Tammy Duckworth: Our Champion in Congress
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COVER STORY  ROLLING INTO POLITICS  24

U.S. Representative and wheelchair user Tammy Duckworth is great on vet and disability issues, and some think she may be our next congressional champion, reports IAN RUDER. Also three wheelers who’ve run for offices ranging from convention delegate to city alderman to state legislator share their strategies with LINDA MASTANDREA.

Cover Photo Courtesy of U.S. Embassy, Bangkok
I received a letter from a reader who’s been taking the anticholinergic drug Ditropan for 30 years and is concerned about a recent study linking anticholinergic use with dementia [see Letters, page 6]. Was it time to throw away his bladder control pills and try Botox, he wondered.

NM columnist Allen Rucker became suspicious of his anticholinergic use a year following onset of transverse myelitis (T10 paraplegia) 18 years ago. “At first I self-injected Ditropan in the hospital, then came home and took Detrol caps by mouth for six to eight months before having memory problems. I was at a mall with my wife. She says let’s take this elevator. I said wow, I’ve never been on this one. She says you have been on it maybe 500 times.”

The fog continued, so he ditched Detrol and relied solely on intermittent cathetering. Without bladder control meds he had continual incontinence problems. “I was an inveterate leaker. I tried some kind of bladder surgery but it didn’t do much. I thought I was stuck with the problem.” Then in May of this year, he asked his urologist about Botox. His doc said go for it.

“I’m ecstatic about it,” says Rucker, now 70. “It is singularly the best thing that’s happened to me since I was paralyzed. Within three days, the leaking stopped. Now, four months later, every morning I wake up and thank my doctor for this. I’ve had no problems. All I can say is, I’m one of the lucky ones.”

Most Botox procedures last between six and eight months before having to be repeated. It may take a few tries before reaching maximum effect. Holly Poupore, a C5-6 quad, recently had her fifth procedure. “The first one lasted between six and nine months, but the third only lasted about four months. Then the fourth went for a whole year. I did the fifth in January, and so far, so good.”

The procedure can be done in a doc’s office using a cystoscope. A catheter rigged with a mini-camera and tiny syringe is passed through the urethra and 30-40 injections are spaced around the bladder wall. Within a week spasms are blocked, creating a flaccid bladder. Those prone to autonomic dysreflexia may have to have the brief procedure done in a hospital setting.

The recent anticholinergic study alarmed me, too. Short-term memory loss is not unusual at my age, 71, but why not eliminate a risk factor? I had my procedure done in a daytime hospital setting not because of AD, but due to a history of heart surgery. A week later my problematic bladder was my new best friend.

For more than 50 years I wore a condom catheter and leg bag every hour, every day and night. Now I go without, with confidence.
Jean Dobbs was named publisher of New Mobility this year, her 25th with the magazine. She began as a grad student-intern in 1991 under disability journalism pioneers Sam Maddox and Barry Corbet, worked her way to managing editor, then editorial director in 1998, before assuming her current position. Those of us on staff know her as a dedicated, multi-talented professional whose judgment is indispensable. Under her guidance NM has won several awards and enduring respect. She is currently working on redesigning the print magazine, raising circulation and expanding digital reach. She hopes to be able to say one day, “New Mobility? Yeah, there’s an app for that.”

Joseph Pierce was born in Florida but moved to El Paso at age 10. He was paralyzed in a diving accident and soon after enrolled at the University of Texas at El Paso, where he earned a master’s degree in speech language pathology in 2003. He now has the pleasure of working with children from three years of age to adults who have communication disorders. His two boys (12 and 7) keep him busy and well-grounded as he tries to master the fine art of enjoying life to the fullest.

Having sustained a T12 incomplete SCI as the result of a suicide attempt at the age of 18, Nancy Xia, now 31, says she loves her life. She works for Spinal Cord Injury Ontario as a resource and education assistant serving newly injured people in a rehab hospital. The jacket blurb on her memoir — Into the Mind of a Suicide (available from amazon.com) — is a reminder of her mission: “I feel like I have an obligation to speak for others who were lost forever to suicide.” She lives in Toronto.

Chicago disability law attorney Linda Mastandrea is perhaps best known for being a two-time Paralympian who has set national, world and Paralympic records and won gold and silver medals in wheelchair racing. Mastandrea is also a frequent contributor to New Mobility and blogger on topics related to wellness, aging, and disability. She has also worked as a consultant on emergency management and disability issues and ran for judge of the 9th sub circuit of Cook County in 2014. She lives in Chicago with her husband Jesse, cat Luna and dog Lucy.
**Great Travel Destination**

As a quadriplegic for over 33 years, I was fascinated to read the “Wheeling in Cuba” article [August 2016]. Approximately 15 years ago I traveled to Key West, and at that point I thought to myself that Cuba, only 90 miles away, would be a great travel destination. This article shows that although accessibility is very limited, the time is now for Cuba to become a wonderful destination for individuals with physical disabilities. The article also made me appreciate so many of the accessibility amenities that we have in the U.S. as a result of the Americans with Disabilities Act.

*Sheri Denkensohn-Trott*  
via newmobility.com

**Now We See**

What is Cuban life really like? Now we finally get a glimpse, along with three wheelers with SCIs who set off on a quest of a lifetime to get a firsthand look at Cuban society through their unique lens (“Wheeling in Cuba”). I began reading the piece with an idea that I would encounter frustratingly chuckle-worthy accessibility disasters as the travelers recounted tales from an archaic land. There were some, but many more delightful surprises than not.

*Richard Bagby*  
via newmobility.com

**Parking Abuse Issues**

The problem is not “regular” people using disabled parking spots without a decal, it’s all the fake disabled people using accessible parking spots (“7 Hard-Core Parking Abuse Strategies,” August 18, 2016 blog). It is very rare that I go out and can find a parking spot reserved for disabled persons. I have a lift on my vehicle that swings out on the driver’s side, and I need a lot more space than a “regular” parking spot to be able to get in and out of my truck. However, these reserved spots are always taken, and not by other people using a wheelchair.

I would say, without being scientific, that roughly 95 percent of the people having a wheelchair license plate or a disabled placard have no mobility disability. I see them everyday walking or running away from their car without any help, any problem, any limping or anything wrong! When I confront them, they all become angry and rude and give me the finger while saying this is not my “freaking” business. An “invisible” disability is not a mobility disability. The other 4 percent I see using these disabled parking placards or plates are either just old people or fat people — neither a disability on their own. Only 1 percent are genuine disabled people using a wheelchair or a walker.

Can we have the wheelchair plates and wheelchair placards issued only to people with a wheelchair or walker? Maybe those who claim they have problems walking a quarter of a mile could get another type of placard? Having a mental problem, a stomach condition, headaches, or being overweight by itself doesn’t qualify for a wheelchair placard.

Law enforcement, states and counties need to do something about this. Too many people have disabled placards or plates, but they can walk without any problem. Leave accessible parking spots and the placards to real disabled people.

*Bernard J. Noel*  
via newmobility.com

**Even Police Get Theirs**

I just thought I’d relate one of my tactics, which is not unlike that of the person blocked by a motorcycle (“7 Hardcore Parking Abuse Strategies”). I simply drop my lift into their door, raise it, and drop it a few more times. Once the offender was a police car. When I called into the school to have him paged, he emerged a bit ticked off that I’d damaged his vehicle. I explained that I start deploying my lift as I approach my van, with the assurance that nobody will be parked in the “no parking area” next to it. Then I simply said that if he hadn’t been illegally parked, his vehicle wouldn’t have been damaged. He grumbled. I raised my lift … and he moved his car.

*Alan Bronstein*  
via newmobility.com

**Family Caregivers**

Regarding the letter writer of “Partner-Caregivers: A Bad Idea” [August 2016 Letters] — she must have had a bad personal experience. I am a 54-year-old C5-7 incomplete quad, happily married for over 40 years. Would not have anyone else but my wife care for me. The same goes for a great friend of ours. And many, many others. Are we the exceptions to the rule? I think not.

*Harry Kember*  
Pompano Beach, Florida

**More on Botox**

Thank you for the follow up on this issue as it did greatly concern me [ParaMedic—“Anticholinergic Medicines and Dementia,” August 2016]. I have been taking Ditropan for over 30 years due to SCI with great success and manageable side effects. I am currently working with my urologist to see if Botox might be a better alternative for bladder management. I’m 67 and fear the onset of dementia/Alzheimer’s. This article has calmed my fears to some degree. An article about the use of Botox by people with SCI would be great.

*Chuck McAvoy*  
via newmobility.com

**EDITOR:** Please search “Botox” on newmobility.com for our archive on this subject. Also, see the Bully Pulpit column on page 4.
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Disability Disaster Response in Louisiana Significantly Improved

The disaster response to those with disabilities during the Louisiana Floods of 2016 was significantly improved from the response during Hurricane Katrina in 2005. That's according to Shari Myers, National Disability Integration Coordinator for the American Red Cross. Previously, Myers was chief operating officer of Portlight Inclusive Disaster Strategies, a nonprofit focused on disaster relief for people with disabilities.

"I'm encouraged by the fact that there are now many people with disabilities who are working in inclusive emergency management and disaster planning. Before now, disaster planning was always a lot of people planning for us, not with us," says Myers.

Red Cross called last month’s flood in Louisiana, “the worst U.S. disaster since Hurricane Sandy,” with over 20 parishes affected. Some even compare it to Hurricane Katrina, which devastated the region 11 years ago.

Since Hurricane Katrina, Louisiana formed an Emergency Management Disability and Aging Coalition to make sure people with disabilities were considered in disaster relief procedures and had equal access to emergency resources. As a result, Myers says better partnerships with community organizations were forged, and resources they could only dream about during Hurricane Katrina have been donated or purchased for Louisiana flood shelters.

Myers says to keep in mind that ensuring shelter accessibility isn’t the first concern of emergency management when a disaster hits. "It may have taken a day or two for accessible trailers to be brought in, but emergency responders at the state shelters were relatively on top of things once the initial chaos died down," she says. "In almost all cases, people only had to stay in safe, but inaccessible locations for a few hours before being taken to an accessible state shelter."

Has the response been perfect? Of course not, says Myers. "But of the eight deployments I’ve been on, this is the best."

Hands-free Pokémon GO Possible

Thanks to Komodo OpenLab’s Tecla Shield, a wireless Bluetooth device, it’s now possible for power wheelchair users to play hands-free Pokémon GO.

Pokémon GO is a game for mobile devices that allows players to hunt and catch Pokémon in real life. Once the app is opened, the Pokémon, cute little cartoon critters, will begin to appear on your phone as if they are right in front of you. You then throw a Pokéball in hopes of catching them — the game’s catch phrase is “Gotta catch’em all!”

But the game requires some hand agility to open the app, swipe the screen and tap buttons, and this is where Tecla Shield comes in. Installed directly onto the wheelchair, the product allows power chair users to access iOS, Android phones and tablets hands-free via Bluetooth. This means they can play mobile device-based games like Pokémon GO.

The Tecla Shield retails for $349. For more information, go to gettecla.com.

People in the News: Ian Cannon Strives to Bring Wheelchair Boxing to the Paralympics

If Ian Cannon, 23, gets his way, wheelchair boxing will one day be a Paralympic sport. But, he acknowledges, there are obstacles that have to be overcome first.

“The sport is not global enough,” says the Glastonbury, Connecticut, native with cerebral palsy. “There are all these little organizations, but we’re not unified in any way.”

Cannon is working with the Adaptive Boxing Organization, based in the United Kingdom and headed by Colin Wood, 44, who has uveitis, a serious inflammatory eye condition. Wood has already spoken to the International Olympic Committee, which says a governing body for wheelchair boxing is needed as a first step to consideration for the Paralympics.

“We are now that governing body,” says Wood, “and we are in talks with organizations in 24 countries to become their umbrella organization in hopes of establishing unified rules.”

Meanwhile, Cannon is working with World Boxing Council President Mauricio Sulaimán to try to stage a major step towards wheelchair boxing’s global awareness — an adaptive match on a nondisabled card.

“When that happens, it’s going to go from one country to another and island hop. Then, the Paralympics won’t have a choice, they’ll have to pay attention to us,” says Cannon. He welcomes inquiries about Wheelchair Boxing via his email, Boxer625@gmail.com.
"I can bring my sister her sippy cup when she’s in the high chair."
- Cassie Kiefer

A. Villegas  My son enjoyed a rodeo thanks to being able to elevate!

R. Nashwinter  My 11-year-old has this and loves it.

M. Evans Stevic  Got mine a month ago. Life changer.

J. Schniers Wellman  Our daughter just received her iLevel and is loving it!!
“There’s nothing more rewarding than seeing the eyes of someone in my audience ‘get it.’”

Hugs with a Higher Purpose

There are a lot of people who turn to motivational speaking post-SCI, but the kind of speaking Brent Poppen, a C5-7 quadriplegic from Paso Robles, California, does, stands out. With his bleached blond hair and his M.O. of “Hugs by Brent,” the happy energy he emanates is unforgettable.

“Much of my presentation centers around hope, acceptance, not giving up and making the right choice in difficult circumstances,” he says. Last year he reached over 30,000 students. “There’s nothing more rewarding than seeing the eyes of someone in my audience ‘get it’ and then be able to hug that person afterwards.”

Becoming a motivational speaker was a natural transition for Poppen. After his injury at age 16 (he was injured while play-wrestling at a summer camp), adapted sports helped him beat depression, eventually catapulting him to the Paralympics. He competed in the 2004 Athens Paralympics in quad rugby, winning bronze, and in 2008 he went to the Beijing Paralympics for tennis. “When speaking, I let my audience wear my Olympic Medal,” he says. “I’ve seen how powerful it can be for others to feel and wear it.”

Poppen also started free adaptive water skiing camps through his job as a rehabilitation counselor at Valley Children’s Hospital. “We do multiple ski camps a year, ranging from two to four depending on private lake access. We also bring jet skis to pull kids with their family in towable rafts.” For more info, visit their Facebook page: “Valley Children’s Hospital Adaptive Sports.”

From penning his autobiography, *Tragedy on the Mountain: from Paralysis to the Paralympics*, to working on his latest invention with the help of a certified hand therapist — a prosthetic to throw a baseball again (see his website for more) — his motivation is nonstop, and the hugs he gives along the way are truly helping to change the world. Go to hugsbybrent.com

New Power Add-On for Wheelchairs

In April Google awarded $20 million to disability nonprofits looking to create innovative solutions. One of the grant winners, the Center for Discovery in Harris, New York, a nonprofit dedicated to helping people with disabilities reshape their lives, was awarded $1.25 million.

The center was specifically awarded the money for indieGo, a new power add-on device for manual wheelchairs that is cheaper than anything else that has been made to date. Even better, the device works as a platform that any manual wheelchair can drive onto. The controls can also be adapted to any ability level.

Even cooler, the team behind indieGo will be making the blueprints available online so that anyone can adapt and use them at no cost. indieGo will have enough power to motor through malls, schools and more. Learn more at theindiego.org

Most Accessible Beach in the World?

Recently opened in Calabria, Italy, the Valentino Beach Club may be the most accessible beach in the world. With dozens of raised accessible private platforms (each with its own umbrella), a seat track pulley system that helps you into the water, and more, this free beach is definitely one for the bucket list.

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People who develop diabetes type 2 as adults often don’t know they have it until a blood test discovers it. In my case, prior to 2013, there was no sign of it. In December 2014, my A1C level, which measures the average amount of glucose in your bloodstream over a three-month period, was 5.8 percent, indicative of a pre-diabetic condition. A year later it was 6.9 percent, and four months after that, it measured 7.2 percent. (Two readings of 6.5 or higher means you join the diabetic club, like it or not.) The doctor broke the bad news to me this past April: “You now officially have diabetes.”

I had enough to worry about already: coronary artery disease, peripheral artery disease, SCI, a below-the-knee amputation from skin complications, bowel and bladder problems. Now a disease that slowly causes damage to other bodily organs? So I started researching diabetes in hopes of finding a way to successfully deal with it.

Here’s some of what I found: If you have SCI with resulting paralysis, you are two to three times more likely to get diabetes than the general population. A 2013 Canadian study concluded that the odds of people with SCI having type 2 diabetes are 2.5 times greater than in those without SCI. An American study of veterans, conducted in 2006, found the prevalence of diabetes in those with SCI was three times greater. In the mainstream United States, the...
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rate of diabetes among both males and females has increased dramatically from 1980 until the present.

So what happens to your body when this hidden disease is at work?

The list of potentially serious complications is alarming. Fortunately, the damage doesn’t happen suddenly. All the more reason to ask your doctor to track your blood glucose levels: When diabetes creeps in, glucose levels rise, causing damage to blood vessels (heart disease), nerves (poor circulation), kidneys (kidney disease or failure), eye damage, hearing impairment, non-healing wounds, even Alzheimer’s. Since your blood circulates throughout your entire body, micro-damage in tiny capillaries and cells results over time.

Frightening, isn’t it?

The good news is that strict control of carbohydrate intake combined with any movement at all (the more the better) and medication (if needed) can help reduce the harmful effects of diabetes or even avoid it altogether.

ACCEPTING THE CHALLENGE

My doctor sent me to a four-week class to learn about diabetes. I was the only wheelchair user in the class. While the instructor was talking, I couldn’t help wondering if I would even be there had I not become paralyzed more than 50 years earlier. To find answers, I would have to learn everything I could and talk to other wheelers like me, outside the class. My first interview was with Kim Harrison, 57, who contracted transverse myelitis at age 45.

“I woke up one morning, my right foot was tingly, went to ER, and by noon I was paralyzed, T10 incomplete,” says Harrison, of Douglasville, Georgia. Ten years later she was diagnosed with diabetes after blood work alerted her doctor. “The A1C level was 11.9, really high, but there were no complications. I felt fine, normal, would never have known.”

She thinks her diabetes has something to do with paralysis. “I went from size 10-12 to 24-26 after my TM diagnosis. Weight has been a problem since then.” But she has been gradually losing weight, mostly due to being active and making wise food choices, and has returned to size 16-18 in pants. “I swim as much as I can. We built a pool. When I’m in water, I can walk. I can use a walker in the house, but my right leg drags.”

She also has a portable mini-exercise machine that automatically moves her legs or allows her to pedal with her arms. “I can pick it up, carry it around, watch TV, crochet, whatever. It makes me feel better physically and mentally.”

As for meds, she was taking metformin for the diabetes, but her dosage has been reduced, and her A1C level is now down to 5.7. “Doctor says if I can stay at that level, I can probably come off the metformin.” She thinks exercise is the key, but keeping a strict diet is also very important. “I have made a conscious effort to eat right. I eat grilled chicken, turkey burgers, whole wheat bread, and veggies when I can. It’s not a diet so much as rethinking the choices I make. At restaurants I take one small piece of bread. I
used to eat the whole loaf.”

The two main factors in a diabetic diet are limiting carbohydrates and portion control. Since carbs turn to glucose, a form of sugar, in your blood — and diabetes diminishes your ability to convert glucose to energy — you must become an ardent label reader and strictly limit carbs. Processed and starchy foods can drive your blood sugar to dangerous levels. Foods high in protein are beneficial, as are whole foods, especially natural fruits (in moderation) and vegetables. They help your body turn glucose to energy.

“I have conditioned myself to think, ‘this is my food, not what I have to eat.’ I eat just enough, it’s self-control, not a diet. I won’t refuse foods, just cut the burger in half or skip the bun. You can still enjoy the same foods as everyone else, but control portions and carbs.”

Her doctor has told her he can’t get over how far she has come. She is winning the battle against diabetes. What motivates her? “I had to give up so much with TM, I don’t need any more problems. No more pills, fewer pills. Not one more problem. No more concessions.”

Evan Sleight, Brigham City, Utah, 44, sustained a C5 SCI in 2010. Sixteen years before that, he had been diagnosed with diabetes. But everything changed after his SCI. Now he uses a sip-and-puff wheelchair full time. “The stuff I used to eat would burn off, but it won’t do that now. Now I just can’t dive into a meal. I have to know in advance what I can eat and how much. I have to know carbs. My eating has changed dramatically.”

Before his SCI, neuropathic pain did not bother him. Now, if he doesn’t watch what he eats, his hands and feet feel like hot needles are poking him. “Dealing with nerve pain hurts more than just watching what I eat. It is a powerful motivator.”

When he left Craig Hospital following rehab in 2010, he weighed 195. Over the next few years he ballooned up to 300. “Now my weight is 275, and we’re working to get it down to the 200 range. It’s slow with no exercise. You have to be vigilant. You have to say no. Thanks but no.”

But he admits to a weakness for chocolate. “My wife has a friend who is Swiss, and she brings over this fantastic Swiss chocolate. Sometimes I get stupid and overdo it.”

Mostly, though, he eats according to plan. For breakfast he usually has a protein shake — fruit, ice, soy milk and protein powder. For lunch he will have a wrap — taco meat or roast beef, maybe some pickles, in a tortilla, and some veggies. “Not a big burrito, just a simple wrap, maybe with a little cheese. Very few carbs.” And for dinner, more protein — fish, shrimp, or meat loaf — with a small baked potato and veggies.

“I have to keep my protein up because I keep getting pressure sores on my feet. With protein they heal faster. Management of your body is absolutely critical with diabetes, especially your feet.” Sleight never had a pressure sore prior to his SCI. “We have learned so much about
how to take care of wounds. I could not do this without my wife. I love my wife. You have to have a good partner, someone who is as diligent as you could be, checking your feet everyday for abnormalities. My kids call her the “The Skin Nazi.”

Sleight’s diabetes may have a genetic link. “My mom and dad both had it. But they got it later in life. When I got it I was 28.” He and his wife have more than quadriplegia and diabetes to manage. They have six kids. “We have a 20, two 19s, a 17, and two 9’s. Two sets of twins. Sometimes it can be stressful with the kids, but it’s worth it.”

He says the key to managing diabetes is to get a good doctor and stay on top of your A1C levels. “Keeping up with your diabetes is like changing the oil in your car — continual maintenance, especially if you’re a quad — and you will extend your life and stay alive.”

LIVING ALONE WITH DIABETES

Steve Pisano finds it difficult to eat right and manage carbs because he lives alone and works. “I have a lot of excuses,” he says. “I’m not disciplined when it comes to eating. I don’t have anyone to cook for me so I eat out often.” Pisano, 50, a T3-4 para, was injured in 2003. At 5 foot, 3 inches tall, he weighs 187. A year ago he was 10 pounds heavier. “Most of it is in my stomach,” he says.

He lists his occupation as photographer but is developing his own business — Device Doctors — repairing communication devices. “I’ll fix anything — cell phones, tablets, Apple computers. I’ve been doing it about two and a half years.” He lives in Fraser, Colorado, in mountainous snow country.

About two years after being injured, he noticed his urine output had grown tremendously. “Do I have a bladder infection?” he wondered. “Why do I have to cath every two hours?” At the doctor, his blood sugar level tested really high. He found out one of the symptoms of diabetes is increased urine output.

The local doctor tried several meds, but his glucose level played pinball, bouncing high to low and high again. When he found the right combination of two drugs, his insurance company refused to pay for one. His glucose levels went haywire again. Now he is gradually gaining back control, having learned several tricks of eating right as a single man.

At McDonald’s he will get a cheeseburger or double cheeseburger and throw away the top bun. “Or I’ll take it to my office and throw away both buns and eat off a plate. I cut out soda, but I’ll drink Mexican Coke, which is made with cane syrup instead of high fructose corn syrup. Or I’ll drink half lemonade and half unsweetened ice tea. I’ll also drink green tea with honey.”

Instead of plain water, which he dislikes, he buys packets of True Lemon or True Citrus. “It is fantastic. It’s crystalized lemon, cold-pressed. One packet equals one lemon. No artificial sweeteners. Really tastes like lemon. I will fill a bottle of water with ice and put a packet in it, and voila! I buy cartons with 500 packets and it lasts forever.”

He thinks his bouts with autonomic dysreflexia may be related to his diabetes. He gets busy, forgets to eat, and his blood sugar drops. This triggers AD, he says, and then his blood pressure spikes. “I was in the ER for hours trying to figure it out. Because of my T3 SCI level, I don’t feel hunger. My blood sugar gets low, sneaks up on me. Then my body overcompensates.”

Pisano says he had an uncle who was really heavy and had diabetes. “He had it bad.” But no one else in his immediate family. “With diabetes,” he says, “you have to be aware of what can happen, so you know what is happening. It’s an invisible disease. One day, boom, it’s there!”

EAT YOUR VEGGIES

Valerie Alexander, Fayetteville, Georgia, thinks she had diabetes at the time of her injury but didn’t know it. Now 45, she was injured at C5 in a car accident 11 years ago. “They told me to watch my weight and my diet, but didn’t mention
any A1C level. When I was released, I went to an internal medicine doctor for diabetes, but my biggest problem was quadriplegia. They put me in an assisted living home and I went into a diabetic coma. My blood sugar level was so high I had to go to ICU.”

Part of her problem was extreme stress. Blood sugar levels go up under stress. Her husband died in the accident, leaving her with two children, 9 and 11. “I was more worried about them than myself. Not even thinking about diabetes. I didn’t realize it was that serious. Really, really, really serious.”

Alexander, who is African-American, knows that people of her race are more susceptible to diabetes, but says it is “more of a diet thing. We do corn bread, sweet potato pie, mac and cheese, cakes. The carb part is what’s bad. My mom loves to cook and her specialty is sweets and cakes.” Now that she uses a power chair, she knows she has an even bigger challenge than her mom had. “How are you going to burn off the corn bread and donuts if you’re not moving?”

It took two or three years to get her diabetes under control. The key, once again, is strict carb control. She eats veggies as much as she can. “And I’ll drink pickle juice or vinegar and it will keep my blood sugar down. If I eat a sandwich, I take off the top bun. I drink three or four quarts of water a day.”

Now living independently, she asked her daughter to come live with her. Her home health caregivers, she says, were unreliable. The new living arrangement had an unexpected benefit: “She put in a Wii game and now I can exercise. You can dance to good music. I went back to the ’70s and ’80s — Michael Jackson, Whitney Houston, Madonna, Boy George. Wii music has it all. I feel exhausted after doing it. Fatigued, but good for having done it.”

On August 22, four months after being diagnosed with diabetes, I had blood drawn for an A1C test to see if I would have to start on medication. By then I had made an attempt to be more active and radically change my eating habits. Like a lot of kids, I grew up disliking veggies. When I finally ate an entire helping of them in the third grade, my older brother, a seventh grader, made a medal for me that announced: “Timmy ate all his peas.”

On the day after my blood draw, my doc called. “Good news! Your A1C level went down to 6.4, back at the pre-diabetic level. If you can keep it there, you won’t have to be on any meds. Good job.”

I’ve been a good boy these last four months, finally putting into practice what my mom tried to pound into my head: “Eat your vegetables!”

**RESOURCES**
- Spinal Cord Injury and Type II Diabetes, www.ncbi.nlm.nih.gov/pmc/articles/PMC3821709/
- Diabetes Mellitus in Individuals With Spinal Cord Injury or Disorder, www.ncbi.nlm.nih.gov/pmc/articles/PMC1864854/

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ROCK 'n ROLL YOSEMITE:
Adaptive Cycling Camp in Yosemite Valley

“This event attracts people who are making the most of life with a disability, creating a very positive vibe that adds to the experience.”

– Lynn Murray

Photo by Bob Vogel
Crossing over a lush grassy meadow on my handcycle, I stop on the wooden walkway to take in my surroundings — new spring growth on the trees is juxtaposed with the sun's illumination of giant granite walls. The thunderous sound of Yosemite Falls drifts in and out with the shifting breeze as I reflect on the past four days of adventure, scenery, friendship and the outstanding accessibility of this iconic national park in the Sierra Nevada mountains of California.

I had joined 12 other participants for the 10th annual Rock 'n Roll Yosemite adaptive cycling camp, held on May 9-12 and hosted by the City of Sacramento, Department of Parks and Recreation, Access Leisure section, through their Paralympic Sport Sacramento club program. I had been hearing great things about this camp for years — for many wheelers it has become an annual rite — and now I knew why.

The camp, held each year in early May when waterfalls are at their peak and park attendance is moderate, is the brainchild of Rick Mason, the cycling coordinator for Access Leisure. “I got the idea during a visit to Yosemite one spring after a heavy snow year promised spectacular waterfall displays,” says Mason, 58, in his 40th year as a C6-7 quadriplegic. “I brought my handcycle and found there are bike and walking trails throughout the valley floor, and it is the perfect way to explore the area.”

ACCESSIBLE CABINS AND TRAILS
Mason’s event, structured around aspects of camping, is designed to enable a wide range of adaptive cyclists to participate. This includes choosing Housekeeping Camp as basecamp because it has tent cabins — three walled structures with a tent roof and beds that are wheelchair height. Also, the nearby accessible bathrooms have roll-in showers with pull-down benches.

“I chose this campground because it has the benefits of camping without having to set up tents and transfer to the ground,” says Mason. “We had eight people the first year, they had a great time, and the rest is history.”

Since eating well is another component of a successful camping trip, but taxing to prepare after a long day of riding, the event included delicious meals prepared by a camp chef.

Each day consisted of a morning and afternoon ride ranging from seven to 15 miles to explore different parts of the valley, guided by Mark Wellman, a former Yosemite park ranger. Wellman, in his 34th year as a T12 para, is best known for climbing Yosemite’s famous rock faces, El Capitan and Half Dome. He now conducts adaptive climbing clinics around the country and has created adaptive climbing gear to accommodate a wide range of disabilities.

During the rides, Wellman explained the geology and history of the park and stopped to point out well-known sites, including Glacier Point, the start of the John Muir trail and, of course, El Capitan and Half Dome. He shared stories and information from his days as a ranger and what it was like to climb the famous monoliths, including how he and his partner got pinned down by storms on Half Dome and a planned nine-day climb ended up taking 13 days, the last of which was done with no food or water.

Wellman also pointed out features that many people miss in their cars but can be fully appreciated from a handcycle, including Bridal Veil Falls, Ribbon Falls and Sentinel Rock.

All the trails we rode on are ADA compliant. Also, the valley has several roads that are marked “shuttle bus only,” but are open to vehicles showing an accessible placard or accessible plates, as well as to cyclists and hand cyclists. There are accessible walking trails next to the roads.

DISABILITY CREATES A COMMON BOND
Late afternoons and evenings were for socializing and reliving the day’s activities. “This is my fifth year participating in the event,” says Lynn Murray, 70, a T10 complete para since 2004. “In addition to the beauty and accessibility of the park, the attraction for me is meeting up with old buddies. Even more cool is meeting new people and hearing everybody’s stories. This event attracts people who are making the most of life with a disability, creating a very positive vibe that adds to the experience.”

Many of the participants had different disabilities, plus there was a mix of veterans and non-vets. Yet, the experience of having a disability, along with sharing adventures in such a beautiful place, meant the quick formation of common bonds.
Access in Yosemite Valley is, in a word, outstanding. All of the trails we handcycled on meet ADA guidelines, including the trail to the base of Lower Yosemite Falls. This means everywhere we visited is accessible by manual or power wheelchair.

The $30 per car entrance fee is waived with an America the Beautiful access pass, which is a free lifetime pass to U.S. citizens who have a permanent disability. And for those wheelchair users who want to explore the park but prefer not to drive, there are free shuttle buses that make regular stops at points of interest — all equipped with wheelchair lifts and tie downs.

If you want to explore by handcycle but don’t have one, there is at least one handcycle for rent at the Curry Village rental stands. Reservations are highly recommended: call 209/372-8319 or 209/372-1208.

 Lodging options in the valley range from tent cabins to the luxurious “Majestic Yosemite Hotel.” Yosemite Valley has three campgrounds with accessible camping sites: Lower Pines, Upper Pines, and North Pines. Some of the campsites have a raised tent pad. There are also accessible campsites in more remote parts of the park, outside the valley. For more information, check the Yosemite Accessibility Guide. Advance reservations are highly recommended for camping or lodging, especially May through September.

Yosemite National Park is open all year, and the best month to visit is May, when waterfalls and spring foliage are at their peak. Also late September and October are great months, since that is when changing leaves turn the valley into a riot of color. These months are also quieter in terms of number of visitors. From Memorial Day to Labor Day the park gets extremely busy.

Although there is more than enough scenic beauty and activities to occupy four days in Yosemite Valley, if you have extra time, be sure to take the drive up to Glacier Point for an accessible bird’s eye view of the valley. Another cool option is to take a day trip over scenic Tioga pass (Highway 120), which meanders through high alpine meadows before a steep descent into Lee Vining and Mono Lake.

Resources
- America The Beautiful Pass Info: www.store.usgs.gov/pass/access_pass_application.pdf
- Lodging Options: www.travelyosemite.com/lodging/yosemite-lodging-experience/

“IT was interesting to see how we all got to know each other during the event,” says Margie Donovan, 54, who worked as a Veterans Affairs visual impairment service coordinator at the San Francisco VA hospital. She has been blind since age 14, and cycles by riding on the back of a tandem bike. “It was obvious that most of the participants were not familiar with folks who are blind, as the first night everybody was overly helpful. By the second night I went up and got my food, and people just continued their conversation, which is what I want — if I need help I will ask.”

At first, the military veterans seemed to gather together in one area, sharing stories about their experiences with the VA. But within 24 hours, vets and non-veterans integrated and began sharing stories about their disability experiences.

This is Army veteran Marv Tuttle’s fifth Rock ’n Roll event. “I keep coming back for the camaraderie,” says Tuttle, 66, a T12 para for 18 years. “All veterans share a common thread that a civilian will never know, and I hope they never have to know, just like people with disabilities share a common thread that non-disabled people will never know. We are all in the same boat, whether we are military or non-military, which makes it easier to form lasting bonds.”

Evenings also included speeches and video presentations — projected on a sheet hung from a clothing line — about other forms of adaptive sports as well as a viewing of Crank it Up, an off-road handcyle documentary produced by Wellman.

Those of us who stayed up a bit later were treated to a star-filled sky, silhouetted by the surrounding granite walls and peaks.

ROCK CLIMBING AND WATER FALLS
On the third day, Wellman brought out his adaptive climbing gear and a few local guides set up a route for us on Chapel Wall. “The route was much higher than my portable climbing wall, and included the opportunity to check out a portaledge, which is the cot climbers sleep on during multi-day climbs,” says Wellman.
“Climbing on real rock, being up a lot higher than the portable climbing wall is very cool,” says Michael Jorgenson, 50, an L1 complete para for 31 years. “Especially sitting on the portaledge imagining trying to get a good night’s sleep 1,500 feet off the ground.” An Army vet from Kerman, California, Jorgenson enjoyed his second year at the event.

Another highlight of the day was riding close enough to the base of Yosemite Falls to be overwhelmed by the roar of water. We were blasted by mist and high-speed winds emanating from the cascade of water completing its 2,500-foot descent down the granite wall.

Donovan had never been to Yosemite before and found it phenomenal. “For me, being blind, the smells and sounds, the textures under my feet when I was walking ... it was incredible,” she says.

“Especially the thundering sound from Yosemite Falls, as well as riding by the Merced River, and the long ride going by Bridal Veil Falls. I love water, so that was especially great.”

The event was probably best summed up by Reese Levasseur, 42, an L1 incomplete para. “It was awesome, beautiful. There was adventure, great camaraderie, and it was great to be around a group of people with disabilities that are enthusiastic about handcycling as well as seeing other things that are possible,” says the former Marine sergeant from Vallejo, California. Then he added a sentiment everybody felt while packing up on the final day. “If I get the chance to do the Yosemite ride again, I will for sure.”

RESOURCES
- Access Leisure and Paralympic Sport Club: www.cityofsacramento.org/ParksandRec/Recreation/Special-Needs. For information regarding camps and Paralympic sports, please contact Program Coordinator Jenny Yarrow at jyarrow@cityofsacramento.org or 916/808-6017.
- Housekeeping Camp: www.travelyosemite.com/lodging/housekeeping-camp/
- Mark Wellman climbing clinics and adaptive climbing gear: www.nolimitstahoe.com

This event was funded in part by a grant from the United States Department of Veterans Affairs. The opinions, findings and conclusions stated herein are those of the author and do not necessarily reflect those of the United States Department of Veterans Affairs.
If you haven’t heard U.S. Representative Tammy Duckworth’s story, a quick YouTube search of her name will catch you up. You could easily start with one of her speeches from the last three Democratic National Conventions, where she eloquently and passionately describes how a rocket-propelled grenade blew up the Black Hawk helicopter she was piloting in 2004 during the Iraq war. That attack left her a double amputee with a severely wounded right arm, and subsequently the experience led her to a career of public service and eventually a seat in the House of Representatives.

But for a better understanding of her appeal and why she is currently leading her opponent in her bid for Illinois’ open Senate seat, you might be better served by watching one of the many videos of her 2013 confrontation with an IRS contractor who had abused his military disability rating to secure beneficial government contracts.

Duckworth starts her questioning of Castillo with a smile and a cordial welcome and then proceeds to highlight how he cynically took advantage of the system, making it clear that “twisting your ankle in prep school is not defending or serving this nation.”

By the end of her time she eviscerated Castillo’s weak defense and articulately exposed problems inherent in the VA’s service ratings. “You broke the faith with this nation and you broke the faith of the men and women who lie in hospitals right now at Walter Reed and Bethesda, at Brooke Army Medical Center. You broke the faith with them,” she said. “And if this nation stops funding veterans’ health care and calls into question why veterans deserve their benefits, it is because people like you have poisoned the public’s opinion on these programs.”

Actions like that, combined with her broad demographic appeal as a female, minority veteran with a disability, make it easy to see why some think Duckworth has a unique opportunity as she continues her political career. “She is somewhat unprecedented in terms of she’s a good across-the-board progressive. She’s good on gay rights, she’s good on equality issues, she’s a veteran,” says Andy Imparato, executive director of the Association of University Centers on Disabilities and a leading voice on dis-

“Despite all the progress we’ve made to date, the one outstanding goal that still remains to be fully achieved is fully integrating the disability community into everyday American life.”

— Rep. Tammy Duckworth
ability on Capitol Hill. “I just see her as someone who can connect with a lot of different constituencies in a way that I don’t know any other politician can.”

**Disability is Part of Her Political Identity**

This November 12 will be the 12th anniversary of the attack in Iraq that changed her life. Four days prior to that, on election day, she will find out if she is to become the first female double amputee ever elected to the U.S. Senate. That’s a pretty intense week, but after her rapid rise to political relevance, Duckworth is likely used to such things.

In 2004 and 2005 Duckworth spent 13 months recovering from her injuries and learning to live with the new physical obstacles facing her. “Every day, dozens of times a day, the medical staff asked me: ‘Tell me about what happened.’ They make you tell your story, over and over again (and then a few more times for good measure), to help you begin viewing your injuries as a chapter of your life instead of a defining characteristic,” she says. “That helps you move forward. My injuries will always be a part of me, but they aren’t all there is to me.”

Doctors amputated her left leg just below the knee, her right leg a few inches below her hip bone, and her right arm was reattached after nearly being torn off. Therapists spent months helping her learn to walk with prostheses and a cane, but she often uses a wheelchair. She still suffers from phantom pain.

She credits visits from former Senate leader Bob Dole and other veterans with helping inspire her to get involved in politics. Her new physical reality was never far from her mind. “One of the ways in which Duckworth stands out is that she had her disability when she started her political career, so her disability was always part of her political identity,” says Imparato. Duckworth has told reporters: “I’m not ashamed I’m in a wheelchair. I earned this wheelchair. I’ve always insisted it’s not something that we hide.”

In her first foray into politics, Duckworth lost a bid for Illinois’ 6th congressional district in the House of Representatives in 2006. She was soon after appointed director of the Illinois Department of Veterans Affairs. In 2009 she left that position when President Barack Obama nominated her to be assistant secretary of public and intergovernmental affairs for the United States Department of Veterans Affairs. She resigned that position in June 2011 to campaign for Illinois’s 8th district. In November 2012 she became the first disabled female veteran to be elected to the U.S. House of Representatives. She won with 55 percent of the vote in an election that drew national attention for insensitive comments about her injuries by her Republican opponent, Joe Walsh.

**Finding Her Way in Washington, D.C.**

Duckworth was appointed to the Armed Services Committee, Oversight and Government Reform Committee and the Select Committee on Benghazi, and emerged as a strong voice for veterans. While she quickly found her political footing, the physical realities on Capitol Hill. “I just see her as someone who can connect with a lot of different constituencies in a way that I don’t know any other politician can.”
Hill weren’t always easy. Lots of elevators and tight official schedules took some getting used to.

“When the Speaker announced that he was going to begin strictly enforcing the 15-minute time limit for votes, most of my colleagues probably didn’t bat an eyelash,” she says. “But for me, it forced a change in how I operate. I have to leave hearings and meetings earlier than other members to ensure I have extra time to make it to the House chamber.”

Educating her fellow legislators about accessibility is important to Duckworth. Even though she can walk with the aid of her prostheses and a cane, she started a policy of turning down invitations to wheelchair-inaccessible events. “I want the organizers to think about what they can do to improve accessibility.”

The citizens of Illinois sent Duckworth back to Washington for a second term in 2014. During her three-plus years in the House, Duckworth has helped secure the passage of key veterans and disability legislation, including the Achieving a Better Life Experience Act, the Workforce Innovation and Opportunity Act and the Clay Hunt Suicide Prevention for American Veterans Act. She proudly cites the latter, on which she was a co-sponsor, as evidence of the importance of bipartisanship. “Our bipartisan legislation will help reduce veteran suicide by increasing access to mental health services at the VA, addressing the shortage of mental health care professionals and improving accountability and care through third-party evaluations,” she says.

Duckworth has earned numerous accolades and awards for her advocacy, including the 2007 Hubert Humphrey Civil and Human Rights Award in 2007 and the 2015 Disability Rights Champion Award from United Spinal Association. James Weisman, United Spinal’s president and CEO, says Duckworth was an easy choice. “She has been outspoken, she has been perfect for people with disabilities, as she encourages them to get into politics, to run for office and to get jobs in government,” says Weisman. “She has just the right approach.”

When accepting the United Spinal award, Duckworth gave a rousing speech encouraging the hundreds of attendees with disabilities to get involved. “My message to the disability community is to continue making your voices heard.”
Never take the progress we’ve made for granted. It’s so important for everyone to get involved, to reach out to their members of Congress and let them know your priorities and how laws such as the ADA have improved your lives,” she says. “One thing I tell everyone thinking of running for office is you have to start somewhere. Whether that’s a state office or your local school board, having that experience of putting yourself out there and speaking up for what you believe in is invaluable.”

We Need a Disability Rights Champion

Duckworth is currently fighting to take her message across Capitol Hill to the Senate, running against Sen. Mark Kirk for the seat he won in 2012. In an interesting twist, and possibly a Senate first, the winner is guaranteed to be a wheelchair user. Kirk mainly uses a wheelchair following a serious stroke in 2012.

Many pundits have tagged the race as one to watch in the battle between Democrats and Republicans to control the Senate. Politico deemed Kirk “the most vulnerable Republican on the ballot in 2016,” in large part because of the higher turnout for a general election and Illinois’s status as a solid blue state. With the extra attention have come the seemingly inevitable missteps. In March the National Republican Committee tweeted, “Tammy Duckworth has a sad record of not standing up for our veterans.” The tweet was later deleted.

Should Duckworth prevail she will find herself in what could prove to be an enviable position. The retirement of outspoken disability advocate Tom Harkin in 2014, along with the 2009 death of Sen. Ted Kennedy, has left a void in the Senate leadership on disabilities. “We need a go-to person,” says Weisman. “With Tom Harkin’s resignation there is not a go-to person for people with disabilities. There isn’t a champion of disability rights in the Senate.”

Imparato, who has bipolar disorder and worked for Harkin prior to his retirement, suggests that Duckworth could fill that void. “I definitely see her as one of the people who is well positioned to pick up the mantle from Senator Harkin and Senator Kennedy and hopefully be a leader in the Senate and our community for a long time,” he says. He is optimistic that legislative attitudes about disability are improving and the opportunity to pass beneficial legislation is on the upswing. “There was a long period where things felt very partisan, and it didn’t feel like we were a priority, and we weren’t making big things like the ADA happen.”

“If you think about the period between 1990 and 2000, arguably the most significant bill that passed that was clearly a disability bill was the Ticket to Work Act, and it just wasn’t that important compared to the ADA. It was fine, but nobody was really excited about it,” says Imparato. “Between 2000 and 2010 the biggest thing we got done was the ADA Amendment Act, which was a big deal and was very bipartisan. Since 2008 when that passed, we’re kind of back on a better path.”

Asked what one change she would make policy-wise to improve the lives of the 57 million Americans living with disabilities, Duckworth responds, “Integration.”

“Despite all the progress we’ve made to date, the one outstanding goal that still remains to be fully achieved is fully integrating the disability community into everyday American life,” she says. Better job training, better jobs and better accessible transportation to get to those jobs are at the heart of her integrated vision. “Most of America may take it for granted, but those of us with disabilities know just how critical reliable transportation is for the ability of Americans living with disabilities to maintain an independent life. What good is a job or a degree without a way to get to class or a meeting?” She supports the Transitioning to Integrated and Meaningful Employment Act, “which would help people with disabilities reach their full potential in integrated, meaningful jobs,” and the Transit Accessibility Innovation Act of 2015 to help realize that vision.
Should She Win the Senate Seat

How much impact Duckworth will have on that goal depends, of course, on the result of the coming election. Should she win, Imparato says to watch which Senate committees she lands on.

“If you look at her House committee status, it seems like her veteran status was more important than any other status in terms of the committees she was put on. When you’re in the House, you don’t have a lot of committees and you don’t have a lot of staff. Now she’s coming over to the Senate, and I think it would be very significant if she goes on Armed Services and Veterans Affairs, which would kind of be the path of least resistance, or if she instead chooses the Health committee or Finance or Judiciary, where she could have a bigger impact on civil rights for people with disabilities.”

Weisman is excited about the possibilities and thinks she can have a wide-ranging impact should she win. “I think she can be great on veterans’ issues because she’s living it, she understands how different your life becomes because she’s living it. She has already spoken on behalf of the rights of people with disabilities. If she’s in the Senate she’ll have an even better platform for doing it.”

Before Duckworth can concern herself with decisions like committees, she has to focus on winning the race she is currently running. Looking back on her time in rehab at Walter Reed, she marvels at how far she has come and how much more she has been able to accomplish than she could have imagined those first few days lying in a hospital bed — including having a baby. Two years ago she and her husband, Bryan Bowlsbey, welcomed their first child, Abigail.

“We have been so lucky to be able to spend time with her and watch her grow,” she says. “So when I get frustrated by the difficulties I face or tired of explaining the realities of living with a disability, I look at all the good in my life and am able to say, “you know, things are pretty good — they could be a lot worse.”

Duckworth’s strong ties to military life make her an obvious choice for Armed Services and Veterans Affairs committees, should she win the Senate seat. But some in the disability community hope she’ll assert herself in other areas that could have a greater impact on the civil rights of people with disabilities.

Daughter Abigail helps Duckworth choose items for a USO care package.
There are myriad reasons why people, both disabled and nondisabled, don’t want to run for office. It’s expensive. It’s intrusive. It’s exhausting. And dealing with party politics can be a pain.

But for those who are willing to stay the course and put up with the rubber chicken dinners, endless cocktail party chitchat, and knowing there are people out there just waiting for you to screw up somehow so it can be tomorrow’s front page news, the rewards can be satisfying.

Lex Frieden, Nick Sposato and Chuck Graham are a testament to those rewards.

PARTY POLITICS

Lex Frieden, widely hailed as an architect of the Americans with Disabilities Act, ran headlong into obstacles when he first tried to enter the political fray. Running as a delegate to the Democratic National Convention in the late 1970s, he made it through the regional election. Next stop, Texas Democratic Convention. That’s where things quickly went south.

“The chairman got up on stage and invited all candidates to join him,” says Frieden, a quad since 1967. “There was no ramp or lift. I went to the front and said I’d like to be considered but couldn’t get up on stage.”

What happened next stunned Frieden. The state chairman told him, “Don’t trouble yourself. We already have our slate selected. The vote is just a formality.”

Frieden was incensed at a process that he saw as anything but democratic. A group of women from the back of the auditorium joined him up front, yelling together with him, “This is not fair!”

Hoping to quell the disruption, the party chair asked Frieden, “What do you want?” Frieden said he wanted to go to the state convention. The state chair said, “I’ll give you my seat. If I do that will you be quiet?” Frieden agreed, and soon after attended the state convention where he was elected to be a delegate to the DNC.

“I was so excited!” Frieden recalls. “Until the state party chair called me about a week out. He said, ‘Mr. Frieden, we know it’s going to be hard on you to go, so we moved you to a reserve position as an alternate delegate.’” And just like that, Frieden was off the slate to make room for a former governor of Texas who wanted to go.

“I was terribly dismayed and disillusioned by the heavy-handedness and outright disregard for democratic principles by party insiders, and I ultimately disassociated myself from the party,” says Frieden. “At the same time, I was attracted to the Republican party by what I perceived then to be a commitment to personal freedom, individual choice and opportunity. Thus, I became a Republican.”

Frieden’s party switch was influenced by Justin Dart, Jr., an influential Republican in Texas at the time, in addition to being a fellow advocate for the passage of the Americans with Disabilities Act. “Justin was a great mentor, friend and confidant, and he convinced me that while many of our colleagues believed that Republicans would never support disability rights, thoughtful leaders like Ronald Reagan, George Bush, Bob Dole, Lowell Weicker, Orrin Hatch, John Chafee and Steve Bartlett certainly would. And, of course they did.”

Disillusioned with the Democratic Party, Lex Frieden became a Republican many years ago, believing that thoughtful conservatives would support disability rights. He was right.
Why are parties important?

“Party affiliation and party volunteerism are important from an organizational and advocacy perspective,” says Frieden, a fixture in his state’s political scene. He also directs the Independent Living Research Utilization program at TIRR Memorial Hermann, which launched the nonpartisan #REVUP America — Make the DISABILITY VOTE Count campaign in February.

“In our political system, parties by and large determine who the candidates will be, and they establish the platforms that project the philosophy and commitments on which candidates stand.”

A WIN BY THE ‘AVERAGE JOE’

When Nick Sposato, 38th ward alderman in the city of Chicago, was a firefighter, he was diagnosed with multiple sclerosis. He kept working for several years, until one day, “I was working back-to-back fires on a 90-degree August day and found I couldn’t get myself off the roof.”

A Democrat, he was always interested in politics and remembers wanting to be an alderman even from an early age. In 2007, after his MS made firefighting difficult if not impossible, Sposato transferred his energies to campaigning for office.

Coming up against a very powerful organization, Sposato ran as an independent with a much looser organization and a much smaller purse — $40,000 to his opponent’s $300,000. “I only got about 25 percent of the vote that time,” he says. Undeterred, Sposato came back again, and in 2011 won his election against a crowded field and without the party’s blessing.

Sposato, who dropped out of college after a year and half, was referred to in a Chicago Sun-Times story that ran during his second campaign as an “Average Joe.” Far from being upset by it, the pride in Nick’s voice is evident. “I went from being a truck driver, to a firefighter, to being the first alderman elected to serve two different wards.” He previously served the 36th Ward, and when its lines were redrawn, won the election to serve the 38th in 2014.

He has tried to keep his MS from being an issue, whether on the campaign trail or in his day to day work, so far with success. “While the media tried to make it one, my MS was never a factor in my election,” he says. Though he’s changed mobility devices — first a cane, then a walker, now a wheelchair — he’s found city hall to be accessible, and his fellow council members and constituents treat him with the same respect as before.

It’s obvious Sposato enjoys his work and is dedicated to the residents of his ward. “I am working 70-80 hour weeks,” he says. “If a constituent wants to meet me, I don’t want to tell them ‘OK, I’ll see you two weeks from Tuesday’ when they’re in my office right now.”

EARNING RESPECT

Chuck Graham wanted to be in the state legislature from the time he was 11 and met his Missouri state representative on a Boy Scout camping trip. A car accident at age 16 left him a T3 para, but never once did he consider a change in career plans.

In 1996, he threw his hat in the ring for the 24th district House seat in Missouri, winning election that year and three times after that, and in 2004 added a term in the state Senate as well.

Graham showed he could and would do anything any other candidate was doing from knocking on doors to putting up signs to attending events. “I think I got a lot of respect,” he says. “People said, ‘Hey, he must want that job pretty bad if he’s out there putting in his own yard signs.’”

Graham is still the first and only wheelchair user elected to the Missouri legislature, a fact Joe Biden was unaware of during a 2008 campaign stop, urging Graham to “stand up and be rec-
ognized” — a highly publicized ‘oops’ that was even the subject of a South Park episode.

That gaffe aside, Graham says he never felt disabled until one day when a bill he was pushing stalled at 71 votes and he needed 82 to get it through. “I couldn’t get up and down the aisles because they were too narrow, so I had to grab my labor friends to whip for me.”

In spite of that experience, he believes it is extremely important for people with disabilities to run for office. “We are the largest yet most invisible minority,” he says. “People think we all want handouts. What they don’t realize is most of us want to work and pay taxes!”

Graham recognizes that running for office is often out of reach for the average American with a disability. “It is really expensive,” he says. “You need to raise a million and a half in Missouri for a job that pays $35,000 a year.”

He is nevertheless quick to tout the value of people with disabilities jumping in. “When we get involved in the political process, we become a beacon of hope not just to people with disabilities, but parents of kids with disabilities.”

A GOOD PLACE TO START
Running for office is hard, messy work. But more people with disabilities are testing the waters because of our obvious need for representation, and volunteering for campaigns is a great entree into the political process. “Let’s say you aren’t ready to run for office but you care about public transit,” says Frieden. “Perhaps you’ll consider volunteering for a mayoral race or a city council race and talk to your candidate about getting a seat on the transit board.”

Graham agrees with Frieden. “When you volunteer for a campaign, you’re building relationships,” he says. “Relationships that will bear fruit maybe years down the road.”

Frieden says we need to engage in politics for the long haul, not for short-term solutions. He recounts how he and a group of disability advocates supported a Houston mayoral candidate back in 1992, asking him to commit to appointing people with disabilities to high level positions in his administration. He agreed, but lost the election.

Fast forward to 2016. Houston inaugurates a new mayor — Democrat Sylvester Turner, the very man Frieden and his colleagues supported in 1992. “Two weeks later, he asked me to serve on the transit board, honoring his commitment from 24 years before.”

Sposato says once you’ve made up your mind, it’s important to be strategic — you can’t just decide to run. “You’ve got to build up a resume. I had a lot of volunteerism on mine,” he says. “Chamber of Commerce. Lions. School Council. I coached the kids’ sports. Volunteered at the food pantry.”

Being a fireman didn’t hurt, either. “People love firemen! If it wasn’t for the generosity and support of my fireman friends, I’m not sure I’d have gotten elected,” says Sposato.

His story is one that resonates. How can a guy who dropped out of college and isn’t even a lawyer become an alderman of not one, but two of the most powerful wards in the city of Chicago? “If I can win an election, anyone can do it. Don’t let anything hold you back.”
A funny THING HAPPEned
ON the WAY to the ROMAN SUBWAY

BY NANCY XIA

L

ast year, my parents and I smashed our
piggy banks and took a two-week va-
cation to travel from Toronto, Canada,
to Paris and Rome.
While boarding the eight-hour flight, my
mind was busy setting rules and expecta-
tions for this vacation: First, I shall become
no more than two shades darker — tan-
ning is not an Asian thing. Second, when
confronted with endless food and dessert,
I shall practice restraint. It could happen.
Lastly, maybe I will meet a “Jack” whom I
will die with in a hopefully romantic, yet
no less fatal, maritime disaster.

Somewhere above the Atlantic Ocean,
I began to think about weightier topics. I
was told there are a lot of cobblestone
roads in Europe. How will my wheelchair travel
over them? Accessibility could be a concern
in many older parts of these cities. And
what about the people, will they be kind?

The LAST BOAT of the DAY
As soon as we left the Paris airport, I real-
ized I should have learned more French, as
Bonjour and Merci did not get us very far.
We were like three giant pandas in a world
of polar bears and it was impossible to com-
municate with the locals for directions.
Fortunately, body language is universal,
and maybe a few lucky guesses, we man-
aged to find our way.

I was mesmerized by the beauty and
majesty of Paris — the creative and deli-
cate minds of the city planners were truly
gifts from the divine. Also, the cobblestone
roads in Paris were not as hard on my
wheelchair as I thought they would be.

After strolling around the city for hours,
I was still going strong in my wheelchair,
but my poor parents had to walk. “Slow
down!” they constantly commanded me,
their weary feet as slow as turtles.

We decided to conclude our day by tak-
ing a boat tour and were lucky enough to
buy tickets for the last boat of the day, which
was scheduled to come in 10 minutes. Then
we realized in order to reach the dock we
had to go down a steep stony staircase that
had at least 20 steps.

It was a downward spiral to hell.

“Looks like the only way to do this is
carrying you on my back,” said Dad. As he
squatted down, I saw his legs were shak-
ing. He had just climbed the Eiffel Tower
30 minutes ago! “OK, hop on,” he said, his
voice betraying his confidence.

“Dad, I don’t think this is a good
idea,” I said.

From afar, we saw our boat slowly ap-
proaching, adding panic to our situation.
Then we heard someone ask in Chinese,
“Do you need help?” That simple line was
poetry to our ears.

We turned around and saw another gi-
ant panda. And oh boy, was this man in-
deed a giant! He was half times taller, thick-
er and younger than my dad. His son and
wife looked up to him as a hero, and I made
it to the bottom of the stairs on his back. We
are forever grateful.

DO NOT SAY ‘PIZZA’
My time spent in Rome was even more
memorable. Most of the subway stations
were wheelchair friendly and the an-
nouncement for each stop was bilingual
— English never sounded so musical back
home in Canada. A visit to the Vatican is
now the pinnacle of my spiritual encoun-
ters, as I was refreshed and humbled by
that experience.

However, what happened afterward was
even more worthy of mentioning.

On our way back from the Vatican, we
were lost. A few miscommunications led us
even further from the nearest Metro. Ask-
ing for directions was an act of humility, as
it hurt our pride when people brushed us
off, and so we took turns.

When it was my mom’s turn to ask for
directions, her strategy was to approach a
young person who she thought might have
learned some English in school.

“So, what did he say?” I asked in hope
and anticipation. “I don’t know! I can’t be-
lieve he cannot say ‘left’ and ‘right’ in Eng-
lish,” said my mom.

Being the empathetic person that I al-
ways am, I scolded her. “We are in Italy! It’s
their country! Name one sign on this street
that you can pronounce,” I said. “DO NOT
say ‘pizza!’”

Finally, it was my turn to give it a shot.

I closed my eyes and decided to ask the
very next person I saw. When I opened my
eyes, a priest was walking toward me. “Do
you speak English?” I asked. “We are trying
to find the nearest Metro.”

“Oh! We are going there, too,” he said,
and I realized he was with five other people.
One of the ladies in his entourage said, “We
asked him the same thing earlier and he is
leading us, too.”

They were all English speakers with per-
fect North American accents! It turned out
the priest was actually from Toronto and in
Rome for a conference. More amazingly,
we would be getting off at the same subway
station! Apparently prayers offered from
inside Vatican City reached Heaven faster
than anywhere else.

The nine of us had a pleasant walk to the
subway station, but when we arrived, we
discovered it was an older one without an
elevator. There was a long staircase leading
down to the platform.

Hell had opened up its bloody mouth
again.

The priest asked if he thought he and his
companions could carry me and my wheel-
chair down, but I was too embarrassed
about the scene that would cause. “Father,”
I said, “I don’t think this is God’s will.”

So he pointed us in the direction of
the next station, which he said had a lift, pressed a kiss on his fingers, anointed my head with a hint of saliva, and drew a cross before departing from us.

Lost, Again!

We walked in the direction the priest had pointed, but could not see the Metro sign anywhere. All at once, our hearts became heavy. We were lost again.

My dad stopped to ask a young mother of two young children for directions, but she spoke no English at all. The only word she understood was the name of the subway station. From her lengthy explanation, of which we could not understand a single word, we figured it would be another long and complicated journey.

My dad suggested we take a taxi, but there were none in sight.

Then, suddenly, that young mother came back and beckoned us to follow her. She wanted to lead us to the subway station! The older of her two children, a little girl around 6 years old, wasn’t happy about this. Fortunately I was not able to understand what she said, but the tone of her voice suggested she was very upset. Her mom’s replies sounded equally fierce and determined.

Occasionally, the young mother turned around and checked to see if we were still following along.

Twenty minutes later, she pointed out the sign for our Metro station and we could not thank her enough. “Grazie! Grazie! Ciao! Ciao!” — that was all the Italian I knew, and it proved to be truly useful. She nodded and walked back in the direction we had just come from. We were incredibly touched.

On my flight home, I reflected upon our adventure. I experienced humanity in different shades and tongues, and came back with a deeper love and appreciation for Canada. Life is just great!
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MY TAKE
It came as no surprise to El Pasans that our city was voted the third best place in America to raise a family. Cost of living is relatively low, the crime rate is below the national average, and the climate is preferred by many, especially by those who have gotten tired of colder climates and shoveling snow off driveways and sidewalks every winter. A combined metropolitan population of 2.7 million people (El Paso, along with Las Cruces and Juarez, Mexico) constitutes the largest bilingual, binational workforce in the Western Hemisphere. There are great work opportunities for bilingual wheelers in the telecommunications sector, such as customer service representatives. Commute times throughout the city are relatively low and accessible housing is abundant. The city continues to grow at an exponential rate allowing for new facilities at both ends of the city with great accessibility.

RECREATION AND SPORTS
The local wheelchair basketball and tennis teams — the Air Wheelers and the Desert Rats, respectively — are always looking for new members. If you prefer watching, the Chihuahuas, the AAA affiliate of the San Diego Padres, play at Southwest University Park, which was named ballpark of the year by USA Today Sports Weekly in 2014. Finally, for outdoorsy people, Wyler Aerial Tramway at Franklin Mountains State Park offers a scenic view of 195,742 acres of rugged rock formations and a spectacular panorama of the majestic wildlife that encompasses the area.

DISABILITY COMMUNITY
The available support for durable medical equipment is not stellar in our city, and therefore we must depend on each other for assistance. Luckily, El Paso has a closely-knit community where we help one another. Wheelers throughout the city help each other out on short notices be it for simple advice, supplies or to help fix a broken chair. Just recently a disabled group known as “DIO” came together to support a talent show composed of primarily disabled participants and donated all ticket sales to the local wheelchair basketball team. Another example of wheelers coming together to benefit the community is the “Greater El Paso District Annual Run, Walk & Roll.” The El Paso Physical Therapy District has been sponsoring the annual event for over 20 years. A portion of the proceeds are donated to the Rio Grande Chapter of the United Spinal Cord Injury Association. Our latest spinal cord injury group initiative is the incorporation of adaptive yoga lessons.

HEALTH CARE
El Paso has four major rehabilitation hospitals and three long-term acute care hospitals throughout the city. However, El Paso has a long history of having a healthcare provider shortage. Doctors, nurses, dentists, and allied health professionals who have decided to call El Paso home are often overworked and over-booked. Ultimately, higher wages and greater opportunities often lure healthcare professionals to other markets. Fortunately, state and city leaders are determined to reverse the trend. An aggressive campaign has been started to recruit healthcare professionals from other parts of the country by offering higher wages and incentives such as bonuses to attract enthusiastic professionals to the area. In addition, a “Health Enterprise Zone” at the newly established Medical Center of the Americas is a new initiative. City leaders project that it will jumpstart the migration of new health care workers to the area.

SKINNY ON THE CITY
El Paso is situated in the farthest west region of Texas on the Rio Grande River, nestled in the southern tip of the Rocky Mountains, also known as the Franklin Mountains. El Paso has been voted one of the safest large cities in the United States, making it an ideal place for wheelers to raise a family.

MUST SEE, MUST DO
Because El Paso is centrally located, inexpensive day trips are a great way to escape the city and venture out to nearby scenic adventures. The small artisan town of Ruidoso, New Mexico, has adaptive skiing facilities that members of our local SCI group flock to during our mild winter months. The nearby Carlsbad Caverns National Park is a great way to explore the natural beauty of scenic rock formations and underground caverns. If camping and fishing is more to your liking, Elephant Butte Dam and nearby Caballo Lake State Park offer accessible camping and fishing spots. Keep in mind that parts of these parks are not fully wheelchair accessible.
After 11 days, 300 miles, three umbrellas and over 90 hours of driving full speed ahead in his power chair, Ian Mackay tilted back in a corner of Portland, Oregon’s Cascade Brewing with a wide, if exhausted, smile. Surrounded by friends, family and the strong smell of sour beer from the keg that exploded minutes before his arrival, he savored the magnitude of what he had just accomplished. But that smile also could have come from the sight of a server laying out a table full of beers in front of him.

On Aug. 13, Mackay, a C2-3 quad, set out from his home in Port Angeles, Washington, determined to raise awareness of the need for more accessible bike and multi-use trails. Instead of simply writing his legislators or trying to get an article in a newspaper, Mackay had devised a more elaborate and much more ambitious plan. Dubbed Ian’s Ride, Mackay’s plan was to roll almost the entire length of the state over a mere 10 days. Traversing 30 miles a day in a power chair would be a feat in itself for anyone, but it was even more ambitious considering Mackay uses sip-and-puff controls and a ventilator at night.

Mackay’s mom, Teena Woodward, wasn’t sure what to think when her son first broached the topic. “He sometimes talks big, so I just said oh really — and waited to see if he brought it up again,” she says. “He did, and I told him I’ll help you if you want to do it. Let’s make it happen.”

For Mackay, the Ride was more than an adventure or a publicity stunt. Before he was paralyzed, Mackay loved riding his bike and found solace in exploring nature. A bike accident eight years ago changed things.

Ian Mackay’s 300-Mile Sip-and-Puff Ride for Accessible Trails

Reinforcing the Need for More Trails

To actually cover 300 miles in such a short period required lots of planning. For funding, Mackay reached out to local businesses and all of the suppliers he relies on for his wheelchair and independence. He was overwhelmed by the response, led by a financial donation by Invacare, media assistance and a new iPhone and Mac Book from Apple.

“I’ve learned that if you feel strongly about something that will help more than just you, people are willing to get behind you. It doesn’t hurt to ask — it’s hard to be willing to say you need help, but by doing that I was able to make this happen.”

With help from the internet, Mackay plotted a route and enlisted his mom and two friends to head the roster of what would be an ever-
Evolving support team. His mom would drive his accessible van, filled with supplies and his backup power chair for when his battery died, while his friends would ride bikes alongside his chair. Other friends, family and supporters would join the Ride when they could.

Rarely slowing below his chair’s top speed of 7 mph, Mackay rolled out as planned on Aug. 13.

With the exception of a blistering heat wave, a few close calls with semi trucks and a lack of accessible trails and paths, almost everything went according to plan. Neither chair broke down and no one got hurt.

“When I first was planning this all out, I did expect a lot more bike paths and multi-use paths, and that wasn’t the case. Probably three-quarters of the Ride was on roads and highways. Whenever we could we’d jump on trails, but there are only so many trails. There were some days that were awesome, where it was 30 miles of trail all day long. Other days we were hardly on trails.”

The disparity made for some sketchy and dangerous situations but helped Mackay’s goal. “It solidified the point. It wasn’t the goal, but it reinforced the lack of bike paths and trails in our state and the need for better access,” he says.

As a result of the ride, the Washington state governor’s office reached out to Mackay, as have numerous other access advocates. He admits to being a little overwhelmed by the outpouring of support and the impact his Ride has made.

“The first thing I’ve got to do when I get home is go through all the emails and the messages,” he says. “I’m going to start talking to the people who know what they’re doing.”

If the Ride’s success has shown anything, it is that Mackay is one of the people who knows what he is doing. Mackay’s longtime friend, Kenny Salvini, founder of the Here and Now Project, is excited to see him embrace his new role as advocate. “You see the quality people that are around him and it is directly proportional to the kind of guy he is,” says Salvini.

It’s all still new to Mackay, but he is excited about the possibilities. “It’s all about getting people in chairs out in the world. There are so many of us, and I was one of them who are home-bound … if I can change any of that, then all of this was worth it.”

Find out more about Ian’s Ride at www.iansride.com.
This year marks United Spinal’s 70th Anniversary. What began in 1946 as a small, determined group of World War II veterans advocating for greater civil rights and independence in New York City has grown into the largest nonprofit organization dedicated to enhancing the quality of life of people living with spinal cord injuries and disorders across the country.

Back then we were just a few dedicated individuals fighting for accessible housing and public buildings. Who could have imagined 70 years later, we would be advising designers and architects nationwide and crafting accessible building codes and regulations at all levels of government?

Where our founders faced widespread discrimination, United Spinal now successfully advocates to expand civil rights and constitutional protections. From writing parts of the Americans with Disabilities Act to improving wheelchair access in New York City and Philadelphia bus and subway systems, we’ve fought tirelessly to help our members realize a full, productive and rewarding life.

Where we once struggled to educate the public about the needs and concerns of people with disabilities, today we are a leading voice for change — raising awareness across the country and around the world with our educational publications such as Disability Etiquette and our award-winning wheelchair lifestyle magazine NEW MOBILITY.

All those years ago it was a challenge simply to understand the variety of issues facing people living with spinal cord injuries and disorders, not to mention finding effective solutions. Today, working alongside community groups, rehab facilities, nonprofits, corporations, and our committed chapters, we are able to make incredible strides to improve the lives of those we serve — engaging thousands of individuals with disabilities and their loved ones annually, offering hope and support when it’s needed the most.

Although times have changed, United Spinal adheres to our founding principle — to provide programs and services that enhance the lives of our members. Today, we celebrate our roots and the hard work of our predecessors, with the hope to continue their tradition of service for years to come.
It’s often said that we live in a global economy. This is particularly true when it comes to innovations in wheelchair technology. It wasn’t that long ago when if a mobility product was made in a country even as close as Canada, we didn’t know about it in the United States, and we certainly couldn’t get it. Today, however, many of the mobility innovations from abroad quickly make their way to our awareness through the internet and social media. And, it’s not too long thereafter that we have access to them. In fact, if you attend an Abilities Expo nowadays, it’s astounding how many of the new, cutting-edge mobility technologies are from other countries.

So, when scouring the new wheelchair technologies from abroad, what are the hottest of the hot?

**Formula 1 Tech in a Folder**

Motion Composites’ Veloce, from Quebec, Canada, might be the most high-tech folding ultralight ever designed. Starting with T700 high-modulus carbon fiber from the Formula 1 industry, the Veloce is a molded masterpiece, combining both the rigidity of a box frame and the sleekness of a cantilever frame. Capitalizing on carbon fiber’s ability to create contours, welds and abrupt seams are replaced by wicked curves that Motion Composites refers to as the “Mantis” frame. Such an exotic material and frame design doesn’t just add up to great responsiveness, but a scant complete chair weight at under 18 pounds — very light for a folder. Despite the Veloce’s high-end attributes, it’s remarkably adjustable, featuring all of the tailoring of a traditional ultra-light folder — from seat angle to center-of-gravity to seat-to-floor height, and so on. With so much technology and awesome adjustability, one might be surprised at the exceptionally reasonable MSRP: $4,795.

**The World’s Lightest Ultra-Light**

In the realm of rigids, the carbon fiber Panthera X from Sweden claims to be the world’s lightest ultra-light at just over 10 pounds complete, with a transport weight of 4.6 pounds. If seeing is believing, this writer, indeed, has never felt a wheelchair anywhere as light. The secret to the Panthera X’s insanely light weight is in its minimalist carbon fiber frame and backrest. Arguably, no chair features more use of carbon fiber, with fewer components. And due to the forming possibilities of carbon fiber, the Panthera X is as sleek and sexy as it gets — the Ferrari of ultra-lights. With all that said, it’s not a chair for those needing adjustability, as all is very custom and fixed, nor is it for those who aren’t sitting on thick wallets, with a U.S. MSRP of around $10,000. I guess the Ferraris of wheelchairs aren’t cheap, either.

**A True Spine for Your Spine**

The Tarta backrest — imported from Italy by Stealth Products — is revolutionizing back support for wheelchair users. Traditionally, even the highest-end backrests are simply a solid surface with some fixed shaping and contours. The Tarta backrest is the complete opposite: it’s based on a mechanical spine and ribs, replicating the human anatomy. Just as the human spine is formed of vertebra, so is the center of the Tarta backrest. It bends, curves and flexes like your spine. By loosening the minimal hardware on the Tarta’s spine, it can bend rearward for lumbar tailoring; it can bend forward for kyphosis tailoring; and it can simultaneously curve left or right, even in an S shape to address various forms of spinal curvature. Further, because the Tarta’s spine uses individual pads at each vertebra instead of a solid
pad, it is height-adjustable and allows positioning of each pad for exact support, with the ability to work around scarring or protrusions. From the spine, ribs extend for lateral support with the same type of adjustability, conforming to and supporting virtually any postural asymmetry.

Not only is the Tarta arguably the most adaptable backrest ever engineered, it has one more unique feature. Once fit, all can be locked in place for solid support, or its unique structure can allow dynamic movement, so it flexes with your movements, reducing fatigue and strain for some. Whether you have extreme postural complexities, want a truly customized backrest or the ultimate in a sports backrest, the Tarta covers it all.

The Ultimate Balance in Power Assist

Making its way to the United States from France is AutoNomad Mobility’s Nomad power assist add-on for ultra-light wheelchairs. The Nomad is traditional in that you add on wheels with hub motors, a battery pack and a joystick. And, yes, you can switch between push rim activation or joystick control. However, here’s what differentiates the Nomad from every other power assist system: the Nomad features a self-balancing mode, where you can not only sit on a wheelie, but drive over curbs and the roughest terrain on only the rear wheels. We all know that the limiting factor in ultra-light propulsion can be the front casters digging in and catching. The most coordinated, skilled ultra-light users master the art of the wheelie to traverse curbs and such. By using gyroscope technology, the Nomad takes the specialized skill and risk out of wheelie-propulsion in an ultra-light. At the push of a button, the Nomad self-balances, and with the joystick drives as such, including up and down curbs, over grass and rough terrain. It’s not sold in the United States yet but is on its way, so visit their site or jump on YouTube to see this astounding innovation.

As wheelchair users, global innovation dramatically improves our lives because we don’t just get the talented minds in our own country, but benefit from the innovations of all of humanity.

Resources

- Motion Composites, www.motioncomposites.com, 877/667-6811
- Panthera, www.panthera.se, 855/546-0711
- Stealth Products, www.stealthproducts.com, 800/965-9229

Q. I’m 44 and in my 20th year as a T8 paraplegic. I recently found out I have Charcot’s spine [June 2016 New Mobility] and my L1 vertebra has seriously deteriorated. I was referred to a surgeon who wants to extend my rods down to L3. He says he has done lots of this type of surgery, but hasn’t done it on someone with a spinal cord injury.

In the X-rays my spine is nice and straight, and it isn’t causing me any pain. If anything I seem more flexible, so I’m unsure whether or not I really need the surgery, and if I do, if this is the best surgeon to do the job.

I feel kind of weird asking for a second opinion, sort of like I’m going behind my surgeon’s back. On the other hand I don’t want an unnecessary surgery or end up worse off than I am now. How do I find the best surgeon for my condition? And how do I go about getting a second opinion?

— Todd

B. ecause it is common to put doctors, and even more so, surgeons on a pedestal, questioning their recommendation, and/or seeking a second opinion can seem daunting, which is unfortunate because lack of questioning and getting second opinions sets up the potential for a poor outcome — bad for patient and surgeon alike. The medical professionals I asked said questions, including asking your doctor to consult a physician trained in physical medicine and rehab, or seeking a second opinion, should be welcomed by your physician. If it isn’t, that is a red flag.

“The first thing to remember is to treat each doctor appointment like an interview process. Don’t be afraid to ask questions,” says Andreanna Lawson, RN, of the Craig Hospital Nurse Advice Line.

To find a top surgeon, start by finding one that specializes in the type of surgery you are having done, such as spine or joint (shoulder or hip), rather than a general orthopedist, says Dr. Douglas Garland, an orthopedic surgeon and former director of neurotrauma at Rancho Los Amigos Rehab Center. Garland advises that you want a specialist who performs a minimum of 50 or more of that type of surgery a year. Also, top surgeons often come highly recommended from other doctors, as well as from nurses and therapists (PT and OT) and former patients.

Unfortunately, part of finding a surgeon comes down to your insurance carrier and ability to travel, says Garland. However, you can try making a case to your insurance company for going “out of network” if they don’t have a comparable surgeon in their system. If travel is an issue, be sure to compare the temporary burden of travel to where the best surgeon is with the importance of having the best chance at a good surgical outcome, especially for more complex surgeries.

“These days you can research the web for medical centers and specific doctors that practice there, including information on their training, background, area of specialty and qualifications, which makes finding the best surgeon much easier,” says Garland.

First, says Garland, whether it is a new spinal cord injury, acute injury, or chronic problem, contact one of the Model System Centers — hospitals that do collaborative research on SCI and provide information and resources to people with SCI, their families and health care professionals (see resources).

Additional excellent places to find top surgeons are university teaching hospitals, says Garland. For instance, University of Washington, in Seattle, has a medical center with a prominent Physical Medicine and Rehab program. Search “University of Washington Medical Center” and their page comes up. From there you can fine-tune your search to SCI or specific types of orthopedics (such as spine). You’ll see a list of their physicians, training, background and qualifications.

Kathleen Dunn, clinical nurse specialist and rehab case manager, adds, “Surgeons who practice in trauma centers are usually the most experienced in spinal surgery, and this includes a lot of teaching/university hospitals.” Another way to look up a top surgeon is to ask your primary care physician or your PM&R doc — they often know the experts in this area and can make a referral, says Dunn.

“It is important to find a surgeon who either has good knowledge of SCI or is willing to consult with a PM&R doctor,” says Lawson. Craig Hospital has a consultation system for surgeons to consult with PM&R physicians via the Craig Hospital CNS Medical Group — eight on-site physicians whose full-time practice is spinal cord and brain injury rehabilitation. “If the surgeon is willing to do this, it is a big plus in their column,” says Lawson. “It’s a red flag if your surgeon isn’t willing to do a consult, and perhaps, time to seek a second opinion.”

“Before your appointment, prepare a typed list of specific questions about the problem you are having. Keep the questions succinct and to the point,” says Lawson. “Be sure to write down the answers the physician gives you, while he or she is giving them.” Dunn adds that it is important to ask how many of these surgeries they have done on a person with chronic SCI. “Don’t be their first, if at
all possible,” she says. “It is also appropri-
tate to ask how many of these surgeries
the doctor does in a month or a year.
For most surgeries, if it is less than 10 a
month, I would look elsewhere.”

As far as second opinions, Dunn says
a surgeon should not be threatened or
upset if you tell them you want another
opinion, and some may even be able to
give you some referrals. “My preference is
that the physician with the second opin-
ion practices at a different hospital or in a
different group practice than that of
the first surgeon if at all possible.”

When it comes to seeking second
opinions, Dr. Jon Arnow, 60, a retired
ear, nose and throat specialist and
surgeon from Reno, Nevada, in his
16th year as an L1 incomplete para,
concurs with Dunn. “As a surgeon, I
can say that a skilled, confident phy-
sician will be fine with their patient
seeking a second opinion,” he says.
“In fact a second opinion, or rather a
referral from another surgeon, saved
me intolerable pain.” It turns out his
pain was emanating from aggravated
nerve roots caused by poorly aligned
rods installed to repair lumbar spinal
damage that was caused by years of
mono-skiing. Surgeons in the Reno
area said there is nothing more that
could be done for his unbearable pain.
However, one of his previous surgeons
has a brother who is a spinal surgeon
at UCSF Hospital in San Francisco.
“He got me in to see their top spinal
surgeon, Dr. Sigurd Bervin. He did an
extensive surgery, including custom-
formed rods. He managed to straighten
my spine, and the nerve root pain
in my hip is gone.”

Arnow adds that unless it is an emer-
gency situation, take your time and
research your surgeon. The extra time
you take researching your condition as
well as your surgeon, and seeking sec-
ond opinions — which may end up say-
ing “the surgeon you are with is the best
in the business” — gives you the highest
probability of a successful outcome.

The last but not least word on second
opinions comes from Eric Stampfli, 58,
from Danville, California. Stampfli has
had too many surgeries to count in his
40 years as a T11 para, from skin flaps to
a secondary spinal fusion. “Although the
web is a great resource to find a first or
second opinion, I’ve learned that among
the best resources is asking therapists,
X-ray technicians, and nurses as well as
other wheelers,” he says. “They are a valu-
able source of information because they
see the outcome of a surgeon’s work, or
in the latter case, quite literally ‘where the
rubber meets the road.’”

For more information and questions to
ask prior to a major surgery, see “Hospital
Stay Survival Guide” in the March 2013
issue of New Mobility: www.newmobility.
com/2013/03/paramedic-hospital-stay-
survival-guide/.

Resources
• Charcot’s Spine, a Potential Complica-
com/2016/06/charcots-spine/
• Craig Hospital Nurse Advice Line, 800/247-0257
• Craig Hospital CNS Group, craighospital.
.org/about/medical-staff
• Model Systems, www.msktc.org/sci/
model-system-centers

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There are a lot of news items and Hollywood movie scripts where the story goes like this:
Crippled person thinks being crippled really sucks so he/she expresses a wish to die. The community rallies around said cripple in the name of staunchly defending his/her right to make this “dignified choice.” Cripple dies a beautiful death. The end

But there aren’t a lot of news items, and definitely no Hollywood movie scripts, where the story goes like this:
Crippled person thinks being crippled really sucks but he/she doesn’t want to die. The thing that sucks most about being crippled, this cripple thinks, is that in order to get your butt wiped every day you have to move into a stinkin’ damn nursing home. The cripple expresses a wish for there to be a publicly-funded community support network through which cripples can live in the community with everybody else and hire friends and neighbors to be their butt wipers of choice. The community rallies around said cripple in the name of staunchly defending his/her right to make this “dignified choice.” Historic federal legislation is passed creating a nationwide, publicly-funded community support network and all the cripples move out of nursing homes. The end

Wow, imagine if Hollywood was to make a movie based on the butt wiping scenario. Who would play the crippled protagonist? Tom Hanks? Julia Roberts? But it’s a waste of time even thinking about it because it ain’t never gonna happen no how. It would be a box office disaster. The suicide scenario has a nice, easy-to-follow dramatic arc: The story of a handicapped man’s bold quest to die with dignity. But the dramatic arc for the butt wiping scenario is all zig-zaggy and complicated: The story of a handicapped man’s bold quest to get his butt wiped.

Plus, it brings up a topic polite society is very uncomfortable discussing publicly, which is wiping the butts of cripples. Polite society is much more comfortable publicly discussing how to help cripples die.

Yeah, that butt wiping scenario is all sunny and idealistic and all, but Hollywood fantasy doesn’t work that way. Reality doesn’t work that way either. If cripples want to die, there are plenty of well-funded groups with names like The Compassionate Choice that are eager to help turn our death wish into reality, like ghoulish travel agents. But there is no such dedicated volunteer brigade ready to answer the SOS calls of cripples who just want to get their butts wiped.

Maybe someday our culture will evolve to the point where there are well-funded organizations with butt wiping as their mission. They will have names like Choice and Compassion. Or maybe there will be a new government volunteer service program mobilizing citizens for that same hygienic purpose. It can be something like Americorps. University campuses would be fertile recruiting grounds. I’ve even got a catchy recruitment pitch: Sign up for a two-year stint after graduation and “wipe away your college debt.” This butt wiping service corps could also be used as an innovative prison work release program. Serve on a community butt-wiping crew and earn points for good behavior. I think it beats the hell out of working on a chain gang, though not everyone will agree.

But again, reality doesn’t work that way.

If you’re looking for someone to grant your death wish, you’ll find plenty of sympathizers. But the best bet for many cripples who are looking for someone to grant their butt wiping wish is to rub the hell out of an oil lamp and hope a genie emerges. But even then the genie will probably say, “Uh, sorry, but that’s one thing I won’t do. It’s too yucky. But how about I give you a pony instead?”

And forget about asking Santa Claus for that kind of help. He’s got to draw the line somewhere, too. You’ll probably get further asking him to smother you.

The least polite society can do for all the cripples, both real and fictional, who want to have their public death wish fulfilled, is present them with an award for sportsmanship. Because that’s what they’re doing. They’re being good sports. They allow everyone to continue to avoid having a national dialogue about butt wiping, which is a very sporting thing to do.

If these sportsmanship awards are presented with enough high-profile pomp and circumstance, it may convince other cripples to be good sports, too.
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BACKBONES’ REVECA TORRES TAKES ON BP

I saw a BP [British Petroleum] ad highlighting the sponsorship of five Paralympian athletes. I was very happy to see this and then immediately wondered if these disabled athletes are able to pump their gas. Is it a daunting task as it is for me? For many of us with disabilities, exiting our vehicle and navigating gas pumps is very difficult. For others with limited dexterity and reach, like myself, it is an impossible task. The law requires every gas station to pump my gas when there is more than one employee on duty, which has really not helped much in my case. …

BP sponsors Paralympics — great, keep it up! Please continue to do so because they need you! … However, the core product BP offers the public is not very accessible to 15 million drivers with disabilities.

— Reveca Torres, “Olympic-sized Fail by BP — Sponsoring Paralympic Athletes but are they pumping their gas?” HuffingtonPost.com http://tinyurl.com/gtxvdnr

LET YOUR GR-R-REAT OUT

This gr-r-reat commercial that aired during the Paralympics shows Frosted Flakes mascot Tony the Tiger encouraging a young chairskater to hit the skatepark. Watch on YouTube:youtu.be/neph9_Zwyw4

I’m currently at 36,000 feet and reflecting on the last two weeks of Rio. I shot over 10,000 photos. The last 1,000 were some of the most exciting I’ve ever experienced as the Team USA Wheelchair Rugby team unfortunately came up one goal short in a double overtime loss to Australia in front of nearly 13,000 vocal spectators. Not the outcome the team wanted but they gave every fan their money’s worth in a thriller that was truly a nail biter. No kidding, I had to remind myself to breathe more than once.

— New Mobility photographer and community partner Loren Worthington, posting to Facebook from his plane ride back home to Phoenix from the Rio 2016 Paralympics. Look for more of his Paralympics photos in our upcoming December issue. Follow him on Twitter @rollingphotog.
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