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Cory Lee Woodard has become the face of accessible travel, having appeared on segments for Lonely Planet and CBS, written for National Geographic and won the prestigious Lowell Thomas Award for best travel blog. The only continent he hasn’t visited — yet — is Antarctica. And now he has another honor to add to his growing list: New Mobility’s 2018 Person of the Year. BY JOSIE BYZEK

Cover Photo by Sandy Gilbreath
Contents Photo by Nathalie DuPré Photography

FEATURES

18 ELECTION WRAPUP
Several wheelchair users ran for office in the November elections. SETH MCBRIDE checks in with three winning candidates to see what put them over the top.

32 SURVIVING THE FIRES
Climate change is producing the worst fire seasons in recent history. ALEX GHENIS reports on how the devastation is impacting wheelchair users in California and what they are doing to stay safe.

37 TAKE TO THE SKIES
After years of being out of production and hard to find, hand controls for general aviation are on their way back. MIKE COLLINS explains.
REFUSE TO SETTLE

One of the benefits of being the editor of New Mobility is getting to talk with fascinating people from all corners of the wheelchair-using spectrum. The search to find interesting stories to share with you often leads me down a rabbit hole of people who are pushing the boundaries of what is possible and redefining society’s expectations.

I’ll let you in on a secret if you promise not to tell: It can be pretty overwhelming.

Community leaders with nonprofits that are saving lives, activists and advocates who are fighting for laws to help us, award-winning athletes, authors, inventors ... the list goes on. It’s just as rich and deep as the list for society as a whole, and to be honest, I think the obstacles and complexities its members face make it even more interesting.

I don’t know what it’s like to deal with all of those obstacles, but I’ve dealt with my fair share and watched friends and people I know deal with them, and I know one thing: It’s never easy. Life is hard enough as is, but when you add in whole new levels of social and physical complications, well …

It’s never easy. Life is hard enough as is, but when you add in whole new levels of social and physical complications, well …

This brings me back to feeling overwhelmed by the general “kickass-ness” of our community. When I talk with people who are doing cool things, it inevitably leads me to the same question: How do these highly successful people do it? What is it about the way they live their lives that allows them to keep pushing forward?

Examining my own life and the choices I’ve made through this lens has been eye-opening. From little things, like adjusting a slightly out-of-kilter arm rest, to big things, like taking the risk of replacing a competent caregiver in hopes of finding a better match, I’ve worked to identify areas where I’ve been settling and take control. The changes have been empowering.

As we kick off 2019, I encourage you to do the same. I’m not suggesting you have to become a Paralympian or write the great American novel — though by all means, if that’s what you want to do, go for it — just that you honestly look at your life and see if there are areas where you are settling. Maybe it’s disability-related, maybe it’s not. And maybe, if I’m lucky, I’ll find you on my interview list.
NM Executive Editor Josie Byzek can’t believe it’s been only five years since Cory Lee Woodard launched his award-winning blog, Curb Free With Cory Lee. “I could swear I’ve known him longer than that,” she says. “He lives to share his travels with as many people as possible, and I enjoy virtually tagging along on his adventures.” As she pulled back the curtain on our 2018 Person of the Year, Byzek came away even more impressed. “On the surface he is this jovial, affable guy who makes travel seem effortless, but that takes a tremendous amount of work.”

As a Californian who specializes in disaster readiness policy at the World Institute on Disability, Alex Ghenis anxiously followed the two most devastating fire seasons in state history. He pitched this month’s feature because he wanted to give fire survivors a voice and educate readers about best practices as environmental disasters become more frequent. “I want to give people ideas of what they can do to be safe.”

Mike Collins has made a career out of finding interesting people and sharing their passions in the pages of New Mobility. After years of focusing on car enthusiasts, this month he turns his eyes to the skies to write about pilots using hand controls in commercial planes. Says Collins, “The farther I got into the story, the more aware I was that I was delving into a land that was inhabited by pretty amazing people whose desire to fly helped them overcome any obstacles in their way.”
Video Motivation
These videos on SPINALpedia are like a 24/7 support group that motivates people to do what they previously thought was impossible ["Explore SPINALpedia," November 2018]. Seeing someone else with a similar injury overcome barriers in life is incredibly empowering. Great work, Josh and Tiffiny!

Joe Barrett
Newmobility.com

A Pricey Ride
For that starting price of $18,000, I'm wondering what the heck is this thing made of? ["The Terrain Hopper," November 2018]. According to the article, it only has one battery and each wheel has a motor with independent suspension. It only seats one person, doesn't have a heater or a radio and doesn't come with a roof or windows. I can buy a brand-new Smart car starting at $13,000. I could spend another $600 and put taller rims and tires on the Smart car and come out with a better deal. What the heck, Terrain Hopper?

James Ozburn
Newmobility.com

Open-Door Policy
I'll always remember a miniscule restaurant on Manhattan's Upper West Side that, as I waited, took the door off the men's room [to make a ramp into the building] ["DIY Ramps to the Rescue"].

Edith Prentiss
Newmobility.com

Insta-Ramps
I made a short ramp several years ago for my disabled daughter's power chair ["DIY Ramps to the Rescue"]. I went to Harbor Freight and bought a pair of ramps designed to load four-wheelers, etc., into a pickup. It was easy to lay them out, apply plywood between them and secure with a few bolts — you have an almost instant ramp.

Mark Barbee
Newmobility.com

RIP, Wheelchair Junkie
Prayers for comfort for his family and friends ["Mark E. Smith — 'The Wheelchair Junkie' — Has Passed Away," Newmobility.com, November 30]. He was such an inspiration and will be missed by so many.

Martha Guthrie
Newmobility.com

Table-Top Solution
Thanks for the clear, comprehensive overview ["DIY Ramps to the Rescue," November 2018]. One small local theater I went to propped a rectangular folding table at the door step to let me in. Even though you didn't include this expedient option, I do admire your article.

Shirley Zak Brownstein
Newmobility.com

Cushion Query
Please give me the info on your current cushion ["Finding My Life-Changing Product," Bully Pulpit, November 2018]. I have used a Jay Active gel cushion I've loved for over 20 years! Jay has discontinued the cushion and I have been buying the fluid-filled gel part of the cushion, which is the most important part. But the rest of my cushion is wearing out and I cannot wrap my head around using, or even liking, the style and the cushion that Jay has replaced it with. Thanks.

Alan Duboyce
Newmobility.com

Editor: Alan, I use a Ride Custom Cushion by Ride Designs, ridedesigns.com.

When ‘Accessible’ Isn’t
I send an email with my specific requirements and questions about bed, toilet and shower bench height ["Booking an Accessible Room Reservation Shouldn’t Have to be This Hard," Newmobility.com, October 24]. I also send pictures of what a roll-in shower looks like and the difference between a shower bench and a shower chair. But still, over 50 percent of the time, something goes wrong. If I have time and there are little access issues that can easily be resolved, I have a sit-down chat with the manager and politely explain the problems and possible solutions. My last hotel stay started great, with auto door openers and a good roll-in shower, but when I got to the sink, the mirror was so high it only showed the very top of my head. WTH? Keep working on this — there has to be a way.

Chuck McAvoy
Newmobility.com
Mark E. Smith, whose writing and upbeat personality brought joy and enlightenment to so many in the disability and mainstream communities — including thousands of New Mobility readers — passed away Sunday, Nov. 25. He was 47.

Born with cerebral palsy into a family wracked by alcoholism, Smith’s life was a textbook example of overcoming long odds and succeeding beyond traditional expectations. But to those who knew him, his accomplishments — borne of an impressive intellect, energetic drive and infectious positivism — were no surprise.

Smith was best known for his work with Quantum Rehab for the past 18 years, where he served as a general manager. Besides supplying expert consumer feedback on research and development projects, he handled public relations for the company, working closely with the industry’s trade publications. He also employed his expertise in wheeled mobility and gift for writing in ways that benefited the disability community at large. Known as “The Wheelchair Junkie” for his website of the same name, he answered thousands of consumer questions year after year and later turned to more personal writing in his blog, powerchairdiaries.com.

From the mid-2000s to the present, New Mobility was fortunate to publish Smith’s blogs, and later his “Innovations” column on a regular basis, as well as occasional feature articles. He also authored five books and spent time lecturing and speaking. Smith was well-known at Medtrade and other industry shows and exhibits for his technical knowledge, lively personality and sense of humor, which had a way of shining through despite a serious speech disability due to cerebral palsy.

“In print, Mark won over readers with his crisp writing and candor. In person, his smile and gregarious approach were even more effective,” says New Mobility Editor Ian Ruder. “He was the consummate professional and a perfect embodiment of exactly what New Mobility is about. His voice, his insight and his friendship will all be missed.”

Smith, never a complainer, battled cancer in his final months in his typical style, remaining grateful for his life, work and family despite pain and loss of mobility. In one of his final blog entries, posted September 20, Smith wrote: “There’s little finality to death for the living. Those passed remain with us, alive in so many ways. This realization, based on my experience, has brought me tremendous comfort, both toward those I’ve had pass and toward those who will one day experience my passing.”

Smith is survived by his wife, Holly, daughters Emily and Annabelle, siblings Steve and Amanda, and numerous nieces and nephews. Donations to The Muscular Dystrophy Association can be made in lieu of flowers.

IN MEMORIAM

NM CONTRIBUTOR MARK E. SMITH — ‘THE WHEELCHAIR JUNKIE’: 1971 - 2018

Smith, pictured with wife Holly and daughters Emily and Annie, attended a butterfly release event in September. Read Emily’s tribute to her father and Mark’s many blogs at powerchairdiaries.com.
Awesome PWDs Make *Bitch Media*’s Top 50

Senator Tammy Duckworth, activist Alice Wong and model Aaron Philip were among a number of prominent honorees with disabilities on the 2018 Bitch 50, a list recognizing “the most impactful creators, artists, and activists in pop culture whose imaginations extend beyond normalizing and affirming the same mainstream messages.” See the list at bit.ly/2RTgcTn

One Small Roll for Mankind

South African disability rights activist Eddie Ndopu spent International Day of Persons with Disabilities with his wheels firmly planted on the ground, but if he has his way, next Dec. 3 he will boldly celebrate where no person with a disability has celebrated before. As part of the run-up to this year’s IDPD, Ndopu, 27, announced he is working with an aerospace company and the United Nations to realize his dream of becoming the first person with a disability in space. “The idea is to address the U.N. from the International Space Station for next year’s International Day of Persons with Disabilities as a call to action on disability justice and to support the Sustainable Development Goals,” he explained to MTV. The cable station will chronicle his efforts for broadcast.

Born with spinal muscular atrophy, Ndopu takes great pride in pushing the boundaries of what is possible. “My biggest accomplishment has to be outliving my prognosis — I wasn’t supposed to live beyond the age of 5, and on November 29 I turned 27. I’m continuing to live a full life despite the predictions, aspersions and limits set for me both by society and medicine,” he told africanleadershipacademy.com. The first black person with a disability to graduate from Oxford, he heads Amnesty International’s youth activism program in Africa, started the Evolve Initiative and was named by *Pacific Standard* as one of its Top 30 Thinkers Under 30.

Model Representation

Jillian Mercado was one of three models with disabilities to grace the online cover of *Teen Vogue*’s September issue and to be prominently featured in the magazine’s in-depth look at “What it’s like to be a disabled model in the fashion industry.” Mercado, who has spastic muscular dystrophy, has modeled for Nordstrom, Diesel, Target and more while becoming one of the prominent faces of disability in modeling. “It’s such a beautiful moment in time now that we have the ability to voice our opinion, to voice our frustration that we’ve always been in the room but for some reason we’ve been invisible,” she tells *Teen Vogue*. “And for casting directors to finally put their glasses on and see us.”
Power Chair Power

End your device charging woes and stay connected and powered up while you are on the go with the Cheelcare USB Adaptor/Charger. Designed specifically for power wheelchairs and scooters, the charger clamps on and draws power from your battery without restricting your ability to drive. Starting at $45 at shop.cheelcare.com

Drive With Your Face

Remember when your mom told you that if you keep making that face it might get stuck that way forever? Well, now it might also help you drive your power wheelchair, thanks to a new app from Intel and Brazil-based Hoobox Robotics. Their new app, Wheelie 7, works with 95 percent of motorized wheelchairs and allows users to control their chairs by making 10 facial expressions, from smiling to winking. The app relies on facial recognition software and an Intel 3D RealSense Depth Camera that mounts on the chair. Endgadget reports the app is already being tested by 60 wheelchair users in the U.S. Watch a demo atyoutu.be/okr-JY98iec.

Bathe Better

If you’re seeking the safety and ease of a roll-in shower without the hassle of remodeling, the Shower Bay could be the solution. Designed by a brother and sister caregiving duo who were looking to improve the experience of the people they worked with while also making it easier to assist them, the Shower Bay provides an easy alternative to bed baths. With no tools or plumbing modifications required, just snap the roll-in unit together anywhere you can connect to a standard faucet, turn on the pump, and you’re set. If you decide to move, or simply want a new view while showering, it’s easy to disassemble and reassemble. Listed at $3,450 at showerbay.com.

Wheelz Gets Hot Wheels

Aaron “Wheelz” Fotheringham is famous for inventing WCMX, holding four Guinness World Records and recording the world’s first backflip in a wheelchair, but his latest accomplishment may be even cooler — he is the first wheelchair user to have his own Hot Wheels. “It’s unreal,” says Fotheringham, who has spina bifida. “I always thought the wheelchair is like a toy, and now it actually is.”

For over a year, Fotheringham worked with designers from Hot Wheels to refine the Wheelie Chair. “Right off the bat they made it look super cool,” he says. The actual toy is modeled on the green wheelchair with orange casters he made famous. The packaging depicts Fotheringham doing a handplant at the top of a skatepark bowl, with his “Wheelz” signature featured prominently below. “I think it’s really cool that little kids are now able to have a wheelchair to play with.”

Based on the social media response to Fotheringham’s reveal on Facebook, the toy is going to be a huge hit. Since Nov. 14, over 7,300 people have liked his post and over 4,500 have shared it. One wheelchair-using mom’s comment summed up Fotheringham’s impact. “Whenever my son wants me to jump a curb, he says, ‘Mom, Aaron Fotheringham it!’ You’re a verb in our house!!”

Fotheringham admits to being caught slightly off-guard by the reaction. “I guess I didn’t fully expect the response I got,” he says. “It’s been such a positive thing.”

The toy is available at retailers and online. Asked how he could top this, Fotheringham laughs. “I don’t know,” he says, “I think I’m just gonna retire.”
MEMBER BENEFITS
unitedspinal.org

United Spinal Association is dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders (SCI/D) by providing programs and services that maximize independence and enable people to be active in their communities.

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Membership in United Spinal Association is free and open to all individuals who are living with SCI/D, their family members, friends, and healthcare providers. Visit unitedspinal.org or call 800/962-9629.

United Spinal has over 70 years of experience educating and empowering individuals with SCI/D to achieve and maintain the highest levels of independence, health and personal fulfillment. We have 50+ local chapters and 190+ support groups nationwide, connecting our members to their peers and fostering an expansive grassroots network that enriches lives.

UNITED SPINAL

CORAZZA NAMED TO LEAD VETSFIRST
Danielle Corazza started as the new vice president of VetsFirst on Dec. 17, but it is fair to say she has prepared for the job her whole life. Both her parents are veterans, she grew up on a military base, she got out of high school early to join the Army, and she served in the National Guard after completing her active duty tour. Since then, she has worked for the Departments of Defense and Homeland Security and has been an outspoken advocate for veterans, and their family members and caregivers. She also worked as the National Outreach Coordinator for the Center for Women Veterans in the Office of the Secretary of the Department of Veterans Affairs.

Her experiences in the military and the government have reaffirmed her belief in the power of authentic storytelling and the need for advocates to share their experiences. “Behind every military community member is a deeper story than what shows on the surface,” she says. “We’ve all had battles to fight, and we are stronger for connecting and working together to resolve the difficulties we face.”

When she’s not working, Corazza is a mom to two elementary-aged kids, an avid reader and self-proclaimed data nerd, consuming dozens of articles and reports every day. She is also a devoted caregiver to a retired Army veteran with terminal cancer and says her experiences as a caregiver have heightened her awareness of the many obstacles facing people disabilities while increasing her drive to address them.

A disabled veteran herself, Corazza is excited to embrace the VetsFirst platform to continue serving veterans with disabilities. “Creating awareness of the resources available and removing barriers to access to programming that exists to serve the veteran community is my number one priority. Great programs and services that go unused or that are difficult to access serve no one.”
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EASY ONE-PAN MEALS

As kids, hearing, “Supper’s ready!” was music to our ears. As adults with disabilities, the thought of pulling together a healthy dinner each night is much less harmonious. Orchestrating weekly meal plans, grocery shopping, washing, chopping and cooking can be daunting and difficult.

It is well documented that many people with disabilities experience malnutrition. Common deficiencies include everything from protein to micronutrients like vitamins, minerals and essential fatty acids.

Numerous challenges — whether chronic pain, transportation access or limited upper extremity function — can make it difficult to buy and prepare fresh, quality food on a regular basis. So many people with disabilities frequently rely on unhealthy, processed/fast foods that are low on vitamins and fiber, yet high in trans fats, which further deplete nutrients from the body. Leftovers might not be sexy, but reheating a two-day old dinner is a lot better for your body than skipping a meal because of time constraints or consuming a nutritionally deficient replacement.

Apart from the big picture of calories and macronutrients like protein and carbohydrates, getting quality micronutrients in your system is vital for managing the complications of disability. The nervous system requires specific nutrition, such as that provided by B vitamins and essential fatty acids, to function optimally. Therefore, it is essential that individuals with neurological conditions, such as multiple sclerosis, continue to eat these vital nutrients every day.

Long term vitamin and mineral deficiencies in individuals with disabilities can contribute to the development of many common, recurring and potentially life-threatening secondary health complications such as constipation/bowel obstruction, bladder infections, sepsis and pressure sores, as well as cardiovascular and respiratory disease. These secondary conditions, in turn, then place additional demand on the body for nutrients.

But as one-pan dinners show, putting nutrients into your body doesn’t have to be complicated. Asparagus contains high levels of vitamins C, A, K and E, as well as folate, potassium and phosphate; chicken is high in vitamins B5 and B6; potatoes are high in vitamin C; garlic has excellent anti-inflammatory properties; and olive oil provides essential fatty acids. The recipe above contains all of these ingredients and more.

My hope is this simple cooking method will soon have you singing, “Supper’s ready!”

HELPFUL, INEXPENSIVE KITCHEN GADGET TO MAXIMIZE MEAL PREP

One Second Slicer: For $25 or less, it slices, dices and chops, and is perfect for people with limited dexterity, upper body weakness and/or hemiplegia. It’s also easy to use, clean and store. At amazon.com.

ONE-PAN LEMON HONEY CHICKEN

2 chicken breasts or thighs (add more chicken for leftovers the next day)
1 bunch asparagus (or if you prefer, broccoli, cauliflower or Brussels sprouts)
1 small bag new potatoes
2 garlic cloves chopped
1 lemon
¼ cup olive oil
2 tablespoons soy sauce
2 tablespoons honey

Pre-heat oven to 400 F.
In bowl, mix olive oil, garlic, honey, soy sauce and the juice of one lemon.
Spread chicken, potatoes and asparagus on a baking sheet. Pour sauce mixture over everything until well-coated, and cover with foil.
Bake 25 minutes.

Great One-Pan Dinner Sites:
• joyfulhealthyeats.com
• thelemonbowl.com
• cookinglight.com
JOINING THE CLUB

I did not want friends who use wheelchairs because I was not going to be “one of them.” I just wanted to go back to the way things were — without anyone noticing the very obvious wheelchair my butt was planted in, probably for the rest of my life. Although I was disconnected with reality — and with my body and mind — it wasn’t obvious to me how much I was isolating myself until, years later, I met others with spinal cord injuries.

A select few were determined to be my friends. They pushed me to try new things, and included me in activities like adaptive sports, going to bars, and just spending time together without explaining the SCI stuff. It became comfortable and safe ... and even though a group of wheelchairs out in public attracts all surrounding eyeballs, I realized I did not feel out of place.

Now, my resistance to wheeled companions has disappeared (I wish it hadn’t taken so long), and I have befriended some of the most resilient, beautiful, comedic, creative and determined beings. I’d like to say that somehow I would have met them anyway, but that is highly unlikely. A life-changing moment bonds us, and what we experience — daily, individually or collectively — makes us a community.

We are not alone. Our lives intersect even if we haven’t met yet. I feel lucky to be connected to others who know what it’s like to wake up in the morning positively determined to conquer the day but who also understand the effort and challenge it can be to just get through it sometimes.

I am “one of us.”

To see more of Reveca Torres’ original art, follow @revecart on Instagram.
Katie Smith has traveled the U.S. and the world, tried most adaptive sports, advocated for international disability inclusion and, most recently, began serving as the chapter leader for the Western Pennsylvania Chapter of United Spinal. It’s a full life that gives her plenty of experience for her day job — teaching youth with disabilities how to self-advocate as they transition to adulthood.

Life Lessons Through Adaptive Sports

Smith, a C6-7 quad, remembers the first time she went to a wheelchair rugby practice, fresh out of rehab and still figuring out life with a spinal cord injury. “I was in this big wheelchair with a seatbelt and anti-tippers, and it was just too wide for me, and they were like, ‘What are you in?’” she says. “They threw me in a rugby chair, knocked me around a little bit, and I never stopped going back.”

She loved how the sport provided an outlet for intense physicality even with her limited function, but even more she loved the engagement with her teammates. “I learned how to use a wheelchair in rehab, but I learned how to live life in a wheelchair from my peers on the rugby team,” Smith says. “One of the players, I ended up borrowing one of his old wheelchairs. It was much smaller and better fitting than the one I was in. And after I started driving, they taught me how to get that chair into the car on my own.”

As much as the practical pointers, the life experience of some of her more experienced teammates motivated Smith to expect more from her new life. “These guys have wives and kids and jobs, and they travel,” she says. “It’s stuff that you’re not sure you can still do or how you’re going to do it, and here they are doing it.”

Smith’s first independent travel experience after her disability was for a rugby tournament. One of her teammates picked her up, and the girlfriend of another teammate helped her with the tasks she still needed assistance with, like getting in and out of bed and showering. “It was such a supportive environment,” she says.

The support of a strong adaptive sports community in Western Pennsylvania has let Smith dabble at all sorts of different activities including boccia, horseback riding, yoga, Alpine skiing and handcycling, to name a few. In general, Smith has made a habit of saying yes to most opportunities that come her way.

Smith has fairly severe scoliosis, which she says is due to her spasticity and muscle tension. Massage helps, as does the muscle lengthening and tension reduction of adaptive yoga. Perhaps surprisingly, horseback riding also helps. “I CAN’T LIVE WITHOUT: My Contigo water bottle. It has a loop to hook your thumb into and rubber coating, so it bounces when you drop it.

BEST THING ABOUT HANGING OUT WITH LITTLE KIDS: They have no filter and say exactly what comes into their heads.
got involved with riding as a therapeutic tool to help with my scoliosis and strengthening my core," she says. "I feel my best when I’m engaged in yoga and horseback riding."

By being willing to try just about anything, Smith has found ways to make taking care of her body and managing some of the secondary complications of SCI enjoyable. And in addition to the health benefits, recreation has taken Smith all over the world — she’s twice attended the international women’s rugby tournament in Paris, and the boccia world championships in Liverpool, England.

That first-hand experience in connecting with other wheelchair users across the globe motivated Smith to get involved with the Harkin Summit, which seeks to improve worldwide disability inclusion and employment. She’s attended all three summits held so far. "It’s really neat to see some ways that disability impacts the cultures and the way that all the different delegates come together to solve issues," she says.

Smith, who has degrees in psychology and education, spent time substitute teaching in an elementary school before transitioning to her current job. While teaching, she made sure her kids’ experience with a wheelchair user was a fun one.

"Kids always wanted to know why I’m in a wheelchair. I used to explain it the first time I met them, but a friend suggested, ‘No, then they’re getting to know your disability before you.’ So, I started saying, ‘Oh, that’s a great story but I’ll give you that after recess.’ That way, they get to know me as a teacher, my funny stories and favorite children’s books, then I’d tell them why I’m in a wheelchair and explain spinal cord injury to them.

I encouraged every child to ask questions if they had them. They’d all raise their hands and ask questions like, ‘How did you get here?’ ‘Did your mom drop you off?’ I’d explain to them, ‘Oh no, I drove myself, and I just get into the car seat.’ And they’d ask, ‘How do you get out of your wheelchair?’ So I’d transfer onto the table to show them. Kids are very concrete thinkers — they’d be looking at you and the chair as one. When I’d transfer out onto the table, all of a sudden I’m no longer a Transformer."

EXPLAINING THE WHEELCHAIR

‘I’m Not a Transformer’

**DREAM ADAPTIVE EQUIPMENT:** One of those track chairs. I live in the woods, and I’d really like to be out there picking up logs and stuff.

**WHY I JOINED UNITED SPINAL:** I had done some peer support at the spinal cord injury unit at Mercy Hospital, and when the Western Pennsylvania chapter started, they asked me to come back and be involved with their peer support program.
GEAR HACKS
By Seth McBride

Cheat Power-Assist from Scooters

Electric scooters can be hard to miss lately. Since the scooter rental company Bird first launched a fleet of scooters on the streets of Santa Monica in September 2017, they’ve spread to cities across the globe, and have affected urban transport in a way that few could have guessed. The scooter craze has many wheelchair users crying foul, as abandoned scooters and inconsiderate riders often block sidewalks and curb cuts. But intrepid wheelers are figuring out how to take back the streets by turning e-scooters into their own adaptive mobility devices. I caught up with a few of them to see how they did it.

The No-Gear Hack
Tyler Masterpiece followed the rise of e-scooters, hover boards and other powered personal mobility devices, and instead of being annoyed, he wanted in. “I was getting envious of just being able to jump on one of those things,” he says. “They looked like a lot of fun.”

When Masterpiece, who has a C7 SCI, recently traveled with his girlfriend to Mexico City and saw people on e-scooters buzzing all over, he started to think how he could ride with his wheelchair. “I thought I could probably just put my footplate on the front of that thing,” he says, “and as long as I could reach the handles I should be able to at least go.”

The Zocolo, a historic plaza in the heart of the city, provided the perfect location for an attempt, with its flat obstacle-free layout. Masterpiece’s girlfriend held the Bird scooter upright and he did a wheelie to get his footplate over the back wheel. He scooted his chair as far forward on the scooter deck as he could to bring the handlebars just close enough for him to be able to reach. The Bird scooter required a push start, so after paying and turning it on via the company’s app, his girlfriend gave him a shove and off he went.

“Those electric motors get you going pretty quickly,” he says. “You go from thinking you’re going to full-throttle the thing to slowing it down a bit because it doesn’t feel like you’re really well-secured on there.”

The only things holding him on the scooter were gravity, the back edge of his angled foot plate and his grip on the handlebars. Masterpiece says a scooter with lower handlebars would be easier to operate, as he was at full arm extension just to hold on — not the best for control. But...
once he started to get comfortable, he found that he was able to lean the scooter to turn, a technique similar to how he rode motorcycles. He says he’d want the handlebars closer to him and a way to secure the footplate to the scooter to make it functional for riding on sidewalks or streets. But for a few dollars, messing around on vacation? “It was certainly a lot of fun,” he says.

**A More Secure Connection**

Before his accident in 2009, Andrew Angulo used to go scootering with his kids for something fun to do outside. Angulo, who sustained a T7 SCI in a motorcycle accident, wanted to figure out a way to adapt that hobby. He bought a Currie Technology IZip Stealth 1000 e-scooter, and with the help of his father, got to work. The model Angulo purchased had a seat on the back, so the first step was chopping that off, along with a high fin that covered the rear wheel. Once those were removed, he could pull the front end of a spare wheelchair over the rear wheel and drop his footplate onto the deck of the scooter. As with Masterpiece, he found that the best positioning was with his footplate as far forward as he could go.

To secure his chair to the scooter, he decided to use a heavy-duty door hinge. He bolted the hinge to the deck through two holes, folded the hinge over and secured two other bolts with the threaded ends sticking up away from the deck. His spare wheelchair had a slotted footplate, which he was able to drop onto the bolt ends. He then secured the footplate to the scooter deck by tightening some wing nuts on the bolt ends. “All in all, it took us a few hours and about $10 worth of materials,” says Angulo.

That’s in addition to the $500 he paid for the scooter, but it’s still a fraction of the price of typical powered mobility devices. Angulo says he had no issue driving the scooter, other than having to lean into turns when he wanted to take them at speed. The 1000w motor let him go 15-17 mph on the flats, and he says the battery would take him 12-15 miles on a charge.

**DIY Tips**

If you’re looking to convert an e-scooter for yourself, look for something that doesn’t have a rear seat or fin over the real wheel, and you can save yourself from any cutting. If, like Masterpiece, you’re looking to try out one of the rental options available, a piece of thin foam to provide extra friction between the footplate and scooter deck, a strong bungee cord or strap and some practice could get you a lot farther than you think.

Angulo made a video of his e-scooter conversion that provides a great visual of how he went about the modification, available at: youtube.com/watch?v=SB_Zi5LUUo&v=19s

There’s also a product called the Pop N’ Drop that lets you easily secure a manual chair, depending on your footplate width, to an EcoReco e-scooter. At $300 (plus $1,000 for the e-scooter), it kind of defeats the DIY ethos we have here. But it may provide some inspiration for your own design, and the promo videos are fantastic. Available at myfastwheelchair.com
Why do 15-year-old nephews and 9-year-old daughters make good campaign aides? Because they’re willing to knock on doors. And as anyone who’s been shaken down by an elementary school popcorn salesman knows: It’s hard to say no to a kid.

Of all the barriers to running for office as a wheelchair user — misplaced metaphors aside — the most pervasive is front steps. There is no substitute for old-fashioned door-to-door canvassing, especially when you’re campaigning at the local level. But private residences, you may have noticed, usually have steps.

Nick LiBassi, vice president of partnership expansion for United Spinal Association and newly elected township committee member for Rochelle Park, New Jersey, worked around this by appointing his 15-year-old nephew, Mac, as his honorary campaign manager. LiBassi would roll as far as he could get, then send Mac to the door: “Hi, my uncle Nicky is running for township committee — would you be interested in talking with him?”

Mariana “Muffy” Davis, who was recently elected to serve as an Idaho state representative, recruited her 9-year-old daughter. The long hours crisscrossing her district in rural Hailey, Idaho, gave Davis and her kid some quality time together, along with an added benefit: “Everybody’s pretty nice when a cute, little 9-year-old knocks on their door,” she laughs. “They’re not going to yell at you.”

For Darryl Fairchild, a pastor turned community organizer turned city commissioner in Dayton, Ohio, a larger voter pool meant having to rely on multiple door knockers. “I’d go out with two or even four volunteers and they would go ahead of me, sending out people who were willing to talk,” says Fairchild. “That way I was able to talk to as many people as possible.”

If you want to win an election as a wheelchair user, creative thinking and being able to work around an inaccessible world are requirements. And though LiBassi, Davis and Fairchild came in with different politics, varying experience levels and distinct electorates to appeal to, they share some essential commonalities: work ethic, a passion for leadership and a deep commitment to the communities they’ve been chosen to represent.

The Grind is What You Make of it

Campaigning is a grind, mentally and physically. You make calls, you shake hands, you drive, you write, you attend meetings, you make speeches, you strategize, along with a thousand more menial tasks, and you do it all again and again and again.

“Whenever I wasn’t working my full-time job, I was doing something for the campaign,” says LiBassi. “And even when I was traveling, at night I was working from the hotel room, editing things and putting together the list for where I wanted to hit the next night.”

LiBassi, who uses a wheelchair due to a spinal cord injury, estimates that he and his nephew knocked on 1,600 doors in Rochelle Park from April through October, in addition to hundreds of other houses with his nondisabled running mate. LiBassi also attended as many community events as he could — from Little League games to ribbon cutting ceremonies, visiting senior centers, churches and the American Legion, to name a few. He refuses to call it hard work though. “I told myself before the campaign that if I was going to do it, I was going to have as much fun as possible,” he says, “and that’s what I did.”

Nick LiBassi, pictured with his nephew and honorary campaign manager, Mac, now represents his community on the Rochelle Park, New Jersey, township committee.
A self-described “people person,” LiBassi already had a strong connection to Rochelle Park — he grew up in Maywood, the next town over — but he says that the campaign strengthened that connection even further. “I thought I knew the town pretty well, but it’s a lot different going door to door, pushing those streets, seeing the condition of the sidewalks, hearing about people’s concerns that they are in a flood zone or about street lighting that’s not adequate around a turn,” he says. “You get to see some of the issues firsthand.”

In today’s highly polarized political environment, some of the animosity of national politics filtered down to LiBassi’s local campaign. LiBassi defines himself as a conservative Republican, but he committed to knocking on everyone’s door, Republican, Democrat or Independent. “We had doors slammed in our face,” he says. “Being a Republican or Democrat at this level, I’m not voting on border walls or abortion. At the end of the day, those people and I all want the same things — the roads need to be paved, to make sure the snow is cleared. We need clean streets and safe schools, and to know the ambulance and fire department are going to respond to you in time.”

Those who were willing to listen tended to agree with that message. LiBassi was elected by a comfortable margin, and with 3,800 votes cast, it’s a safe bet he met a large majority of the people who voted for him.

**The Rookie**

LiBassi at least knew what he was getting into, having served as the vice president of his town’s Republican Party organization, as well as serving on the local zoning board for six years before he decided to run for office. Muffy Davis, a para from a skiing accident, didn’t have much of an idea how campaigns actually worked before she started managing one. In fact, Davis had never thought about getting into politics until the morning after the 2016 presidential election. While her county is best known for being home to the Sun Valley ski resort, most of her district is rural, with expansive fields of alfalfa and malting barley sold to some of the biggest breweries in the country. Like most agricultural areas in the West, Hailey has a large immigrant population, mostly Latino.

When Davis woke up her daughter, she told her what had happened in the election. “All my friends have to leave,” her daughter responded and started crying, fearing her friends would be deported. “That’s not going to happen,” Davis responded. Right then, she decided she needed to get involved. She connected with her local chapter of Indivisible, a national grassroots advocacy organization, and started volunteering on women’s rights and healthcare access issues. Local...
Democratic Party organizers were looking for potential candidates, and they approached Davis about her interest in running. Born in Sun Valley, Davis has strong roots in Blaine County, and locals knew her name thanks to a decorated career as a Paralympian in sit-skiing and handcycling. All of this made Davis a prime candidate.

Still, Davis didn’t think she was ready to run for office. But winning an election to the International Paralympic Committee Governing Board — “sports politics,” as she calls it — gave her some confidence. And some others factors were lining up to give her a real shot — a Republican was currently serving in a local seat that had traditionally been held by a Democrat, and advocates across the state were making a big push for Medicaid expansion, one of her core issues. She announced her campaign at the January 2018 Women’s March in Ketchum.

That same march, the year before, had been her first real experience with the power of grassroots organizing. But as far as campaigns go, “I didn’t know anything,” she says. “I just knew I wasn’t going to miss that opportunity.”

Davis got a major boost when she received a scholarship to go to a Progressive Change Campaign Committee candidate training event and another when she decided to run a coordinated campaign with Democratic candidates for two other posts in her district. “It was amazingly helpful for me, to be that close to both of them...
Davis and her daughter share materials with a voter.

and have them as mentors to guide me through it,” she says.

The coordinated campaign helped with events and messaging, among a host of other things. Adding that to the support of the advocacy organizations she’d been involved with and her lifelong connections through her local community provided the base of her campaign. “There was a huge group of people who were already rallied and wanted this to happen and to be engaged,” says Davis.

Davis had a strong base to build on but still had a lot of work to do connecting with voters in the rest of the district. District 26 is so big, she says, that it would take her three hours to drive across it. So drive she did, putting in thousands of miles and countless hours to even get to the front doors of her would-be constituents. Apart from front steps, rural Idaho presented particular obstacles for a wheelchair user — sidewalks are lacking, and some towns didn’t even have paved streets. “It was way more arduous than I had anticipated,” she says.

It all paid off though. Davis unseated the Republican incumbent. And Idaho voters passed Medicaid expansion. For Davis, and hopefully Idaho, November 6 was a good day.

Third Time’s a Charm

Darryl Fairchild, a para since a bicycle accident at age 26, had more experience with campaigning than either Li-Bassi or Davis when he set out to win a Dayton, Ohio, city commission seat in a special election last spring. That’s because he had previously lost two city commissioner races. For his third campaign, he made “Fairchild Doesn’t Quit” a campaign slogan and leaned into those defeats to connect with a city that has shouldered more than its fair share of hard times.

The two previous runs had taught Fairchild a lot about the ins and outs of campaigning, something that came in handy when longtime Dayton City Commissioner Joey Williams retired unexpectedly in February. The special election to replace Williams was set for May, leaving only a 10-day window to gather
enough signatures to run, followed by a compressed, 60-day campaign.

Fairchild knew his campaign would have to be efficient in delegating the workload so that he could spend the bulk of his time out in public, meeting voters and spreading his message. “There are three resources that every campaign has — money, volunteers and the candidate’s time,” says Fairchild. “You can always raise more money and recruit more volunteers, but you only have so much time.”

In addition to knocking on doors, Fairchild’s campaign volunteers would call ahead to scout his event locations. If there were stairs or other accessibility issues, Fairchild would make sure there were people ready to help him get where he needed. Navigating an often-inaccessible world to reach voters became another way of demonstrating

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**Other Candidates**

There is currently no comprehensive list of people with disabilities who serve in public office, so it’s impossible to say how disability representation in 2018 compared with other elections. Following is a list of wheelchair users who we know ran for office in 2018. Please let us know if we missed anyone.

**Newly Elected**

- Jennifer Longdon, State Representative, Arizona
- Muffy Davis, State Representative, Idaho
- Darryl Fairchild, City Commission, Dayton, Ohio
- Nikki Villavicencio, City Council, Maplewood, Minnesota
- Nick LiBassi, Township Committee, Rochelle Park, New Jersey

**Not Elected**

- Billie Sutton, Governor, South Dakota
- Jean-Marie Lawrence, State Representative, Tennessee
- Kati McFarland, State Representative, Arkansas

**Re-elected**

- Jim Langevin, U.S. Representative, Rhode Island
- Greg Abbott, Governor, Texas
- Darren Jernigan, State Representative, Tennessee
that he had the problem-solving skills and passion required to take on the issues that faced his city.

Fairchild already had a lot of support throughout Dayton from his work as a pastor and a community organizer. He’d helped found Lift Greater Dayton, a collection of both religious and secular community organizations that worked on diverse issues such as voter registration, education initiatives, job creation and safe neighborhoods. That work had taught Fairchild the campaign should be more about the community than him. “While your name is on the ballot, it’s really not about you, but about the ideas and values and the team you bring along with you,” he says. “You can’t run for office without a lot of support, and not everyone with a disability has that.”

That’s true for all aspects of building or maintaining a full life as a wheelchair user — you need a great deal of support. You have to be able to work with people, ask for help and be willing to try, fail, adapt and try again until you make a little bit of progress and then start it all over again. Those are traits many people want to see in elected officials.

In the end, Dayton got behind Fairchild’s experience and message of resilience and community. Though his opponent had the endorsement of the local Democratic Party, Fairchild won with a slim, 492-vote margin and has already started serving on the city commission.

Fairchild, Davis and LiBassi were consistent in their advice for other people with disabilities who are thinking about running for office: Do it. It’s hard work but incredibly rewarding. Fairchild echoed a line from President Obama’s farewell address that should ring true regardless of political philosophy: “If something needs fixing, lace up your shoes and do some organizing. If you’re disappointed by your elected officials, grab a clipboard, get some signatures, and run for office yourself.”

Resources
• “Including People with Disabilities in Your Political Campaign: A Guide for Campaign Staff”, ncil.org/campaign-guide
• “Resources on Running for Office”, ncil.org/run-for-office
World traveler and award-winning blogger Cory Lee Woodard, 28, works from a 55-item bucket list and just crossed off a big one. Right below “Go to a Luau in Hawaii” and above “Get a Cocoa Facial in Hershey” is number 37 — “See the Taj Mahal.”

“You guys! I visited the Taj Mahal,” he gushed on Facebook. “Seeing this spectacular monument has been a lifelong dream for me, but I realistically wondered if it could ever happen, due to there being a lack of any accessibility in India until pretty recently. But I made it! Thank you Enable Travel for seeing a lack of accessibility and doing something to improve the situation, I’ll be forever grateful.”

His followers wanted to know all about it. What was most surprising? Was the accessibility OK? How was his mom handling the food?

“I’m probably most surprised by how fascinated everyone is with my wheel-

Cory Lee Woodard recently crossed “visiting the Taj Mahal” off his bucket list.
Chair. I’ve been asked for selfies, gawked at and sort of feel like an animal in a zoo, but it’s totally fine. I know they’re just curious,” said Woodard, who has spinal muscular atrophy. “I’m also surprised at how accessible some of the attractions are ... much better than I expected, but still need some improvements of course.” And his mom found pizza one night, so she was able to survive until they made it back home to rural Lafayette, Georgia.

That’s the Way He Is
On the surface, Woodard’s posts about the Taj Mahal just seem like words from a guy who enjoyed his vacation. But if you study them, they demonstrate three reasons why he is a popular blogger with both fellow wheelchair users and other travel professionals. First, his down-to-earth, enthusiastic style is easy to engage and absorb. He’s fun to read and is a social media crackerjack, as he optimizes his platforms by tailoring unique and interesting messages for each one. He has 26,600 followers on Twitter, 17,462 on Facebook and 11,200 on Instagram. Their clicks on his links drive traffic to his info-rich blog, which then is leveraged for sponsorships so he can stay in business and keep traveling. He has the largest social media following in the accessible traveling field and makes it look easy as he raves about the interesting places he visits — from South Africa, where he was almost eaten by a camel in Morocco.

“You guys! I visited the Taj Mahal! Seeing this spectacular monument has been a lifelong dream for me.”

Cory Lee’s Craziest Travel Experiences:
1. Trapped on a Burning Bus in Washington, D.C.
On a lovely autumn day while in Washington, D.C., I decided to venture to the National Zoo for some fun. Public transportation in D.C. is some of the most accessible in the world, so I never could have imagined what happened next. I boarded a bus in Chinatown with my friend and within about two minutes, the wheelchair lift on the bus started smoking.

I alerted the driver and he exited the bus. Everyone else followed suit, leaving me and my friend alone inside. The smoke started getting worse, and a flame emerged from the lift. So there I was trapped on a burning bus with no way to get off. As you can probably imagine, I was freaking out. Where was the driver?! Who knows ...

Luckily, right before true disaster struck, a fire truck rounded the corner and parked beside the bus. It got there at the perfect time. A few firefighters rushed in and carried me and my heavy power wheelchair down the steps.

I never saw the bus driver again, but I assumed that he called and reported the issue. Instead of going to the zoo that day, I went to a restaurant and stress-ate. When I eventually did visit the zoo a few weeks later, the whole ordeal made my visit even more worthwhile.

Woodard is proud (and relieved) that he did not fall off this camel in Morocco.
a hippo, to North Carolina, right up
the coast from his hometown.

Second, he is gracious and open to
new experiences. He knows that just
as he is surprised, charmed, moved,
excited and drawn in by the places
he visits and the people
who live there, so might
they be by him. Have
most people in India
never seen a guy in a
power chair like his be-
fore? Well, that’s OK. In
a few days he’s used to
the stares and decides
he likes the attention.
#CelebrityofIndia, he
posts, jokingly. #Wheelchairinvader.

“That’s the way he is,” says Sylvia
Longmire, who runs Spin the Globe
travel agency. A wheelchair user
with multiple sclerosis, she went on
a seven-day accessible cruise through
Scandinavia and Russia with Wood-
ard in August 2017.

“I came across his stuff on Ice-
land, and he inspired me to start
my own blog,” says Longmire, a
professional writer for 14 years.
“I’ve seen what he’s done and tried
to follow in his footsteps, but now
I’m established and work hard to
differentiate myself.”

Which brings us to
a third and final point.
Woodard doesn’t shy
away from an adventure
just because it may be
difficult. “I work full-
time with influencers
and have met hundreds
of them over the years,”
says Elisabeth Rundlöf,
project manager with
the city of Helsinki’s
marketing department.
She met Woodard when
he was accepted into the
prestigious Helsinki Se-
cret Residence program
in 2016. “Cory stood out
because of his respect-
ful, down to earth and
life-loving attitude,” she
says, and especially lauds his work
ethic. “He decided to visit Helsinki
during winter, even though it would
have been easier to travel to Finland
in summer — I think that spoke
about his strong character! He’s nev-
er afraid to take on a challenge.” She
says he was genuinely curious about
her city, “and we continue to have a
friendship since his visits here.”

A Life-Long
Love of Travel

When he was 4, Woodard’s whole
family went to Disney World for
Europe. I had studied the German language for
years in school (I took five semesters of German
and then peer-facilitated for two semesters, to
be exact) and I was super excited to finally be
in the place I had been dreaming of. However,
on my first night in Munich, things got a bit
interesting.

Before the trip, I researched how to charge
my power wheelchair in Germany and bought
the required converter and adapter. On my
first night, we set everything up and plugged
my wheelchair charger into the outlet with the
converter and adapter. Immediately, sparks
flew and the power went out throughout the
hotel for about 15 minutes. Luckily, the hotel
never found out that I caused the outage.
The next morning, thanks to a couple hours
of searching Google and really testing my Ger-
man skills, I hunted down a wheelchair repair
shop in Munich. They actually sold a 240-volt
charger that worked with my chair, but it cost
$250. This experience taught me to always take
extra money for the unexpected and to find a
local wheelchair repair shop before I visit any
destination, just in case I need it.

Despite his mishap with an incompatible
wheelchair charger, Woodard enjoyed his
time in Munich, Germany.
breath, is still his favorite traveling partner. He's her only child, but he has two half-sisters on his dad’s side, one older and one younger. Today she is a Medic-aid specialist at a nursing facility. “But if I’m going somewhere, she always wants to go, if she can get off work,” he says. Although his mom goes on most of his trips with him, Woodard sometimes travels with aides, friends or other family members as well.

Gilbreath couldn’t be prouder of her son. “To see his drive, his motivation and his desire to push forward and live life to the fullest is admirable and I am truly blessed to share life and our many experiences together,” she said in a public Facebook post after their trip to India. “Thank you, son, for showing me how to live life and to be thankful for each and every day.”

“He and his mom are incredibly sweet,” says Longmire. She recalls tour-
ing the State Hermitage Museum with Woodard while in St. Petersburg, Russia. “His mom would rather poke her eyes out with a fork than look at history, but she loves her son so kind of rolled with it,” she says. “They’re fun, very easy going.”

Finding His Way
It’s an understatement to say Woodard wasn’t sure what he wanted to study in college. “I changed my major five times,” he says. There were just too many topics that interested him. “I wanted to do a lot of different things. I knew I loved traveling and maybe wanted to do something in that area.” He started with international affairs, switched to German and then communications, and eventually settled on marketing. He graduated with his bachelors from West Georgia in 2013.

Once he got that marketing degree, he says, “I didn’t know how I

Going on an Alaskan cruise was number 54 on Woodard’s bucket list.

CORY’S BUCKET LIST
Cory Woodard says creating a bucket list is important for any traveler. “I am constantly adding stuff to it as I discover new things that I want to do.” Reading about where he’s not been is almost as much fun as reading about his adventures in places he has visited.

Right above the list on his blog, in large letters, he announces that he’s not achieved his life goal: to visit all seven continents. Although it’s a safe guess he won’t be arranging a group tour of Antarctica any time in the near future.

He’s yet to snorkel the Great Reef Barrier in Australia — that’s second on the list, right below “See the Super Bowl” — but did manage to ride a camel without falling off during his April trip to Morocco. “The camel seemed much bigger in reality than I imagined it would be, and as it got closer I looked in its eyes,” he wrote. “I tried to telepathically let him know that he was the best camel in the whole desert, in hopes that he would spare me from face-planting in the sand.” His trip’s sponsor, Morocco Accessible Travel Consultants had rigged a secure adaptive camel saddle, and Woodard was as safe as could be.

Pizza still awaits him in Italy and Carnival in Brazil, although he did manage to hike in the Amazon. The Amazonian blog entry is grossly entertaining, as it recounts what happened when his guide pointed out the chontacuro worm. “He placed it on a leaf to show us up close and said that it is considered somewhat of a delicacy to many of Ecuador’s indigenous people,” wrote Woodard, and you can see where this story is going. “Jokingly, and stupidly, I asked if I could eat it.” Others in the group chanted Do it! Do it! “I’ll admit that I easily give in to peer pressure, so I said that I would. … As I started chewing, I could feel the worm’s insides burst all over my tongue. It was an interesting sensation but didn’t taste all that bad compared to other things that I have eaten around the world: fermented shark in Iceland, kangaroo in Australia, and just a couple days before chowing down on this worm, I ate guinea pig in Quito. I’m an adventurous eater, but this was the first living thing that I had ever eaten.”

Most of his adventures aren’t quite as … squishy, shall we say. Read them all on his blog at curb-freewithcorylee.com.
would use it. I thought maybe in an ad agency or something like that.” Then he saw a post on a website about how to start a travel blog. “I’d been planning a trip to Australia and saw there wasn’t a lot online about accessibility there, and those two things happened at the perfect time.” He decided to start his own blog — first called Cory Lee Goes and then Curb Free with Cory Lee — and chronicle what he learned in his quest to go down under.

He wasn’t sure what the goal of his new venture ought to be. “In the early days, I thought maybe I should focus more broadly on travel because it’s a much bigger market and I thought it might give me more readers. But I thought no, I am going to focus strictly on accessibility from today to forever. It’s a big market, although a lot of destinations don’t think so, or understand how much money is in it or how many of us do travel.”

Defining his niche and sticking to it helped him build a loyal and dedicated audience who reads his articles and counts on his accessibility information. “I’m glad in the early days I didn’t try a broader market and have been pretty firm with my decision.”

But there was a point where he almost gave up. “Four months after I started blogging, I completely quit for three months because I thought no one was reading it,” he says. “And I started receiving messages from people that they miss me writing about my travels. They motivated me to come back, and I’ve been go-go-go ever since.”

Deciding he needed more knowledge, he read and watched all that he could find on how to be a successful travel blogger. From Everything Everywhere’s Gary Arndt, he learned to never say no to an interview. “I will take any publicity I can get — online, print, podcast, anything,” Woodard says. From a piece in The New York Times, he discovered not all advice is equal. “There was an article that said you should always be on 60 social media channels at all times, and that’s insane,” says Woodard. “I focus on three or four platforms and try to be the expert on them and use them as best I can to get more readers and followers.” He even took classes on how to optimize web searches so his work is more likely to show up when someone Googles his keywords. “There is a lot more that goes into it than simply writing an article — that’s the easiest part.”

And he learned to network. “Then I started doing speaking engagements, Abilities Expos, as many opportunities as I could get.”

Traveling by rickshaw in Morocco was a treat.
He’s Out There Doing It

“I knew right away we wanted Cory,” says Sarah Laucks. She was director of education and events for the Abilities Expo when she scheduled his first appearance at the February 2015 Los Angeles show. “He has a great story, he’s out there, he’s traveling internationally with his passport in hand. He’s figuring it out — what will I do if it’s not accessible, or on long flights, what about bathrooms on planes? He’s tackling all those obstacles and it’s so good. We need people like Cory who are getting out there and doing it. Once you see Cory, you know you can travel, too.”

Roughly 30,000 people attend each expo, and travel is consistently the number one topic of interest.

“It was my first speaking gig in front of other people with disabilities, and they came after saying, ‘I learned something,’ or ‘I never thought I could fly in an airplane,’” says Woodard. “It motivated me to keep going. And a writer from the Los Angeles Times, Catherine Hamm, was at that speech and interviewed me for an article. Being featured in one of the biggest newspapers in the world also motivated me to keep going.”

Like most who meet him, Hamm, the travel section editor for the Los Angeles Times, remembers Woodard well. “Cory’s approach seems to be that almost anything is possible if we put our minds to it, use our collective experience and trust that the best will happen after the research has been done. It’s a positive approach that elevates conversations and lifts hearts.” She appreciates that he knows his stuff, tells her when he doesn’t know an answer instead of trying to bluff his way through, and that he has a sense of humor. “He was and is the trifecta,” she says.

Woodard is a hard worker and a meticulous organizer. “I start planning six to 12 months in advance to have time to research a destination to see if they have accessible transportation, what hotel I can stay at, anything like that, even if I’m pitching a press trip,” he says. “They’re not used to people pitching that early. So when I

CLOSE ENCOUNTERS OF THE HIPPO KIND

By far the craziest and scariest experience that has happened to me while traveling was in South Africa. Toward the end of my trip, after going on an incredible safari in Kruger National Park, I had the chance to meet Jessica, the world’s most famous hippo. We’re not talking about just being famous in South Africa, Jessica is famous worldwide and has been on everything from The Oprah Winfrey Show to CNN. She’s well-known because she is not your average hippo.

When Jessica was a baby, a man and woman found her struggling to stay alive. She was swept away from her hippo family during a flood and was struggling to make it on her own. The humans nursed her back to health, and Jessica began to grow. Her new mom and dad had to widen the doorways in their home, and they even built a special bed inside the house for her. She can now go in and out of the house as she pleases. Her residence has become a South African tourist mainstay.

When I went to meet Jessica, her human “dad” handed me a sweet potato to feed her. She was down in the water, so it was difficult for me to lean over and drop the potato in her mouth. It was taking me a while, when Jessica decided that she wasn’t going to wait. All of a sudden, she lunged up out of the water, grabbed the side of my wheelchair with her massive teeth, and started pulling me into the water. I literally blacked out and don’t remember too much, but right before I became Jessica’s lunch for the day, her dad stepped in and yelled for her to stop. Thankfully, she was a good daughter and listened to her dad, so I’m alive today. Yay!
pitch that far in advance, it throws them off, but a lot of places have gotten a great education on what it takes to plan an accessible trip. It’s been a big eye-opener for destinations that I’ve worked with.”

All of that research, networking, granting interviews and securing speaking engagements is paying off, as Woodard’s business is now profitable. “The first two years I didn’t make hardly anything from it at all, but I kept working at writing good, quality content and growing my social media numbers,” says Woodard. This attracted offers for sponsorships and more speaking engagements — including keynoting this year’s TBEX, which bills itself as the largest conference and networking event for all sorts of travel industry professionals.

“This coming year will be my biggest schedule, more speeches and paid press trips,” says Woodard. “Travel is great but if it’s not paying me, then I’m missing out on other opportunities.”

Where will Woodard travel to next? He still has a few dozen items left on his bucket list.

What Comes Next
Where will Woodard be off to next? After all, he still has destinations to check off of his bucket list, and he’s only visited six out of seven continents. Perhaps he’ll make it to the Great Wall of China or celebrate St. Patrick’s Day in Ireland. Wherever it is, he will find a way to share the excitement and joy it brings.

“Five years ago if you told me I’d be at this level, I’d be shocked,” says Woodard. “There are so many notes scattered all over my desk … goals, places I need to be pitching.”

What keeps him going is knowing how appreciated he and his work are. “When I get discouraged, I remember the reason why I’m doing it and started it in the first place,” he says. “Without the encouragement of readers and followers, I would have given up.”

For others with disabilities who may also want to find a way to build a business around their own passion, his advice is humble. “Just learn what works for you. It’s tough to find it, but when you do, it’s worth it,” he says. “No matter what you’re doing, try to stay motivated and remember the reason why you do the thing you do.”
Lake Kowell didn’t have long to respond when the Tubbs Fire reached her Northern California home in October 2017. The evening of October 8, Kowell, a T11 para, saw far-off flames and heard chimes clanging in strong winds. Around midnight someone pounded on her front door and told her to evacuate. “Smoke and planes were everywhere,” she says. By the time she rolled away from her house, everything had changed. “It was like Mordor.”

Fortunately, Kowell had an emergency plan, which included a bag with supplies to last about a week, connections with neighbors to help with evacuation, her own wheelchair van for transportation and a place to stay with family in nearby Petaluma. A strong network of friends and neighbors helped her through the disaster. “I didn’t feel afraid,” she says, “I felt supported.”

Kowell credits the skills she learned living with a spinal cord injury for helping her stay calm during the disaster and recovery. “When something traumatic happens, it changes your whole perspective,” she says. “You just do what you have to do to survive.”

Kowell stayed in Petaluma for a week, returned home when everything was safe and immediately got back to work at the Disability Services and Legal Center in Santa Rosa, helping others affected by the fire.

Sadly, Kowell’s trip through Mordor was not an isolated experience. The horrors of California’s 2017 fires gave way to the most devastating wildfire season in the state’s history in 2018. The trend of longer and more damaging fire seasons has Californians growing more concerned about what Governor Jerry Brown described as the “new abnormal.” This new abnormal has hit people with disabilities especially hard.

Not all of those affected by the fires had outcomes as positive as Kowell’s. Many evacuees struggled to find accessible hotels or temporary housing, and those who sought refuge in shelters sometimes had to wait for appropriate beds to be brought in. Medication, durable medical equipment and personal assistance were often hard to acquire or difficult to manage. Even those who weren’t forced to evacuate were heavily impacted. In areas affected by smoke, people with respiratory problems could not leave their homes, and many suffered asthma attacks or worse. At one point, over 250,000 people were under evacuation orders, unable to remain in their homes.

Unfortunately, this may be par for our new course — as climate change progresses, many types of natural disasters will become more frequent and disruptive. Personal preparedness, government planning and community response will only become more vital as we move forward.

THE LONGEST NIGHT

On Nov. 8, just days after the Camp Fire became the most destructive blaze in California’s history, another wildfire hit Southern California’s Ventura County and nearby areas. Pushed by the powerful Santa Ana winds, the Woolsey Fire sparked a few miles inland, jumped the 101 freeway
and roared west, sending thick plumes of smoke over the Pacific Ocean. It burned 97,000 acres in under two weeks and forced 295,000 people to evacuate.

Giselle Friedman, a C4-5 incomplete quad, was one of the 295,000. Her first warning came on Nov. 9 at 6:32 p.m. when the local fire department called and texted seniors and people with disabilities to suggest they voluntarily evacuate. Friedman, three years out from her spinal cord injury, is able to use canes or a walker, and like many people with disabilities, requires supplies for personal routines. She began searching for necessities to get her through a week or more, and a friend helped her put together a single backpack,
though she lamented her lack of ability to grab and carry more. “I was really scared,” she says. “There’s so much more I could’ve taken with me.”

When the full mandatory evacuation warning hit around 8 or 9 p.m., Friedman’s friend carried the quickly-filled backpack and some dog food to the car waiting outside. Friedman’s dog in tow, they drove to the home of her friend’s 85-year-old mother in nearby Westlake Village and stayed awake, glued to the television.

Around 3:15 a.m., the TV news broadcast a sheriff’s announcement: Westlake was now in danger. For the second time in 24 hours, Friedman was forced to evacuate. She, her friend and her friend’s mom piled into the car and headed to Friedman’s mother’s tiny one-bedroom/one-bathroom apartment — a snug fit for its new crew of four people and a dog. They settled in during the early hours of the morning and prepared for a long stay.

Friedman kept a close eye on her neighborhood through the news and social media over the next couple of days. When it was clear her area was unscathed by the fire, she drove back. She believes that if she didn’t have a disability, she would have remained at her mother longer, but says the convenience of having her own modified house made it difficult to stay away.

The whole ordeal motivated her to develop a comprehensive plan for any future disasters. “I know what I need to do now,” she says. Atop her list is keeping a lightweight, wheeled carry-on bag packed with a week’s worth of supplies and asking her network of neighbors to check on her apartment during an emergency.

The Woolsey fire was a difficult experience, but Friedman is confident her new strategy will make her much safer going forward.

Anthony Tusler lives in Penngrove, a rural area in Sonoma County north of San Francisco. He ran into a different problem when he was placed on evacuation notice during the Nuns Fire in 2017: securing accessible lodging. “For eight days I had my bags packed and ready to go,” says Tusler, an L1-2 para. “The hardest thing was finding a place to evacuate to, because all the hotels were booked.”

While some people end up in disaster shelters, many others stay in hotels or short-term lodging services such as Airbnb, or bunk in the spare bedroom of nearby friends or family. All of these options are often difficult for people like Tusler who need accessible entrances, bedrooms and restrooms. He eventually connected with a friend who lives 30 miles away and has a single-level home without any front steps. Tusler
kept his friend on call in case he needed to evacuate. Luckily, the flames spared Tusler’s home, but the difficulty of securing accessible shelter kept him in Penngrove when otherwise he might have left his house as a cautionary measure.

THE POWER OF PLANNING
As Friedman and Tusler learned, planning is invaluable during fast-moving disasters like California’s wildfires. A well-thought-out Personal Emergency Evacuation Plan could literally be the difference between life and death, and at a minimum is a guaranteed way to alleviate stress during what is sure to be a difficult time. A PEEP should include everything from preparing an emergency supply bag to identifying transportation to connecting with friends and neighbors. It is also wise to sign up for local emergency notifications — which is how Friedman received her initial voluntary evacuation message. Sometimes, though, individual actions can only do so much.

California has developed a network of organizations and advocates focused on preparing for disasters and responding once they happen. The Department of Social Services deploys Functional Assessment Service Teams to Red Cross shelters, where they assess residents’ disability-related needs and request necessary supplies and support. Independent Living Centers also organize deliveries of durable medical equipment donated by individuals, DME vendors and recyclers. In just the last two years, these donations have provided hundreds of pieces of equipment to people in shelters, hotels and other temporary housing. Given what people may lose in fires, this DME can be life-saving.

LINGERING EFFECTS
Ana Acton got a first-hand look at how devastating the fires can be for people with disabilities as she collected donations, such as DME, wheelchairs and vans, and helped coordinate responses to November’s Camp Fire in Northern California. Acton is a T12 para and the executive director of FREED, an independent living center that serves Yuba and Sutter Counties.

Before it was subdued, the 155,000-acre Camp Fire incinerated over 10,000 structures and killed 79 people en route to becoming the most destructive wild fire in California’s history. It destroyed most of the town of Paradise, where a high percentage of residents were older, had a disability and/or an income below the poverty level. In fact, a report in The Sacramento Bee found that almost 25 percent of the 9,500 people in the Paradise area had a disability. That’s more than twice the statewide rate, as is the percentage of residents with an ambulatory difficulty in the three counties affected by the fire (11.8 percent).

“Butte County just lost a large amount of their affordable housing,” Acton says.

As difficult as it is dealing with immediate loss of property, long-term recovery is also arduous. The 2017 Tubbs Fire, for example, destroyed more than 5,600 homes and businesses and left evacuees scattered around Northern California. One CIL that serves an area affected by Tubbs reports that its caseload increased by about 20 percent after the fires hit and remains at that level over a year later. This isn’t just because some new clients are evacuees; the overall higher demand on the area’s limited housing and services has triggered a cascade effect.

Accessible housing in the Santa Rosa area is still “nonexistent,” confirms Kowell. “Our resources are all tapped out” from residents’ post-fire needs, she says. In addition to losing their homes, many evacuees with disabilities also need new sources for supplies, services and personal care supports.

LOOKING FORWARD
To survive and recover from destructive wildfires requires both personal responsibility and public initiatives. There are steps everyone can take to increase their own chance of making it out, and then there are actions that can only be done by communities working in tandem with government agencies.

Acton emphasizes that people who had emergency plans — and lived with housemates or who knew their neighbors — were more likely to be checked on, evacuate their homes and make it to safety. “Independence includes having your personal assistants and community support,” she says. She urges people to include personal care attendants and other possible supporters on their PEEPs.

State and local service providers in California are working to improve their services and response. If there is any positive to the fires, it is that responders can analyze their responses and actions and figure out what worked, what didn’t and where new solutions are needed. As an example, the shortage of accessible housing near Santa Rosa in the wake of the 2017 fires has motivated advocates to push for universal “visitability,” where most or all homes have doorways 32 inches wide, at least one first-floor bathroom and a no-step entrance. Surely, other lessons will come out of the disasters that can hopefully minimize the impact of similar events across the state and elsewhere.
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Cruising through the sky at 120 mph, the Cessna flown by Quincey Carr is indistinguishable from any of the others flying over Northern California. And unless you are seated beside him in the cockpit — or pulling a highly unsafe Top Gun maneuver — there’s no way to tell that Carr, a paraplegic, is using hand controls.

While there are many options for small planes that fall under the light-sport and experimental classifications, there are only two FAA-certified hand controls for larger, faster commercial aircraft, and they are surprisingly hard to come by.

Manufacturers of the two models ceased production over a decade ago, citing high insurance costs and slow sales, among other reasons. The resulting shortage makes it difficult for pilots with spinal cord injuries or similar disabilities to get the training they need to obtain their commercial pilot’s license. According to Linwood Nooe, the founder of the nonprofit Operation PROP, Carr was lucky to find a used set. “I couldn’t even tell you where to find an old set of hand controls now,” he says. “There are people all over the country who are looking, and you just don’t find them.”

Nooe, whose wife is paraplegic, started Operation PROP in 2014 to improve access to hand controls. After four years of hard work, he is on the verge of doing just that.

Quincey Carr, a certified flight instructor, uses hand controls to fly a Cessna 152. The controls are currently very hard to find, but that should change soon.

A SHORT HISTORY OF HAND CONTROLS
Piloting the friendly skies in a commercial aircraft without the use of your feet or legs was not an option for the first 60 years of aviation. With foot pedals needed to control the rudder, steering and braking, many aspiring pilots with disabilities were kept out of the cockpit.

Navy Lieutenant Commander William Blackwood is credited with changing that. Blackwood served in World War II and the Korean War before sustaining a spinal cord injury when he ejected from a fighter jet during a 1962 training mission. Unwilling to give up the skies, Blackwood devel-
school in Kentucky invented the Blackwood controls’ only rival. Nooe says the group wanted to help a wheelchair-using friend get back in the pilot’s seat and they came up with the Union Aviation controls, patented in 1975. “They never really made any money selling them,” says Nooe. “They did it for all the right reasons.”

Neither model is currently in production, leaving many aspiring pilots on the tarmac. “I’ve got a list of about 30 people who are either pilots or want to become pilots,” says Nooe. “Many already have their light sport license and want to get into commercial, but they can’t do it.”

**OPENING UP THE SKIES**

Without the support of his Northern California community, Carr might still be grounded. An aspiring pilot since childhood, Carr earned his private pilot’s license at 17 and had just passed a key test toward earning his commercial license when he was shot and paralyzed in 2006. The financial realities of SCI and the high cost of pursuing flying helped him make the decision to put his aviation career on hold.

In 2016, he was making a living spinning signs for a nearby business on a street corner less than a mile from the Oakland Airport when a group of local police and firefighters surprised him with a $10,000 award to send him to flight school so he could earn his certified flight instructor rating. His church raised money and bought a set of old hand controls, allowing Carr to pursue his dreams.

Today, Carr is a certified flight instructor at East Bay Aviators in Hayward, California, and has about 700 hours of flight time. He wants to give others in similar circumstances the opportunity to take to the skies. “Once new hand controls become available, I want to purchase a second set so that I can teach other people who need them to learn how to fly,” he says. But giving flying lessons is not his ultimate goal. “Beyond that, I want to purchase my own plane to use in giving those lessons and eventually establish my own flying service.”

Nooe’s goals are along the same lines, and he is closer than ever to achieving them. In early December, Operation PROP received long-awaited approval from the FAA to start manufacturing the Union model. “We should be ready to go by the end of the year, if not January, so hopefully by the end of January we’re going to have hand controls in production,” says Nooe.

Nooe hopes to sell them for around $4,000, and is looking to partner with other non-profits to find funding so that no one who wants to fly is left on the ground. “It’s not just about getting the hand controls back in production,” he says, “there should be at least one flight school in every state in the country that has a set. To me it’s a much bigger picture — it’s letting people know that they can do this, getting the word out and getting the resources together to make that happen. If there is somebody out there who wants a set but can’t afford it, I want to be able to help make that happen.”

**Three Generations of Adaptive Pilots, One Plane**

If there is such thing as an ideal plane for wheelchair-using pilots looking for more power and speed than gliders and smaller airplanes have to offer, it is probably the Cessna Cardinal 177 or 177RG. Chad Colley is a triple amputee and wheelchair user who has owned and flown a Cardinal for many years, and he can testify to its suitability. “It has the biggest door in general aviation at 4 feet wide,” he says. “In addition, the main landing gear is aft of the door, which allows a wheelchair to get within inches of the pilot’s seat with no interference by the landing gear.”

Add in the ability to cover 600 miles cruising at 140 mph and the lack of a wing strut to impede the pilot’s transfer into the cockpit, and you have a great plane for any level of flyer. Cessna introduced the 177 in 1968 and produced it until 1978. Forty years later, a surprising number of 177s are still in use.

For an example of that longevity, and the lasting impact that flying can have, you need look no further than a hangar in Fort Meyers, Florida, where Craig Peterson, 61, keeps one of his two Cardinals. This one is special because of its heritage. Peterson, a C7-8 quad, is the plane’s third owner, and all three have spinal cord injuries.

The Cardinal started out as Jim Maye’s ticket to return to the skies. Maye flew a Phantom jet for the Marines in Vietnam but was paralyzed by a gunshot while on the ground. The Cardinal was the first plane he owned after his injury and he designed and built his own plane in Fort Meyers, Florida, where Craig Peterson, 61, keeps one of his two Cardinals. This one is special because of its heritage. Peterson, a C7-8 quad, is the plane’s third owner, and all three have spinal cord injuries.

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Light-sport Aircraft

If you’re new to flying, or not as concerned with going fast, learning on a light-sport aircraft could be your ticket to the sky. Light-sport pilots have less rigorous requirements to meet than pilots who fly larger aircraft and more options for hand controls and training. If you are healthy enough to get your driver’s license, you can get a license to fly light-sport planes. Also, since LSA take off and land on shorter runways, are cheaper to rent or purchase and use less fuel, they’re also much cheaper to fly than larger planes.

There are many specialized programs to train LSA pilots who need hand controls or similar accommodations in order to fly. One such program is Able Flight, a nonprofit organization based in Indiana. Thanks to corporate sponsors, Able Flight provides flight training scholarships for several students with disabilities each year. Student pilots stay at Purdue University during the intensive six-week course.

Benedict Jones, a C7 quad from Bloomington, Indiana, received one of the scholarships and learned to fly in a LSA. The intensive training he received through the Able Flight scholarship allowed Jones to earn his sport pilot certification in six weeks.

Jones explained his feelings after his first solo flight in a posting on Facebook. “It was like nothing I’ve ever felt, a level of confidence and capability that’s eluded me for too long,” he wrote. “It seemed obvious that this program would be awesome, flying every day, twice a day — if we can — for six weeks. But I never realized how much I would truly love it.”

Resources

- Able Flight, ableflight.org
- East Bay Aviators, eastbayaviators.org
- Freedom’s Wings of Canada, freedomswings.ca
- Freedom’s Wings International, freedomswings.org
- Operation PROP, Inc, operationprop.org
- Philly Sport Pilot, phillysportpilot.com/sport.html

hand controls so he could fly it.

Maye, a T4-5 para, worked on behalf of veterans, first as executive director of the Paralyzed Veterans of America and later in a top position at the Veterans Administration. During that time, he continued flying a Cardinal 177RG with retractable landing gear, before upgrading to a new plane that was faster. It didn’t take much advertising to sell his first Cardinal, as the buyer actually worked for him at PVA.

The second owner of the Cardinal was Larry Roffee, a para from Gaithersburg, Maryland, who was also wounded in Vietnam. Roffee was hired by Maye as legislative director at PVA and, inspired by his boss, decided that he wanted to learn to fly. He did so in an Ercoupe, a low-winged plane that can be flown without using your feet. He bought the Cessna Cardinal from Maye and flew it for 40 years. After retiring from his position as executive director of the United States Access Board, Roffee sold his Cardinal to Peterson three and a half years ago.

Peterson started flying in 1977 after he was paralyzed in a diving accident at the age of 16. When he received his private pilot rating from the FAA at age 19, the examiner thought he was likely the first quad to earn that status. During the 40 years since earning that license, he has owned, rented and flown numerous types of aircraft, from sailplanes and light sports aircraft to the Cessna Cardinals that he owns and flies today.

In his heyday, Peterson says he averaged around 150 hours flying every year. These days, with his kids living closer and less reason for long distance travel, he is down to 35-40. But even after all the hours he, Roffee and Maye have put on the plane, it is still going strong. “It’s in perfect condition,” says Peterson.
ALASKA
Providence Alaska Medical Center
Anchorage, AK; 907/562-2211

ARIZONA
Barrow Neurological Institute at
Saint Joseph’s Hospital and Medical
Center, Phoenix, AZ; 602/406-3747
HealthSouth East Valley Rehabilitation
Hospital, Mesa, AZ; 480/567-0350

COLORADO
Honors Health Rehabilitation Hospi-
tal, Scottsdale, AZ; 480/800-3900

CALIFORNIA
Gaylord Specialty Healthcare,
Los Angeles, CA; 800/672-8653

CONNECTICUT
Gaylord Specialty Healthcare,
Wallingford, CT; 203/234-2800
Hospital for Special Care, New Brit-
ain, CT; 860/827-2761

DISTRICT OF COLUMBIA
MedStar National Rehabilitation
Hospital - SCI Program, Washington,
DC; 202/877-1000

FLORIDA
Brooks Rehabilitation Hospital,
Jacksonville, FL; 904/345-7600

GEORGIA
Emory University Hospital Center for
Rehabilitation Medicine, Atlanta, GA;
404/712-7593

ILLINOIS
Marianjoy Rehabilitation Hospital,
Chicago, IL; 800/462-2366
Schwab Rehabilitation Hospital,
Chicago, IL; 312/200-300

INDIANA
Parkview Rehabilitation Hospital,
Fort Wayne, IN; 260/373-4000
Rehabilitation Hospital of Indiana,
Indianapolis, IN; 317/329-2000

IOWA
Childserve, Johnston, IA;
515/727-8750

KANSAS
Mid America Rehabilitation Hospital,
Overland Park, KS; 913/491-2400

KENTUCKY
Cardinal Hill Rehabilitation Hospital,
Lexington, KY; 859/254-5701
Frazier Rehabilitation Institute,
Louisville, KY; 502/582-7490

LOUISIANA
The Gilda Trautman Newman Reha-
bilitation Center, New Orleans, LA;
504/899-9511
Touro Rehabilitation Center, New
Orleans, LA; 504/897-8560

MASSACHUSETTS
Pinecrest Rehabilitation Hospital at
Delray Medical Center, Delray Beach,
FL; 561/498-4440

MARYLAND
Adventist Rehabilitation Hospital of
Maryland, Rockville, MD;
240/864-6132
International Center for Spinal Cord
Injury at Kennedy Krieger Institute,
Baltimore, MD; 888/554-2080

MICHIGAN
Mary Freebed Rehabilitation Hospi-
tal, Grand Rapids, MI; 800/528-8989
DMC Rehabilitation Institute of
Michigan, Detroit, MI; 313/745-1055

MISSOURI
Ability KC, Kansas City, MO;
816/751-7812

MISSISSIPPI
Methodist Rehabilitation Center,
Jackson, MS; 601/981-2611

NORTH CAROLINA
Cone Health Inpatient Rehabilitation
Center, Greensboro, NC;
336/832-8153
Vidant Medical Center, Greenville,
NC; 252/975-4100
Wake Forest University Baptist
Inpatient Rehabilitation Program,
 Winston-Salem, NC;
336/716-2011
WakeMed Rehab Hospital, Raleigh,
NC; 919/350-8861

NEBRASKA
Madonna Rehabilitation Hospital SCI
Rehabilitation Program, Lincoln, NE;
402/489-7102
QLI - Spinal Cord Injury Program,
Omaha, NE; 402/573-3700

NEW HAMPSHIRE
Northeast Rehabilitation Hospital
Network - Neuro Centers, Salem,
NH; 603/893-9478

NEW JERSEY
Bacharach Institute for Rehabilita-
tion, Pomona, NJ; 609/748-5480
Kessler Institute for Rehabilitation,
West Orange, NJ; 973/252-6367

NEVADA
Renown Rehabilitation Hospital,
Reno, NV; 775/982-5000

NEW YORK
Helen Hayes Hospital, West
Haverstraw, NY; 845/786-4000
Mount Sinai Medical Center,
New York, NY; 212/241-6500
Orange Regional Medical Center,
Middletown, NY; 845/333-1000

OHIO
Metrohealth Rehabilitation Institute of
Ohio, Cleveland, OH;
216/778-3483
Ohio Health Outpatient Neurologi-
cal Rehabilitation, Columbus, OH;
614/684-9600
Summa Rehabilitation Hospital,
Akron, OH; 330/572-7300

OKLAHOMA
Integris Jim Thorpe Rehabilita-
tion Network, Oklahoma City, OK;
405/951-2277

OREGON
Legacy Rehabilitation Institute of
Oregon, Portland, OR; 503/413-7151

PENNSYLVANIA
Allied Services Integrated Health
System Spinal Cord Injury Program,
Scranton, PA; 570/348-1360
Organizational Members
Center for Neuro Recovery
North Palm Beach, FL; 888/875-7659
Florida Spinal Cord Injury Resource Center, Tampa, FL; 813/844-4711
Miami Physical Therapy Assoc., Inc. Miami, FL; 305/444-0074
NextStep - Kansas City Overland Park, KS; 913/451-1500
NextStep - Orlando Sanford, FL; 407/571-9974
Project Walk - Boston Stratham, NH; 603/583-5119
Project Walk - Houston Missouri City, TX; 281/410-8348
Project Walk - Mt. Laurel Mt. Laurel, NJ; 848/800-1563
Project Walk - San Diego Carlsbad, CA; 760/431-9789
Push to Walk Oakland, CA; 201/644-7567
The Perfect Step Claremont, CA; 888/436-2788

Interested in becoming a hospital or organizational member?
Please contact Nick LiBassi at 718/803-3782, ext. 7410 or nlibassi@unitedspinal.org

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ANOTHER HUGE STEP: AXONS CAN REGENERATE

In the October 2018 issue of New Mobility, I told you about a breakthrough experiment in which Dr. Xiaoguang Li and his team of scientists in Beijing had managed to get surviving corticospinal axons to grow down across an injury site with the help of a scaffold (“bridge”) treated with a nerve growth factor. Axons, remember, are the gossamer threads that project out from neuron cell bodies in the brain; they carry your thoughts (brain signals) through the cord to other neurons and eventually on to your muscles. Broken axons are why people stay paralyzed. The conventional wisdom is that once damaged, they can’t regenerate.

The Beijing story is exciting all by itself, but — amazingly — it’s not the only time this year that a scientist has broken that old conventional wisdom into tiny little pieces. Last February, a team at the University of California in Davis did the same thing, but with a completely different method. In their test with animals’ damaged cords, the Beijing team had inserted a tiny, growth-factor-infused plug made of a naturally dissolving material into the gap. Using the same species of monkey, the UC Davis team, led by Dr. Mark Tuszynski, grafted a matrix of living cells into a similar gap.

The Beijing idea was to simply make it possible for surviving axons to get through the famously axon-unfriendly lesion. Tuszynski’s plan was to use cell grafts to create a living relay system right in the injury site. One treatment is about a transplant of friendly cells that grow out in both directions, forming a sort of living relay circuit that’s meant to survive indefinitely and become part of the host’s body.

About those friendly cells. Not a single day has passed in two decades when a researcher somewhere wasn’t attempting to figure out how to use some kind of cells to replace the damaged ones. That’s a lot of cell types and a whole lot of rats. In his rhesus monkey research, Tuszynski used what are called neural progenitor cells. These are not embryonic stem cells. They’re also not mature neurons. They’re progenitors — a little like special grandfather seeds that are able to generate only three specific kinds of grandchildren. NPCs can become neurons, oligodendrocytes, or astrocytes. That’s it.

The reason the offspring of NPCs are so limited is that during pregnancy, fetal cells develop in a way that’s a lot like a tree branching. The trunk is embryonic stem cells; they’re all exactly the same. Over time, though, the cells differentiate, which you can picture as four big branches coming off that trunk. One of those big branches is made up of neural stem cells.

If you go along that big branch further and further until you’re right at the point where the branch splits into three smaller ones, you’ll arrive where the NPCs live. The next thing that will happen is that the NPCs have to make a choice about which smaller branch they’ll take — neuron, oligodendrocyte, or astrocyte? It has to be one of those. Tuszynski’s team used human NPCs from a lab in Baltimore donated by a company called NeuralStem, a for-profit organization that has been investing in neural cell research for a long time. When the Tuszynski team was ready to do its cell transplants, the folks at NeuralStem overnighted their cells to California.

Encouraging Results in the Complicated Quest for ‘Cure’

Going in, the UC Davis scientists had five explicit goals for their cell grafts:

- A critical mass of them had to survive and develop into neurons.
- They had to successfully lure injured host axons down and into the graft.
- They had to form synapses with those host axons.
- They had to extend their own axons down and out of the injury site.
- Those new axons had to form synapses with host neurons below the injury site.

Synapses, recall, are the infinitesimal points of contact between one neuron and the next — they’re the locked-in spaces where cell-to-cell communication
happens. If synapses don’t form, it doesn’t matter how many axons grow, the message won’t get through.

Those five goals were all met, but it wasn’t a straightforward process. The first attempts failed because cerebrospinal fluid filled the injury site so quickly that the new cells just washed away. That problem was solved by tilting the operating table 30 degrees, allowing the fluid to drain off and making time to place the cell graft. The scientists also adjusted the ingredients of the matrix so that it would “gel” into place in a few seconds.

So far, so good. The graft filled the injury cavity and the cells survived — but only for a couple of months. If this treatment is ever going to become a therapy for humans, we’re going to need that transplant to be permanent. Fortunately, a stronger dose of immunotherapy drugs was all that was needed. From the paper:

Grafts occupied the majority of the lesion cavity in all subjects and integrated well with the host spinal cord ... human axons emerged [in both directions] from grafts in extraordinary numbers and over long distances ... corticospinal axons readily crossed the host-graft interface to penetrate distances up to 500 micrometers into the graft [about half a millimeter].

At this point, it would be great to say that these animals then recovered significant function as a result of the transplants. I’m not going to say that, though. The monkeys did recover measurable movement in their front paws, and the evidence shows that this happened as a result of the new cells forming working connections with host cells from both above and below the injury site. But recovery of function wasn’t the point of this particular effort.

Remember the five goals? The researchers wanted to show that NPCs could live, could differentiate into all three kinds of spinal cord cells and could form synapses with host cells. If this had been a human trial, it would have been called “Phase I,” meaning it was not supposed to improve function. But that does not diminish the importance of what the researchers found, and how it is encouraging news for the SCI community.

**Getting At the Source of the Real Problem**

A few weeks ago I was in Vancouver, British Columbia, at the 2018 Working2Walk annual conference, where wheelchair users, caregivers, PTs, researchers, industry representatives, charitable foundations and government regulators had gathered to talk about the gnarly issues that are keeping progress toward cures so slow. The list of issues is very long. But this year’s W2W was heavily concentrated on efforts to improve bowel, bladder and sexual function. These are the daily issues that make life with SCI such a challenge.

A lot of the progress we want to see is currently being addressed through epidural and transcutaneous stimulation, but no one is pretending that this technology is going to be the ultimate answer. Why? It doesn’t get at the source of the problem, at least not in the sense that it restores the full range of motor and sensory function we all want.

For that, we need scientists like Tuszynski and Li patiently moving forward with their axon regeneration work — that is where the ultimate solution lies. The fact that both of them have had success with non-human primates is a giant step forward. Giant.

For a series of reports on W2W, check my blog at w2w2018.wordpress.com.

**Resources**

- “Bridging the SCI Site,” New Mobility, October 2018, newmobility.com/2018/10/bridging-the-sci-injury-site
- “Stem Cell Reality Check,” New Mobility, January 2018, newmobility.com/2018/01/research-matters-stem-cell-reality-check
- NeuralStem, neuralstem.com
- Working2Walk, u2fp.org/working-2-walk/speakers.html

**Did You KNOW...**

United Spinal Association produces more than 30 brochures and pamphlets on subjects like Disability Etiquette, Fire Safety for Wheelchair Users at Work and at Home and Understanding the ADA. You can download them for FREE or order printed copies on our website at www.unitedspinal.org
Looking for TED Hose With a Waist Band

Tom asks:
I am a T12 para and, due to blood clots behind my left knee after my injury, I wear Covidien TED hose any time I get out of bed. They are the type that come up your thigh to your waistline and snap onto a belt. A year ago or so, my supplier told me Covidien no longer sells them in North America, but supposedly they are still available in Europe. I have friends in Germany and they can’t find any either. I have continued to search for them without any luck.

I tried the lowest-pressure rated thigh-high compression hose but the elastic top cut into my thighs too much, making them very painful.

I use the old-style Kendall hose without the belt by safety-pinning the snap area to the bottom of my T-shirt or shirt. That keeps the hose up and my shirt tail down.

So, I’m reaching out to see if anyone out there knows where I can buy the TED hose with the waist band.

Spinal Cord Injury Resource Center Director Bill Fertig responds:
We searched too and couldn’t find the exact combination you are looking for. When a product like this is discontinued, before you begin using another product — one that may not fit properly and that potentially could even cause additional health problems — we highly recommend that you talk with your doctor, preferably with a physiatrist, a doctor of physical medicine with experience treating individuals living with spinal cord injury. In this case, you may also want to read Care Cure Forums’ conversational threads about compression hose (sci.rutgers.edu/forum/showthread.php?181209-Compression-Socks-and-pressure-marks) and review the PVA Clinical Practice Guides on Deep Vein Thrombosis (pva.org/media/pdf/CPG_thrombo_fnl.pdf).

Senior Correspondent Bob Vogel responds:
Unfortunately it isn’t unusual to get blood clots in the acute stage following a spinal cord injury. Constantly wearing thigh-high TED hose might be overkill, so first I would suggest that you get additional information from a physical medicine and rehab doctor, a hematologist and/or a rheumatologist to see if it’s necessary. It is fairly common for people to come out of rehab with thigh-high compression stockings, but eventually most active people are able to stop wearing them.

In my case, I got a blood clot in my right leg three weeks after my injury. I did six months of blood thinners and six months with thigh-high TED hose. After that, my PM&R doc said I was good to go as long as I didn’t get swelling, or edema, in my legs. I managed another 15 years before I got another blood clot — which came with a broken femur. I went back on blood thinners and started full-time knee-high compression stockings because of lower-leg edema. Working with a rheumatologist, I eventually got off the blood thinners, but I still use compression stockings.

Fashion Tips
Jacqueline asks:
It would be great if I could speak with someone who writes about the types of clothing that women who are wheelchair users wear. I would love to know more about the clothing attributes that they look for when shopping.

Editor Ian Ruder responds:
I don’t think we have anyone on staff who is an expert on clothing design, but we’ve run some good articles that might help. In her article “Fashioned Enabled: Clothing that Works in a Wheelchair,” Kate Matelan writes about the adaptive clothing scene: “Now more than ever, designers are getting in tune with their clientele’s needs, researching what works for people with disabilities, and taking that into consideration when designing and choosing fabrics to hold up to unprecedented washing, pulling and tugging.” Matelan’s article can be found here: newmobility.com/2015/10/adaptive-clothing. And here’s a list of the companies she highlighted:

- ABL Denim, abldenim.com
- Able to Wear, able2wear.co.uk
- Adaptations by Adrian, adaptationsbyadrian.com
- Ag Apparel, agapparel.com
- IZ Adaptive, izadaptive.com
- Janska, janska.com
- Koolway Sports, koolwaysports.com
- MagnaReady, magnaready.com
- Rolli-Moden, rollimoden.de/index.php?language=en
- Rollin’ Wear, rollinwear.com
- Spashionista, spashionista.com

We hope this helps!
“I will vault past my inglorious station... by systematically destroying the competition.”

TEENAGE DICK

by Mike Lew

directed by Josh Hecht

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JAN 6 - FEB 3

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PAPER TRAIL
College is a time for experimenting, right? I had always wondered, so I thought that I would give it a try. I decided to use crutches instead of my wheelchair on a date. A movie date. I suggested a tearjerker, trying to show my sensitive side. All went well until nature called. It was near the end of the movie. So, after finishing, I sat in the back row to meet her afterwards. She drove us back to my apartment. I invited her in. Four of my five roommates were home. She came in, but left rather quickly. After walking her out to her car, I could hear hysterical laughter from the apartment. Once inside, through cries of laughter, one of the roommates beckoned me to a full-length mirror and motioned for me to turnaround. There I saw four to five squares of two-ply hanging from my shorts. I have been loyal to my wheelchair since. Needless to say, there was no second date. T.P.

PUBIC HUMILIATION
As anyone with a spinal cord injury knows, there is no modesty in the hospital. The morning after my cervical spinal fusion, my mom was at my bedside while a nurse uncovered my otherwise nude bottom half for whatever reason. As she did, my chatty mom fell silent and inquisitively stared down in the direction of my lady parts. Out of nowhere, she looks over at the nurse and gesturing between my legs asks, “Did the surgeon do that?” Stunned and suddenly mortified, I realized my mom had just inquired if the neurosurgeon, who operated on my neck, was somehow responsible for the bikini wax I had received in the week prior to my accident. The nurse laughed and said, “I do believe your daughter was in charge of that.” To prep for the surgery, they had shaved part of my head, but I can't imagine why they would’ve needed to shave anything else, mom.

Smooth Roller

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