer the use of Model Tee, ParaGolfer and SoloRider accessible rental carts and special group lessons for everyone who wants to learn the game, no matter what their disability.

The most basic accessible golf carts are ramp-equipped models with hand controls that will simply accommodate a wheelchair to travel between shots. It is necessary to unload from the cart in order to hit the ball. Runabout carts, manufactured by PHED Mobility, are equipped with hand controls and can haul two wheelchairs. More complex accessible carts are designed to carry a single rider and allow golfers who cannot stand to remain seated while hitting a variety of shots from tee to green. The Eagle 724 Single Rider golf cart provides hand controls and a swivel seat to accommodate golfers with disabilities. Single rider carts can drive through bunkers or sand traps and across tee boxes and putting greens at most golf courses. Less weight combined with wider tires assure that they will do no damage.

Another early model accessible cart was the Model Tee Widetrack Freedom Rider. While no longer being manufactured, they are still available to rent at many courses, and used Model Tees are for sale on the secondary market. The Model Tee carts feature seats that elevate and swivel, a footrest, and wider tires for driving through sand traps and across greens. Like all carts mentioned in this column, they also have hand controls.

A cart with a similar design is the Golf Xpress, which offers a seat that swivels and tilts forward so that the seated golfer can swing a golf club. Tamara Lawter, a T5-6 para from Kearney, Nebraska,
played golf 22 years ago when she was injured while serving in the military, and she loved the game. She returned to playing golf four years later when she obtained a Golf Xpress cart.

In 2015 Lawter switched to a ParaGolfer through the joint support of The Independence Foundation and the Stand Up And Play Foundation. Both foundations were established to provide veterans an opportunity to participate in recreation. Providing accessible golf carts for tournaments or outings has been a big part of their mission.

Using the ParaGolfer — also called a Paramobile — Lawter found that she could use both hands to swing a club for the first time since her SCI. Unlike some types of accessible carts where golfers usually swing a golf club with one hand while stabilizing themselves with the other, the ParaGolfer has a set of straps and a chest plate to secure golfers while raising them to a standing position so they can swing two-handed. “I think there are advantages to standing up,” Lawter says. “It provides more control over the club and allows me to hit the ball farther. It also helps improve balance and circulation, and I feel like everyone else on the course who is standing up.”

**Paramobile/ParaGolfer: Power Chair/Golf Cart**

Unlike most of the accessible products mentioned in this column, the ParaGolfer was initially developed to meet power wheelchair standards (Paramobile). The person behind the ParaGolfer, Anthony Netto, an incomplete para from Vista, California, was a golf coach before a 1994 auto accident left him paralyzed. Having an understanding of funding mechanisms that allow people to obtain wheelchairs, Netto helped design the Paramobile to be eligible for the same payments.

Netto worked with Ottobock, a European company that makes medical devices, and the Swiss design and engineering company ESORO to create a device that complies with the same standards as a power wheelchair and standing frame. So as not to cause problems while being used on tee boxes and greens, the Paramobile was equipped with turf tires that also work well on snow and sandy surfaces. The cart meets FDA requirements and other international standards organizations that certify wheelchairs. Even with certifications, Netto was unsuccessful in finding a mainstream wheelchair company to manufacture and sell the Paramobile until he found Ottobock.

Development of a smaller model of Paramobile is underway so that it can be used in more indoor environments. The standing-frame capabilities of the machine make it useful for completing workouts on standard exercise machines, and the smaller footprint ensures that it will be welcomed in gyms as well as on golf courses.

Because the ParaGolfer has proved to be a popular choice for golfers with disabilities, Netto founded the Stand Up And Play Foundation in order to raise awareness and help interested golfers get one. The foundation sponsors several golf-related events around the country each year with a focus on letting people try out the equipment.

During 2015 the foundation gave away 34 ParaGolfers, mainly to military veterans with disabilities. Netto showcases the advantages of the ParaGolfer regularly. At a World Championship Long Drive Competition in Mesquite, Nevada, he hit a 305-yard drive, which is now the world record for a paralyzed golfer.

Jerry Donovan, a T6 para from Norwood, Massachusetts, was first introduced to the ParaGolfer at an adaptive sports clinic held at Spaulding Rehab Hospital in 2001. Those clinics are co-sponsored by the Salute Military Golf Association of Boston, a group that assists wounded veterans and their families through rehabilitative golf experiences. Not long after attending the clinic, Donovan obtained a ParaGolfer with the assistance of Legacy Financial and has been using it to play golf ever since.

Donovan points out that he has never tipped over in five years and has done no damage to greens. He continues working to get area courses to purchase additional accessible carts. “My goal is to help other people with disabilities have more fun. Standing is great for the body,” he says. “It helps with circulation, osteoporosis, bowel, bladder and, perhaps most importantly, morale.”

Andrew Hippert, Tampa, Florida, quad and founder of Living Spinal, does not own an accessible cart for his personal use, but he attended a sports clinic put on by the Stand Up And Play Foundation that included a golf tournament and two ParaGolfers available for use. Since he had not played much prior to that time, he admits that simply putting the ball from a standing position was the most fun.

Jim Siegfried, a T5 para from Orange, California, was injured in 1977. Until three years ago he had not been able to try golfing. At that time, with the support of the Stand Up and Play Foundation and instruction from Netto, he tried hitting a golf ball from a ParaGolfer for the first time. His experience was similar to that of many other first-timers. “I couldn’t even hit the ball at first,” he says. “But I would recommend to others that they try it and not get discouraged.” Siegfried has begun playing with family and friends on a regular basis and has even participated in a long drive championship, where he drove a ball 185 yards one-handed (his mid-thoracic level of injury makes it difficult to twist his upper body far enough to allow him to hold a golf club with two hands while driving).

**The SoloRider: A Popular Choice for Golf Courses**

Providing an opportunity for people with disabilities to try golf for the first time is an important role now being played by the largest independent living center in Arizona, Ability360, in Tempe, has a state of the art sports and fitness center and recently received grant funding to purchase four accessible golf carts plus...
a pickup truck and trailer to haul them. According to Phil Pangrazio, president and CEO of Ability360, the four carts — two ParaGolfers and two SoloRiders — will be taken to golf tournaments and disability-related events throughout the region as part of the center’s mobile fitness program.

One Ability360 Sports and Fitness Center staff member is especially looking forward to those events. Tim Surry, a T10 para from a 1988 car accident when he was a senior in high school, had played golf and knew he wanted to do it again. He began by hitting golf balls while seated in his manual wheelchair and has been able to enjoy the game even more now that he has access to accessible golf carts.

Billy Fryar, a T10 para from Conway, Arkansas, owns a SoloRider cart. He uses it regularly at a public course in Little Rock and plays several times a year at other nearby courses. “One course superintendent had some apprehension about me driving on greens,” he says, “but once I showed up and demonstrated the cart’s capabilities on the practice putting green, it was okay. I drove all the way across it and left no tracks.” Fryar recommends the use of the SoloRider to everyone he meets who might benefit from it. For anyone who might think that playing from an accessible cart while swinging with one hand is less effective, Fryar points out that he has made two holes-in-one so far. The last one was witnessed by an entire troop of Boy Scouts who were doing a project adjacent to the course.

Madeline Kennedy of Naples, Florida, diagnosed with ALS in 2012, lost her ability to stand and walk for long distances, which robbed her of the ability to play golf. Then in 2014 she was loaned an accessible cart by SoloRider. “That cart allowed me to have a different view of the world. I could watch the birds and alligators on the course while mingling with my family and friends,” Kennedy says. “It lit up my world again, providing huge emotional benefits even though I can no longer swing a golf club.”

Kennedy had an exciting experience with her SoloRider last year at a golf tournament fundraiser for ALS research. During a live interview with the local television news station, she sank a 78-foot putt while seated on her SoloRider. The TV news clip went viral and was quickly picked up by international news channels and the Golf Channel. It has been televised around the world.

SoloRider carts are a popular choice for golf courses that are becoming accessible in order to comply with the ADA. The single rider accessible carts were first manufactured in 2000 as part of a joint project with Regal Research, a Texas company engaged in military work, and Club Car, a major manufacturer of standard golf carts. In 2004 the partnership was dissolved and Regal Research took over the business. The accessible golf carts are a small part of the company’s business — about 80 to 100 SoloRiders are sold each year. Eric Hatch, SoloRider’s production manager, believes there is a much bigger potential market available. There are about 16,000 golf courses in the United States and only a small percentage of them have stepped up to purchase accessible golf carts.

A grassroots effort by potential golfers with disabilities might improve the situation. If you have not yet called your local golf courses to see if accessible rental carts are available, now would be a good time to do it. The next thing you know you will be scheduling a golf outing with friends and enjoying the outdoors.
Our Mission
VetsFirst leads the way in advocating for veterans living with disabilities and ensuring they achieve the highest level of independence and quality of life.

Our History
As a program of United Spinal Association, VetsFirst has a long and illustrious history assisting and representing veterans and their eligible family members. United Spinal—a VA recognized veterans service organization—strives to ensure the organization remains an instrument for veterans.

About VetsFirst
VetsFirst brings to bear seventy years of expertise in helping America’s veterans with disabilities, their spouses, dependents, survivors and other eligible family members receive health care, disability compensation, rehabilitation and other benefits offered by the U.S. Department of Veterans Affairs. We supply direct representation, proactive legislative and regulatory advocacy, individual support and counseling services, guidance on education and employment, timely news and information and valuable self-help guides.

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Our Core Beliefs
VetsFirst's priorities are based on three core principles that will improve the lives of veterans with disabilities.

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Timely Access to Quality VA Health Care and Benefits — We support improved access to VA health care and compensation and pension benefits that are the lifeline for many veterans with significant disabilities.

Rights of Veterans with Disabilities — We believe that discrimination against disabled veterans that produces barriers to housing, employment, transportation, health care, and other programs and services must be eliminated.

www.vetsfirst.org
President Trump. How do you like the sound of that? Future News Flash: “Today President Trump described German Chancellor Angela Merkel as old, fat, and ‘some- one should do something about that mustache!’ At the same time, he lauded North Korean despot Kim Jong Un as ‘someone he could work with’ because ‘hey, he’s a winner and I like my win- ners with bowl haircuts.’

Couldn’t possibly happen, right? Not a chance in Hades that such a shoot- from-the-hip, trash-talking zillionaire could really be president? Well, think again. Do not sell The Donald short. There is apparently a deep, national vein of anger and disgust for anyone Trump decides to pick on. He seems to be able to channel America’s 3 a.m., f-you, Charlie, psyche. No more patina of niceness toward anyone who is not white, mad as hell, and most likely, in the parlance, a “low-information voter.”

Mark my words: In a Trump presidency, it will be open season on gimps.

First of all, to Trump, gimps are funny. They walk funny, talk funny, and don’t know how to wear nice clothes. Everyone knows by now how Trump, in describing disabled New York Times reporter Serge Kovaleski, waved his arms like an AirDancer in front of Subway. Big laugh. Or how he nailed wheelchair-using columnist Charles Krauthammer by calling him a loser “who just sits there.” Booyah! “Take that, little man who dared to call me a rodeo clown. That’s why I called my new book Crippled America. The whole country is full of lame crybabies just like you!”

The thing about Trump’s unvar- nished attacks on the disabled, not unlike his attacks on Megyn Kelly or John McCain or every person on earth with brown skin, is that no one not being insulted seems to care that much! Television and newspapers can play up these smears like they were an offense against God and his voting bloc will go, “So what? The man speaks his mind. Those gimps are a pain in the keister and finally someone has the guts to say so.”

After decades in which your ordi- nary Joe American would open every door for someone in a wheelchair and tell them that they were doing “just super,” the truth finally comes from the man who has no governor on his mouth. If Trump should win the presidency, then all civility toward the disabled among a huge swath of Americans will be out the window. Soon it will be, “Open your own door, gimpo. I’m not your house boy, and while you’re at it, get a job weaving baskets or something and stop suck- ing off the government!”

Trump hates losers. If you are so cursed as to be in a wheelchair, you are ipso facto a big fat loser. And probably stupid, since losers are generally stupid and vice-versa. And how are you going to help make America great again? In fact, you are standing (or sitting) in the way. No crafty Chinese diplomat is going to cower in the presence of some guy in a wheelchair arguing about tariffs on rhino tusks.

Trump is in many ways the real American id, or childish bully, no lon- ger taking orders from the American superego, or grown up. For decades that collective id has been browbeaten into biting its collective lip in the pres- ence of people who wear towels on their heads, sit around all day in front of Home Depot hoping you will hire them, talk a street patois that you can’t understand, or wheel around the mall shouting, “Excuse me, I’m rolling here,” like they own the place.

Think of a classic American play like Cat On A Hot Tin Roof or Who’s Afraid of Virginia Woolf? Characters in these dra- mas tend to be perfectly nice to one another until they’ve downed a quart of gin and then, watch out! Trump has a gift of doing this kind of mean- spirited truth-telling without the need of getting plastered. He is already plas- tered on himself. He says anything he damn pleases and his adoring crowd whoops and hollers.

If you use a chair, stay indoors and/ or buy a weapon. If Trump becomes president, they’re coming after you. They’ll be rounding up all of the nation’s losers and shipping them off to Canada. That’s a whole country of losers — or as they say up there, hosers.

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RESILIENCE CAN BE MESSY

When Sheri Denkensohn Trott was still in rehab learning to live with quadriplegia, her favorite nurse, John, brought a plate of macaroni and cheese to her bedside, put her fork into her splint, and told her to call him when she was done eating. Trott, 16 at the time, says she was shocked, angry, scared, and in disbelief. For half an hour she yelled for him to come back and sobbed in anger. Then, writes Trott:

“I realized that I was either going to have to try or forgo eating, so I lifted up my arm and stuck my fork into the macaroni and cheese. About half fell off before it got to my mouth, but I succeeded in eating something. Next was green beans. Again, at least half fell off the fork, this time onto my lap, but I did eat what remained on the fork. When I finished, I didn’t feel relieved or proud of my accomplishment. I remember feeling tired, resentful and mad at John for making me feed myself. So I called him on the nurses’ bell. When he came back into the room he looked at the plate and said, “Not bad, next time you will likely eat more.” And he picked up my tray of food and took it out of the room.

I put my head down in silence because I didn’t know what to say or do. And then it hit me, for the first time in over six months I had actually done something for myself without help. And it wasn’t some minuscule task. It was one of the most important activities of daily living, feeding myself! It was a victory. It was hard and it was messy, but it was a victory. And each time I fed myself was easier, less tiring, not as frustrating, and resulted in more in my mouth than on the plate or in my lap.”

Read the rest of Trott’s NM blog entry, “How Macaroni and Cheese and Green Beans Helped Me to Develop Grit” at newmobility.com/2016/04/mac-and-cheese-and-grit/

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