



NEW MOBILITY



THE MEMBERSHIP PUBLICATION
OF UNITED SPINAL ASSOCIATION



PERSON OF THE YEAR:
**Colorado State
Representative
David Ortiz**



Giving Back Helps Us Give More

Since 1946, United Spinal Association has been there for members like you, ensuring that life on wheels is more accessible, affordable, and offers more opportunities for living fully.

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You can also call us at 800/404-2898, ext. 7203.

- \$10 pays for metro card for a member advocate to meet with their elected officials in Washington, D.C. during Roll on Capitol Hill.
- \$20 pays for a year's printing and postage for a subscription to *New Mobility*.
- \$30 provides a New Beginning Backpack filled with resources to someone living with a new spinal cord injury.

Your donation helps United Spinal continue to offer our members resources and advocacy that make life better by providing priority access to personalized problem-solving for living with spinal cord injuries and disorders, a subscription to our award-winning membership magazine *New Mobility*, and other valuable benefits, including representation in local, state, and national advocacy.



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COVER STORY

PERSON OF THE YEAR 26

Recently reelected Colorado state Rep. David Ortiz proved himself a dedicated public servant in his first term by sponsoring or co-sponsoring an astounding 40 bills, several of which aim to improve the lives of people with disabilities. One of his biggest achievements, a Right to Repair law, could eventually change the face of wheelchair repair across the nation. Also honored: retiring U.S. Rep. Jim Langevin, our quad in Congress for 22 years. By IAN RUDER.

Cover and Contents Photos by Bear Gutierrez



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BULLY PULPIT

By Ian Ruder



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AN SCI SOS

During a recent struggle with some especially problematic sediment in my suprapubic catheter, I saved one of my used catheters so I could show my new urologist exactly what I was dealing with. After two decades of living mostly in harmony with the flora that called my bladder home, something new had evolved. Unlike the easily broken up sediment I was used to, the new entity had a sticky, firm texture that was particularly suited to blocking my catheter.

I'd described the situation to my urologist on my previous visit, but I sensed that without seeing the white goo, he couldn't fully grasp how problematic it was. Bringing him the physical culprit seemed like the perfect solution. I'd be the Watson to his Holmes, providing the missing evidence we needed to close the case. I pictured his eyes lighting up when I showed him the Ziploc bag with the grimy tube. He would yell, "To the lab!" and we'd beeline to his CSI-like backroom. We'd run tests on the sediment and devise a plan to treat, and hopefully, get rid of it.

I handed over the bag, but before I could even play out the above scenario in my head, he was handing it back to me. "Oh yeah, sorry, that's great, but we can't actually do anything with that," he said.

Nothing?!

"Isn't this exactly what you're supposed to be doing? Who else is going to tackle urinary-related problems?" I asked myself. I knew my fantasy scenario was over the top, but I'd never considered that the urologist's office would be as ill-suited to analyzing the sample as I was at home.

I must have looked completely lost because he started trying to explain. "We don't have any way to analyze the sedi-

ment. We can send out a urine sample."

I wish this was a freak incident, or maybe just a bad doctor. Sadly, conversations with other wheelers and hours of scouring online forum postings and medical journals confirm that is not the case. Lots — if not the majority — of us are suffering from the same thing: a medical system that, at best, is ill-prepared to respond to our needs. At worst, it simply doesn't care about us.

Whether it's sediment or pain or skin, we've all run into problems that the medical world's traditional answers and approaches simply don't fix. Our issues are often too niche and too mundane to attract researchers or research dollars. Try finding a recent research study on successful treatment techniques for bladder sediment and SCI. Good luck.

Yet these are the very issues that impact our daily quality of life the most. How many lives would be improved if we could steal just one out of every 10 cure researchers and shift their focus to bladder, bowel and skin? Or if an even smaller percentage of general practitioners focused more intently on SCI-related issues?

Don't get me wrong, I'm all for cure research and its future potential, but a lot of us have pressing and potentially serious problems right now. Today.

As long as medical priorities don't change, we'll keep paying the price. For me, the bill for not being able to diagnose the sediment came quickly. A couple of weeks after my doctor visit, the repeated blockages led to a UTI, a trip to the emergency room and a week in the hospital. That's thousands of dollars and hundreds of hours of my life that I'm not getting back. Can't we do better?



BEHIND THE STORIES

With Ian Ruder



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CURB FREE WITH CORY LEE
ROLLIN' RNS
ROOTED IN RIGHTS
SPINALPEDIA
SPIN THE GLOBE
WHEELCHAIR TRAVELING

FEATURED WEB PARTNER:

Find fantastic accessible destinations and resources at Ashley Lyn Olson's long-running website, Wheelchairtraveling.com. Created in 2006, the site works to empower people with limited mobility to experience the world of accessible leisure and adventure travel.



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It's always a pleasure to work with photographer **Bear Gutierrez**, and I was thrilled when I heard he was available to shoot Rep. David Ortiz for this month's cover. I'd forgotten that the two Coloradans had already worked together when Gutierrez shot a series of stunning profile photos for Craig Hospital (see "Redefining Possible Revisited," Sep. 2020). That photoshoot took place long before Ortiz was elected a state representative in 2020. After reconnecting, Gutierrez was impressed by Ortiz's comfort and mastery of politics. "He's one of those people that run circles around everybody with how hard he works," Gutierrez says. "He's an Energizer Bunny."



I'd never heard of the Access City Award until **Emily Yates** pitched a story about it, and if I'm being honest, I didn't know that Luxembourg City — the winner of the 2022 award — is the capital of Luxembourg until I read her pitch. Thankfully, over many years of assignments, I've learned I can count on Yates for thoughtful, fresh stories that are ideal for our community. "I've always got my eye open for fun places to go and novel things to check out," she says. Yates, who lives in Glasgow, brings that same approach to her job as the head of accessibility and inclusive design at human-centered design agency, Mima Group Ltd.

Catherine Tyink met Jared Fenstermacher through a Facebook post asking for support in his effort to complete the Appalachian Trail using a wheelchair. Tyink, who is nondisabled, spent a week hiking the trail with Fenstermacher. "Even though it was hard and even crazy at times, it was a good kind of struggle," she says. The experience gave Tyink a crash course in SCI life and Fenstermacher's favorite sport: wheelchair mushing. "Deep diving into wheelchair mushing, I was swept up with the ascetic beauty and incredible bonds between owner and dogs — and frankly impressed by their trust in the dogs to not throw them from their chairs!" she says.



Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org

United Spinal's Resource Center provides information on any aspect of living with SCI/D. Contact: 800/962-9629; unitedspinal.org/ask-us; 120-34 Queens Blvd, Suite 320, Kew Gardens, NY 11415.

“An accessible home becomes part of your being.”

NOV-DEC 2022

Building an Accessible Home to Fit Your Life

Live and Learn: An accessible home becomes part of your being. Forty years ago, after buying a three-story house, I knew it was a mistake. I swore the next one would be a ranch, which happened 22 years ago. The house cost \$150,000, and I spent another \$100,000 widening doors, adding a garage wheelchair lift and accessible bathroom, replacing the carpet with tile and hardwood floors and adding a door opener. Two years later, \$23,000 more for an outside, concrete wheelchair-ramp with a switchback design and central garden feature (built to last). Stainless steel door kicks, corner reinforcements, door pulls and toilet supports were added as needed. For instance, shower bars were added after I broke my leg in the shower. You learn what was missed from accidents and setbacks. I got a chairlift two years ago and can now explore the basement. I put my first TiLite downstairs for roaming around. It's a never-ending process. Next year I'm lowering the kitchen island and installing a sink and cook surface. Maybe a garden-to-deck wheelchair lift someday.

Stephen Pate
Newmobility.com

Dreaming Big About Little Spaces

Can't Wait to Incorporate: I just read your article and want to thank you for sharing your perspective on how you want your living quarters to be. I got several ideas from your short article that someday — hopefully soon — I'll

be able to incorporate into my living space. For all the wheelers out there: Be open-minded about your space.

Having articles like this one sure is eye-opening in many ways. The part I like best is that Regan's guests have to adjust to her space and not the other way around.

Sharon Omachel
Newmobility.com

Make Life Easier: When I did a bath renovation, I removed the bath and replaced it with a nice shower with great grab bars, a nice bench, a shower and hand-held wand with easy access to controls for me or a standing shower user. I also replaced a plain toilet with a toilet/bidet combo and grab bars on either side. All towel bars are reinforced grab bars so they serve more than one purpose. I also added a stacked washer and dryer to my bedroom closet which shares a common wall with the bath. All plumbing and electrical updates were done within the same wall, which was really great. Make your updates meet your needs, do them once, do them right and don't skimp. Make your living situation easier, if you can.

Nancy Bergstrom
Facebook

12 Products to Make Every Room in Your House More Accessible

Tech Triumphs: These products are great! And as someone who works at Open Sesame (Door Systems Inc.), I know their system can be installed for a lot less, depending on who is doing the installation. Plus, they now have better technology and the ability to be connect-



ed to a voice activation system. Amazing to see how the technology comes along and hopefully helps people a lot.

Charlie
Newmobility.com

Why Some Wheelchair Users Wish They'd Chosen a Colostomy Sooner

Irrigation Helps: Great description of pros and cons of getting a colostomy, though you don't mention irrigation as a way to manage it. With irrigation, it can eliminate constant output during the day and lower the chance of gas. There are also some great clothing hacks that can help (especially women, who want to wear a variety of clothes) so it's less noticeable or not at all.

Tricia
Newmobility.com

Problems Possible: The surgeon told me it would make my life easier. I had some doubts. I'm a T4 complete para and work on cars. I told them how I move around and everything I do working on them. They said that you can do anything with one. Then they tell you, well you shouldn't do *that*. They also fail to tell you that you are highly susceptible to getting a hernia. Plus, they cause spasms right out of surgery. The surgery to repair it is complicated and not a sure thing to fix it.

Jon Jeffers
Newmobility.com



REFRAMED

by Reveca Torres



TIME OF DEATH

I enter the room in my squeaky chair, and people with hunched shoulders look up at me, teary-eyed. Slowly I move toward photo displays showing a whole life. I gaze between mourners outfitted in shades of black and catch a glimpse of the casket. Lying there surrounded by flowers, a stuffed animal and an Aaron “Wheelz” Fotheringham action figure, my friend seems like he might just smile and laugh his typical, full-bodied “Kee, kee, kee.”

Having been injured at a young age, I’ve grown up assuming I’d fulfill future goals and live a long life, but I’ve experienced the deaths of my disabled peers as a teen, in my 20s, 30s and now 40s. Although modern medicine and technology have made it possible for people with disabilities to live longer, in truth, we SCI folks know life can change in an instant, and just one small health complication can domino into disaster and even death.

It scares me that death could cut my time short, and that I might not get to do everything I dream of. But at the same time, I’m cool with whatever comes. Life will continue without me. I think about what kind of tree will be planted where my remains lie and if my wheelchair will end up existing eternally in a landfill. Who will look through my stuff and put together the pieces of who I was?

I am saddened when I lose friends who were advocates helping individuals with disabilities or the disability community at large. Yet I am happy and proud to have known them, learned from them and worked alongside them. My hope is that when I am no longer living, I too will have left sprinkles of goodness in this world, and my loved ones will imagine me smiling or laughing.

Airbnb Aims for More Access

With castles, treehouses and dome homes, Airbnb's new Adapted homes category makes finding the accessible vacation spots of your dreams easier than ever.



The Adapted homes category debuted with 1,000 listings that have, at a minimum, step-free access to the home and step-free access to at least one

bedroom and bathroom, plus at least one accessibility feature in the bathroom, whether that's a grab bar, a roll-in shower or a shower bench.

The goal isn't to provide units that will work for every wheelchair user but to provide a baseline of access, hosts who've intentionally modified their homes with access features and enough variety that you can find something that works for you. "Those features are very useful and sometimes critical for people, but we also recognize that people's needs are very different," says Suzanne Edwards, the accessibility standards lead at Airbnb.

Every Adapted listing has photos pulled from 3D scans of the home, so you can see room setups and accessibility features. Adapted category listings have doorway widths noted on the photos, and unit floor plans with dimensions so you can get a sense of layout and whether you and your family will have enough space to move around.

Read more on NewMobility.com or check the listings at Airbnb.com.



Off Trails, on Track(chairs)

The great outdoors is becoming more and more accessible for adventurous wheelchair users, thanks to a growing number of states providing all-terrain wheelchairs. *The Washington Post* spoke with some of the advocates and policymakers who have secured fleets of these expensive vehicles so a broader audience can appreciate what Mother Nature has to offer.

South Dakota, Minnesota and Georgia all have programs up and running, and Aimee Copeland Mercier, the woman behind Georgia's program, hopes to launch in North Carolina soon. "The goal is to alter the USA," she says. Read all about the exciting expansion at washingtonpost.com/travel/2022/11/08/parks-trails-all-terrain-wheelchairs.

Foldable and Fashionable, but is it Functional?

In a win for graceful looks and the promise of ease-of-use, influential design magazine *Dezeen* has awarded a Japanese design firm with its Product Design of the Year for a new lightweight, foldable wheelchair. With a low, spare profile that complements a stylish S-curved frame, the Wheeliy 2.0 from Quantum Inc. passes the look test with flying colors.* For ease-of-use, the Wheeliy 2.0 checks a lot of boxes: It is a foldable and light 18 pounds. Yellow accents indicate where to place hands for lifting and folding. Footrests flip up. Armrests press down to activate brakes. Whether the Wheeliy 2.0 was actually designed

with the needs of wheelchair users in mind and whether it will ever come to market or vanish like so many other high-design wheelchairs remains to be seen. *Dezeen* also awarded two other accessible designs, including a wearable vibrator to help with erectile dysfunction. Read more at dezeen.com/2022/11/16/dezeen-awards-2022-design-winners.

*Quantum Inc. is not affiliated with Quantum Rehab.



WATCH

THEN BARBARA MET ALAN TELLS THE REAL-LIFE STORY OF TWO DISABLED CABARET ARTISTS, BARBARA LISICKI AND ALAN HOLDSWORTH, WHO FALL IN LOVE AND BECOME THE DRIVING FORCE BEHIND THE DISABLED PEOPLE'S DIRECT ACTION NETWORK. WAVING "PISS ON PITY" SIGNS AND USING PINK HANDCUFFS TO CHAIN THEMSELVES TO INACCESSIBLE BUSES, THEIR PROTESTS PUSHED DISABILITY RIGHTS INTO THE SPOTLIGHT AND LED TO THE PASSING OF THE U.K.'S DISABILITY DISCRIMINATION ACT. DISABLED ACTORS RUTH MADELEY AND ARTHUR HUGHES ARE PERFECTLY CAST AS LISICKI AND HOLDSWORTH. **THEN BARBARA MET ALAN** IS A BBC TWO FILM AND IS AVAILABLE TO WATCH ON NETFLIX.

Women Wow at Rugby World Championship

A record 13 women suited up for October's 2022 Wheelchair Rugby World Championship in Denmark, highlighting the evolution of the traditionally male-dominated sport. The top four finishers — Australia, USA, Japan and Denmark — all had at least one woman on their rosters, and female players saw significant court time in medal rounds and the most competitive games.

Sarah Adam, of Naperville, Illinois, and Liz Dunn, of Warren, Pennsylvania, became the first women to compete for USA Wheelchair Rugby at a major championship. More importantly, their strong play helped USA Wheelchair Rugby win the silver medal, the team's best finish at the event since 2010, when they won gold. "After all the work we put in the last year, it was great to finally take the court as a team and show everyone we were there to win," Dunn says.

Read more about their historic contributions and their thoughts on the changing game at newmobility.com/first-u-s-women-compete-in-wheelchair-rugby-world-championships.



Sarah Adam of the United States pushes against Great Britain at the 2022 World Wheelchair Rugby Championship in Denmark.

Neilsen Foundation Honors Visionaries

A doctor, a mentor and a sommelier roll into a bar. They each roll out with a Craig H. Neilsen Visionary Prize and a million bucks.

No joke. Dr. Oluwaferanmi "Feranmi" Okanlami, Josh Basile and Yannick Benjamin — the three winners of the 2022 Craig H. Neilsen Visionary Prize — raise the bar on what's possible with SCI and are now \$1 million richer. Since 2020, the Craig H. Neilsen Foundation has honored influential leaders in the SCI/D world with \$1 million to spend at their discretion. This year's honorees are worthy additions to the award's prestigious alumni list.

Josh Basile is a DC-based attorney who has mentored



and represented thousands of individuals and families affected by SCI, earning a place in the National Disability Mentoring Coalition's Susan M. Daniels Disability Mentoring Hall of Fame. He also cofounded the popular online social-mentoring and video network SPINALpedia.com, and the "Living with Adventurous Wheels" program that sponsors and organizes adventures and sport outings for SCI families, among other things.

Yannick Benjamin was a Certified Sommelier when he was paralyzed in a car crash in his mid-20s. He reinvented his career, and now is an Advanced Sommelier with the Court of Master Sommeliers, and the successful proprietor of disability-forward New York restaurant, Conteno. He also started

the dynamic disability-centered service nonprofit Wheeling Forward and the successful Wine on Wheels fundraiser, along with other projects.

Dr. Oluwaferanmi "Feranmi" Okanlami is prominent in the University of Michigan community as Director of Student Accessibility and Accommodation Services, and as Director for Medical Student Success in the Office for Health Equity and Inclusion, along with several other national and regional service and advisory roles.

All three honorees have been on NEW MOBILITY'S radar for some time. Basile is a United Spinal Association board member who has written employment columns for NM, Benjamin was NM's 2017 Person of the Year, and Okanlami was featured in our 2019 cover story on doctors with disabilities.

Read more at chnfoundation.org/programs/visionary-prize.

By Shannon Kelly

New Peer Support Group for Gunshot Survivors

The Rochester Spinal Association's popular local peer support group for people paralyzed by gun violence is now open to members from across the country. Porche "Shay" Powell, the group's co-leader and a T8 paraplegic, says there is real value in having a meeting specifically for gunshot survivors. When she shares her story in other peer groups, fellow participants don't always believe her and assume she did something wrong. "I got shot in 2020," she says. "My ex-boyfriend kicked in my door, shot and paralyzed me. I owned my home and had to go back. It was horrible."

Powell's co-leader, Ralph Norman, a C3 quad, also emphasizes the value of a dedicated group. "Finding a group like this one specifically for gunshot survivors is very good for me," says Norman. "In other groups, people say they were hurt in a diving or car accident, and when you say gunshot, it feels uncomfortable."

The group meets daily on Zoom from 4-8 p.m. EST. Email RSA@rochesterspinalassociation.org for the Zoom link.

Porche "Shay" Powell, Marcus Kellar and Nicole Nabors



Khazm

Pennsylvania Lawmakers Get a Firsthand Look into Disability

United Spinal Greater Philadelphia Chapter member Samantha Twining and board member Pat McCloskey attended Disability Awareness Day at the Pennsylvania State Capitol. The day was planned by Sen. Christine Tartaglione, the longest-serving disabled member of the Pennsylvania General Assembly.

The event allowed advocacy organizations, along with public and private providers, to share information about assistive services and technology. It gave representatives a chance to see firsthand the challenges disabled Pennsylvanians face. "Hearing from the people is how a bill becomes a law. It is so important that those representing us truly know the trials and tribulations we face. Lived experience is everything," says Twining. "This is a bipartisan issue because disability does not discriminate. No matter the age, race or gender, things happen and these hurdles that we face could impact you or someone you love in the blink of an eye."

Get involved with United Spinal's advocacy network, at unitedspinal.org/action-center.

Meet New Member King Khazm

C7 SCI, Age 44 from Seattle, Washington
Performing Artist and Organizer

Why did you join United Spinal?

As a person with a spinal cord injury for 40 years, I know the challenges are neverending and can be overwhelming. I joined to be a part of a network and organization that supports, advocates and works to make positive changes in our communities and broader society.

What is the one product you couldn't live without?

My portable ramp! It's compact, light and folds up into a small size, complete with a handle for easy carrying. I keep it in my van and whip it out when necessary.

If you could change one thing in the world to improve quality of life for wheelchair users, what would it be?

I want to see the day when wheelchair users can roll directly onto airplanes. I travel a lot as a performing artist/organizer and being able to roll directly on the plane will prevent days of agonizing tension on my body and overall pain — and save me from worrying about broken wheelchair parts.

Recognizing the Importance of Disability Inclusion in the Workplace

National Disability Employment Awareness Month celebrates the contributions of America's workers with disabilities and showcases supportive, inclusive employment policies and practices. United Spinal Association was proud to recognize NDEAM during the month of October with a variety of events that gave members a chance to meet recruiters, improve their resumes and learn interview tips from pros.

"Diversity and inclusion drive innovation by bringing people from different walks of life to the table," says Lesly St. Louis, director of employment and diversity, equity and inclusion programs for United Spinal. "People with disabilities are constantly innovating and adapting in their daily lives, and these skills translate directly to the workforce."

St. Louis works to drive this message home to potential employers, while also finding time to talk with members about employment-related concerns and obstacles. "They want to work, but they may have caregivers, meds and so on to sustain their quality of life, and fear if they pursue employment, they're at risk of jeopardizing their quality of life," he says. "We work to sustain or improve quality of life. If a job's not doing that for you, what's the point?"

During NDEAM and beyond, United Spinal's Pathways to Employment program will focus on navigating those concerns. Learn more at unitedspinal.org/pathways-to-employment.



St. Louis



Ilan's Ride on the Great American Rail-Trail

Soon after rolling into *Guinness World Records* for longest distance traveled in 24 hours in a mouth-controlled power chair, Ilan Mackay went on to conquer over 400 miles of the Great American Rail-Trail from Washington, D.C., to Columbus, Ohio. Mackay is a board member of both the Here and Now Project and the Washington State Chapter of United Spinal, and founder of Ilan's Ride, a nonprofit dedicated to improving accessible outdoor infrastructure and getting people with disabilities outdoors.

Mackay and his support crew flew from Seattle to Washington, D.C., on Sept. 20, spent a day getting settled, then hit the trails for 12 straight days. Throughout his ride, Mackay connected with many journalists, outdoor recreation councils, and fellow United Spinal members, raising awareness of terrain accessibility, trail crossing safety, accessible parking and the importance of accessible restrooms.

"We encountered just about every terrain we could think of," Mackay blogged. "From the first day to the last, we experienced a temperature range of nearly 50 degrees. We had a number of days of rain. All along the way we were intrigued by the history we were riding through. We are thankful for everyone we met along the way, and all the beauty we were able to see. It's amazing what can be accomplished when you have the support I have, and when you get outside."

For more on Ilan's Ride, visit iansride.com. If accessible outdoor infrastructure is important to you, join the United Spinal Advocacy and Policy Team's Outdoor Access Working Group by emailing Steve at sliberman@unitedspinal.org.



HOW WE ROLL

ACCESSIBILITY ADVOCATE

Tina Pedersen



There are many ways to educate an inaccessible business about accessibility, but no one does it quite like Tina Pedersen of Harrisville, Rhode Island. If a business complains about the cost of renovations, she comes back with positive and practical solutions: contractors, tax breaks and a smile.

RAMPing Up

If Tina Pedersen can't get into your restaurant with her wheelchair, don't worry. She'll pull her own folding table out of her van, set up right in front of your establishment and ask to see a menu.

"It ends up being a comical thing at first, but eventually the business owner starts asking, 'How do I get you into my restaurant so you can dine with us in all seasons?' So I'm always finding a way to open the conversation and bring it around to a positive," says Pedersen, 50.

By positive, she means a noncombative approach that educates the business owner as to how their business is inaccessible, rather than blaming them for that inaccessibility. For example, if Pedersen, a T11 para, can get into the restaurant but not the bathroom, she will often ask the manager to take a roll with her. She'll demonstrate why the bathroom is inaccessible and suggest changes they can implement to make it accessible.

"I never throw a business under the bus or look down on them for being inaccessible. It's never a judgment — whether I come across a business that I can't get into, or I intentionally want to target a business that I know ahead of time is inaccessible — so



it's always an easy conversation to have," says Pedersen. "I always bring up the fact that I didn't realize these things eight years ago when I wasn't in a wheelchair. That takes the chip off their shoulder right away ... so they appreciate the feedback, and everyone welcomes bringing in more business."

Not only is she easygoing and relatable enough to put herself in the business owner's position, but she comes with solutions. Pedersen comes armed with a list of contractors. She also knows all the tax breaks in her state and across the nation that can make accessibility improvements much cheaper and sometimes free for business owners.

"Depending on what the project is — bathroom, ramp, doorway, etc. — I will give them a list of three to four contractors I have worked with over the years through the Rhode Island Builders Association. It's up to the business owner to call them, but if they can't get ahold of them, I will follow up, and that contractor will not get my referral again until they've at least talked to the business owner," she says.

Pedersen's approach became so popular that businesses across

GREATEST ACCOMPLISHMENT: I built my own house with my own two hands with the help of Habitat for Humanity in 2020.



PROUD MOMENT: Rolling up to be crowned at the USA Ambassador Pageant as the first winner to use a wheelchair was an incredible feeling.



Four-time cancer survivor Tina Pedersen guest-hosts the annual Big Stride for Life Walk in Providence, Rhode Island.

the country started asking her to do accessibility roll-throughs at their establishments, and contractors began offering their services. With so many requests, she took her positive, solution-oriented approach and started RAMP: Real Access Motivates Progress.

Founded in April 2019, it's a nonprofit organization with representatives in nine states and allies across the country who do roll-throughs in their own areas using Pedersen's techniques, while also educating the public on accessibility through various activities and public events.

In her effort to refine and improve her approach, Pedersen is currently making worksheets with the tax breaks and grants relating to ADA compliance for all 50 states. Meanwhile, she recommends businesses contact their secretary of state's offices to find out what financial relief is available for making accommodations.

"They should have a list of tax breaks and grants that are available to you, and if they don't, call them out on it," she says. "Honestly, accessibility shouldn't be intimidating. Most of us aren't looking for full ADA compliance. At minimum, we just want to be able to get in the door and use the bathroom."



BEST ADVICE FOR PARENTS WITH DISABILITIES: Nothing is impossible, and everything is adaptable.

Accessible Adventures

Tina Pedersen freely admits that she has gone on more adventures as a person with a disability than she ever did as a nondisabled person. She's pushed her boundaries with rock climbing, sailing and even "floating" in a standing wheelchair.

“I've been to an indoor rock gym where I can use my upper body and I'm harnessed on something to help me get up. I have no feeling in my lower limbs, so it's a thing of determination for me. It's more, 'I can do this and I'm just going to figure it out.' I don't know how to describe that, but it's one of the coolest things in the world. I'm not afraid of heights or anything, but the freakiest thing for me is being in a standing wheelchair. You know you're standing on something, but when you can't feel the lower half of your body, it's like you're suspended in air — one of the freakiest feelings in the world.”



"Steering the boat from my chair was incredibly cool," Pedersen says about sailing on the Impossible Dream.

WHY DID YOU JOIN UNITED SPINAL?

I wanted to be part of a group that knew exactly what I was going through, and United Spinal is that group for me.

EXPLORING AWARD-WINNING

ACCESS

BY EMILY YATES

In 2010, the European Commission created the Access City Award to celebrate cities that are dedicated to improving the accessibility of everyday life for their disabled citizens and visitors. Born and raised in the U.K. and proud to call myself a European for most of my life (thanks, Brexit), I've been aware of and intrigued by the Access City Award for several years. In October, I decided to experience what an Access City Award winner offers and booked a trip to Luxembourg City, the 2022 winner.

Luxembourg City is the capital of Luxembourg and home to just over 124,000 inhabitants of 165 different nationalities. The city is built on two levels with a maze of tree-lined streets, landmarks, upscale cafes and museums on the upper plateau of the fortified old town and more homes, parks, canals, lively restaurants and bars along the lush lower valley.

After applying for the Access City Award every year, only to earn a special mention in 2015 and third place in 2018, Luxembourg City finally took top honors in 2022. The European Com-

mission commended the city for ensuring inclusion is a "bedrock" of all its urban planning and providing free public transport that promotes step-free access and houses digital displays with text-to-speech functions for both audio and visual accessibility. Furthermore, Luxembourg City was celebrated for involving disabled stakeholders in decision-making processes through regular consultation and by ensuring that the city's political meetings are interpreted in sign language and inclusively transcribed.

It's important to understand that the Access City Award doesn't simply recognize Europe's "most accessible city." Instead, it honors cities that continually better their approach to inclusion, present sustainable innovation and/or put consultation with those who have lived experience of disability at the heart of their efforts. It covers everything from the built environment, transportation, public facilities and services to innovative digital platforms. With approximately 87 million disabled people living in the European Union, solutions should also have a pandisability approach, serving those with physical, sensory and cognitive impairments, whether visible or nonvisible, permanent, temporary or situational. In short, the Access City Award encourages an annual stocktaking of accessibility measures and promotes the sharing of ideas, experiences and efforts between cities to create a more equitable Europe for all.

FIRSTHAND RESEARCH

Upon arriving in Luxembourg City, I was struck by how quintessentially European it is: I was surrounded by charming views from the central Place d'Armes, green spaces such as Parc Dräi Eechelen encouraged slightly deeper breaths, and the ornate infrastructure of the Grand Ducal Palace made the city feel like something out of a fairytale. Of course, in true European fashion, there was also rain. A lot of rain.

"The Access City Award recognizes cities that center disability and continually better their approach to inclusion and sustainable innovation."

mission commended the city for ensuring inclusion is a "bedrock" of all its urban planning and providing free public transport that promotes step-free access and houses digital displays with text-to-speech functions for both audio and visual accessibility. Further-



But there were other aspects that immediately set Luxembourg City apart from anywhere I'd ever been before. It was wonderfully clean to the point that my hands did not once pick up dirt from pushing my wheelchair. I noted a grand total of two pieces of litter throughout a five-night stay. (I'm not quite as boring as I've just made myself sound.) But even better was the cocoon of safety that Luxembourg City seems to wrap around its residents and visitors. People are kind, navigation is easy, and the whole experience just felt incredibly nice from start to finish.

The local iteration of international hotel chain Mama Shelter was our home-away-from-home for the trip

IN LUXEMBOURG



Yates (above) enjoyed using Luxembourg City's accessible tram to explore the scenic capital's mix of old and new architecture.



BEHIND THE AWARD

While in Luxembourg City, I was fortunate enough to meet with Nico Bevilacqua and Madeleine Kayser from the city's equivalent of disability services, along with Yannick Breuer, accessibility coordinator for Info-Handicap, a national umbrella organization providing a central hub of information and community for

visible impairments. "It is a prize for everyone," says Kayser, "including our partners and others in the community. No one gets anywhere working solely in a corner. Collaboration and feedback helped us to win."

Bevilacqua says the ethos of those working toward the award and continuing to improve accessibility

in the city is that "everyone has a special need of some kind, even those who aren't disabled" and that society becomes a much more inclusive place when this is not simply

next for the city and its accessibility journey, Breuer shares his excitement that there is to be a new country-wide law instated in 2023 that makes it mandatory for every new public and private building to provide accessibility features, something that Info-Handicap and other organizations have "fought a long time for." Kayser and team are also keen to utilize technology further, providing equitable digital experiences when physical areas cannot.

Year after year, inclusive improvements have been made in Luxembourg City. Bevilacqua, Kayser and Breuer, among many others, want to make even more, acknowledging that accessibility is a journey that never ends. This, to me, is the epitome of what the Access City Awards are about and makes Luxembourg City a truly deserving winner. The group I interviewed shared with me that the aim of Luxembourg's Tourist Office is for the whole country to become "the most comfortable place in Europe." That comfort is precisely the cocoon of safety that I felt throughout my trip, and that I've never quite felt anywhere else.

Skellefteå, Sweden, was announced on November 25 as the Access City Award winner for 2023.

disabled people within Luxembourg. All three emphasized that the city's success in the Access City Awards stems from collaboration between departments and partner organizations striving to provide solutions not just for residents or wheelchair users, but also for tourists and those with varying sensory, cognitive and non-

understood but celebrated.

While the pandemic has slowed further improvements for the time being, Bevilacqua sees a silver lining in the way the pandemic created a broader social understanding of what isolation feels like. He hopes this can drive future inclusion and accessibility efforts. When asked what's

— and fitting as I'd brought my mum along with me for the ride. Vibrant and youthful in both its decor and ambience, this hotel is a five-minute drive from Luxembourg Airport and just five tram stops away from the city center, with the Philharmonie Luxembourg stop directly across the road from the hotel. The hotel entrance is step-free, there's elevator access throughout, and we stayed in a large, accessible room with a wet room. Additionally, I'm happy to report that there is not

a sniff of clinical functionality in the whole property, a pleasant change from many accessible rooms that I, and no doubt you, have stayed in. Expect free in-room movies, a fairy-light-laden rooftop bar, and excellent pizza and cocktails in a ground floor restaurant with a brick-a-brack vibe and street art murals covering the ceiling. A weekly resident DJ makes Mama Shelter an after-work drinks choice for many locals.

Next door to the hotel is Infinity, a small shopping hub of beauty, fitness

and restaurant options. Both floors are accessible via elevator, and there's also a well-kitted-out supermarket for snack supplies. Golden Bean is a lovely coffee shop and coworking space with wooden desks and a meeting room on the ground floor for those who need to work during their trip.

One of the accessibility gems of Luxembourg City has to be its tram service, with a total of 17 stops connecting the Luxexpo transfer hub to Luxembourg Central Station and beyond. There are

The view from the Pfaffenthal Panoramic Elevator is a must-see.



plans for the line to extend further in the coming years, connecting the airport to the route. Access between platform and door is step-free with a minimal gap, promoting autonomy and independence for all. The trams themselves have ample room and prioritized spaces for wheelchair users, and I never had to wait longer than five minutes for the next one. Best of all? The whole service is free of charge for locals and visitors alike.

There are plenty of sights worth seeing, but three not to be missed are the Letzebuerg City Museum, Pfaffenthal Panoramic Elevator and the city's own Notre-Dame Cathedral. Letzebuerg City Museum is free for disabled visitors and their companions and full of artifacts and information detailing the history of Luxembourg City. While getting to the entrance via a steep, cobbled street proved particularly difficult, especially in the rain, accessibility measures inside were impressive. A mesmerizing glass elevator built into the old building's structure takes a whopping 60 visitors to all exhibition floors and the museum's rooftop for panoramic views of the city below. The

Looking up at the Pfaffenthal Panoramic Elevator.



There are panoramic views and sculptures on the rooftop of the Letzebuerg City Museum.



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mixture of modern architecture within old stone walls only adds to the beauty of the experience. The 55-foot panoramic painting of the city center in 1655 by Antoine Fontaine is worth the visit. Several tactile maps and objects are also available throughout the museum for those with visual impairments.

Keeping with cool elevators, the Pfaffenthal Panoramic Elevator is one of the city's most impressive and accessible attractions. It connects the city center to the Pfaffenthal quarter in the Alzette Valley below, offering stunning views from 200 feet above ground level. The elevator is free, and there's step-free access throughout the structure with an accessible toilet provided at ground level. Unfortunately, the lower, valley level of the city is full of flattened cobblestones, which are incredibly beautiful but not very wheelchair-friendly. Luxembourg City's funicular is another free and accessible way to get from Pfaffenthal to the base of the city.

Lastly, the step-free access and powered door entrance provided at Notre-Dame Cathedral made it a particularly welcoming environment for quiet reflection. Entry is free, and a self-guided audio tour of the stunning architecture is available to download.

There are many other sights worth seeing in Luxembourg City. The Cercle Cite, or "city hall" of sorts, commands its place at the top of the Place d'Armes square and includes a library, tourist information and the Ratskeller — an ex-

hibition hub with art, photography and films changing every quarter. The Cercle Cite also houses an accessible public toilet, worth noting for



Enjoying macarons and dessert delights in Laduree.

use when in the city center.

For some luxury shopping in an accessible environment, visit Galeries Lafayette, a six-floor department store catering to all beauty, clothing and accessory needs. If breathtaking views or incredible architecture are your thing, take a stroll either on or under Pont Adolphe, a double-decked arched bridge with a step-free suspended bicycle and pedestrian pathway that connects users to varying parts of the city. A short distance away from Mama Shelter, you'll find Mudam, Luxembourg's contemporary art museum. Inside, it is light, modern and spacious — truly a wheelchair user's dream. There's an accessible toilet, museum cafe

and some interesting visual and sonic exhibitions, allowing visitors to feel immersed in an experience, whether it's "flying" through a derelict city or marveling at the power of everyday objects. I really enjoyed engaging with Tarek Atoui's "Waters' Witness" exhibition, which captures the sounds of port cities. The entrance fee is 8 euros per adult.

While the assistance service on arrival at Luxembourg Airport was the smoothest and speediest I'd ever experienced, and I managed to navigate the city center streets independently due to excellent dropped curbs, the city isn't without its accessibility challenges. Plenty of cobbles (although relatively flattened) can be found in the city center and old town, and finding a restaurant or cafe with both step-free access and an accessible toilet was nearly impossible. That is, of course, unless I wanted to eat at the same predictable fast-food chains that can be found worldwide. We did, however, really enjoy our time at Bazaar, a bar and restaurant opposite the Grand Ducal Palace that has mastered the perfect combination of a high-end establishment with a warming welcome. And I can highly commend the famous Laduree pastry shop for offering step-free access, an accessible toilet and the tastiest combination of hot chocolate and macarons I've ever had.



The Alzette River



Where Have All the **SCI Neurosurgeons** Gone?

BY BOB VOGEL

Spinal cord injury can be the unwanted gift that keeps on giving. Secondary complications and pain can be variable and sometimes progressive, especially for people who develop a syrinx or tethered cord. In these cases, finding a neurosurgeon trained in diagnosing and treating these difficult conditions — ideally with exceptional experience and a mindset to try conservative treatment options first — can be essential for maintaining function and quality of life.

Arguably the two most renowned SCI-focused neurosurgeons of the past few decades have been Dr. Scott Falci, formerly associated with Craig Hospi-

tal, and Dr. Barth Green, professor and chair of University of Miami Miller School of Medicine and co-founder of The Miami Project to Cure Paralysis. But Dr. Green retired his scalpel in 2021, and Dr. Falci's office is no longer at Craig Rehab, where for decades he was a mainstay. He's no longer even mentioned on the Craig website.

So where have the SCI neurosurgeons gone? And what options will people have moving forward?

Still Operating

The great news is that although Dr. Falci is no longer affiliated with Craig Hospital, he is still performing surgery.

The specter of spinal surgery is scary enough on its own, but what do you do when you can't find an experienced surgeon to operate?

He recently moved to a new office across the street from Swedish Medical Center in Englewood, Colorado — where he has always performed his surgeries. Better still, he is passing on his knowledge and skill by creating an institute for treating conditions that can occur with chronic SCI. “I’m not ready to retire yet, but I came to the realization that I need to pass my 30 years of experience on to others,” he says. “There haven’t been a lot of neurosurgeons that focus on chronic spinal cord injury. It’s a real issue globally. Since we get calls from patients from around the world, the only way we can treat them is if their healthcare system can send them over and pay for their care.”

To accomplish this, he has partnered with HCA Healthcare — the parent corporation for Swedish Medical Center — to form The Falci Institute for Spinal Cord Injuries. He says the clinic will try to figure out nonsurgical ways of treating a condition, such as working with a physiatrist, physical therapist or medications, incorporating world-class surgical intervention when appropriate. “I also plan to keep doing cutting-edge research, including in new, nonopioid medications to treat neuropathic pain.” A vital part of this is that Falci will be passing on his surgical skills by recruiting and training the next generation of neurosurgeons focused on chronic SCI.

Complications from a Syrinx

One of Falci’s most recent patients is Brook McCall, 42, in her 20th year as a C4 complete quad. During her initial rehab stay at Craig, McCall was informed that she had a small syrinx at her injury site and that she should keep a close eye on any changes in sensation, spasms, or difference in pupil size — all symptoms of problems with a syrinx. In 2015 she started having new, increasing back pain below her level of sensation and full-body spasms.

In 2016 she saw several neurosurgeons at a top hospital in Oregon. “The

first neurosurgeon said it is likely this will progress to the point of needing a ventilator, and he said he wouldn’t touch it because ‘there was no hope of her walking.’ Another recommended I put off surgery until I had difficulty breathing and swallowing, which left me

“I’m alive. I can breathe, and I’m no longer terrified that a tiny fluid-filled sac is going to take me down.”
— Brook McCall

feeling boggled and bewildered without any guidance,” says McCall. “As a Craig alum, I knew of Dr. Falci’s team and went to see him in October 2019.”

Falci’s testing showed she was losing sensation, and he said — given her injury level — that surgery would carry a high risk of complications, so she should try treating the symptom with medications. “When I diagnose somebody with a chronic spinal cord injury who is having pain, spasticity, sweating, a syrinx or whatever, I rely on my experience working with this population,” says Falci. “It requires a mix of experience, science and art to figure out a diagnosis and a treatment plan that balances the best way to treat the condition with what’s in the best interest for the patient. This may be through a physiatrist, physical therapist, medications, or surgery when it is appropriate.”

The pandemic put off McCall’s next meeting with Falci until September 2021. “By this time my symptoms were to the point where my quality of life was suffer-

ing,” says McCall, “and the syrinx now extended from C4 to my brainstem [the critically important control center linking the brain with the spinal cord], so I decided it was worth the risk.”

Dr. Falci did her surgery in early December 2021. The surgery involved the removal of the back of C1 and C2 — a double laminectomy — and extensive untethering of the spinal cord, but that didn’t open up the syrinx pocket. “Often when I untether the cord, I can see the syrinx collapse right before my eyes,” says Falci. McCall wasn’t so fortunate, so Falci put in two shunts and expanded the space inside her spinal cord to drain the syrinx and keep it from returning.

“I ended up with 200 microsutures on my spinal cord and a scar from below my injury up into my scalp,” says McCall. The surgery alleviated newer, more recent symptoms above her level of injury, including hypersensitivity, pain in her neck and scalp, neck weakness and muscle fatigue. The rest of her symptoms and pain are the same, except she has fewer spasms in her legs.

“The easing of leg spasticity shows there is potential



Brook McCall

for improving older long-term symptoms,” she says.

At six months post-surgery, McCall reports some residual soreness when turning her neck, and she feels chronically fatigued. “I see slow improvement, and I’m coming to terms with my new normal,” she says, adding that the surgery and recovery have been substantially harder than her initial injury. “But being on the other side of things without that weight is huge and makes the surgery a success. I’m alive. I can breathe, and I’m no longer terrified that a tiny fluid-filled sac is going to take me down.”

Finding a Seasoned SCI Neurosurgeon

What if you are far from Colorado and need SCI-related neurosurgery? “Symptoms that indicate potential syrinx problems are not that common, so not many neurosurgeons have as much experience in diagnosing and operating on them as Doctors Falci and Green do,” says Bernadette Mauro, director of information and resource services for the Christopher & Dana Reeve Foundation’s Paralysis Resource Center. “But a great place to start is contacting one of the 18 SCI Model System rehab centers and the teaching hospitals that are affiliated with them. I know that University of Pittsburgh, University of Maryland and Johns Hopkins do DREZ surgeries [Dorsal Root Entry Zone — see “Terms” below]. However, when considering a neurosurgeon for diagnosis or surgery, I tell clients to ask how many untethering and syrinx surgeries the doctor has done. If it is less than 50, I encourage them to continue looking.”

To put things in perspective, Falci has performed thousands of spinal cord surgeries, including DREZ surgery for neuropathic pain, and over 1,600 surgeries for syrinx.

Dr. Uzma Samadani, staff neurosurgeon for the Minneapolis VA Medical Center and president and CEO of US Neurosurgery Associates, agrees with Mauro when it

comes to finding a neurosurgeon. Samadani has been practicing neurosurgery for 15 years and has performed approximately 150 syrinx surgeries to date. “If I had a syrinx, and I wanted to find a good surgeon to untether a cord to treat a syrinx, I would start by asking major spinal cord rehab centers which surgeons they work with, because they will usually know the neurosurgeons who are making people better,” she says. “Certainly experience is important, but there is also a component of listening to your patients that is vital.”

Dr. Steven Kirshblum, chief medical officer at the New Jersey-based Kessler Institute for Rehabilitation, agrees with both Mauro and Samadani. “I have tremendous respect for Dr. Green and Dr. Falci. In fact, Dr. Falci co-authored the chapter about syrinx in my book, *Spinal Cord Medicine*,” says Kirshblum, “That said, every major SCI center has a neurosurgeon that they use who is extremely competent. I also think that every center will agree that Dr. Falci is very well respected, but every case doesn’t go to him. A thorough workup is needed, and then a decision is made on what to do and which surgeon is best.”

When looking for a neurosurgeon, it is important to ask about outcomes in addition to number of syrinx surgeries. “Just because somebody thinks they can treat a tethered spinal cord doesn’t mean they have had the experience and their outcomes will be good,” says Falci. “Unfortunately, it is very common to find that there have been multiple surgeries in attempt to untether the spinal cord that have been unsuccessful, and ultimately the patient has been told ‘there is nothing we can do for you.’ The tethering becomes more severe with each surgery, so it becomes closer and closer to being [unfixable] because the scarring becomes worse

NEUROSURGERY VOCABULARY

Tethered Cord: A formation of scar tissue on the spinal cord at the injury site, which can lead to the formation of a syrinx.

Syrinx: Short for syringomyelia, a fluid-filled cyst that can form on the spinal cord. With SCI, it forms above the tethered cord. It can enlarge and cause a wide variety of symptoms, including an increase of pain or neuropathic pain, new or increasing blood pressure regulation problems, increase in area and/or intensity of spasticity, weakness, and progressive loss of sensation and/or movement.

DREZ surgery: Dorsal root entry zone surgery is intended to relieve severe neuropathic pain. Using a surgical microscope, the surgeon views the damaged spinal nerve roots and creates precise lesions with radio frequency, laser, ultrasound or microsurgery.



Dr. Scott Falci says he's not ready to retire his 30 years of SCI surgery experience.

with each attempt. The goal of the center is to have fellowships to train more people who know how to do this.”

McCall’s advice for others going through a syrinx is twofold: “First, do not settle,” she says. “There are very few surgeons with true expertise in this area, but [those without suitable expertise] will still perform your surgery. This is not an experience you want to go through more than once. At the same time, if you and your surgeon have discussed this and decide you are ready, don’t wait.”

MI



WHEELCHAIR MUSHING

IS MORE THAN A FREE RIDE

BY CATHERINE TYINK

The concept behind wheelchair mushing is simple: You train a dog, or group of dogs, to reliably follow commands, then put harnesses on them, attach them by pull lines to your wheelchair and let them run. Mush-ing isn't a free ride, though. Moving at speed is physical for both human and dog. Add obstacles, like other dogs, people, small creatures, brush and weather changes, all requiring quick adjustments, and you have a sport challenging enough to satisfy committed thrill-seekers.

Three wheelchair users who regularly mush — Rodney Higgins, Don Wheeler and Jared Fenstermacher — have their own unique approaches to the sport, but they share a common message: Wheelchair dog mushing is a hell of a lot of fun.

FIGURING IT OUT

Six years after being diagnosed with Transverse Myelitis, Rodney Higgins was still struggling with the transition to life as a wheelchair user. "I was an outdoor person. While I always had a desk job, I spent my free time in my yard —

pruning, planting, landscaping. I spent vacations camping and hiking. Now, suddenly, I was an indoor person," Hig-gins says. "I lost my connection with nature. It was almost like being deficient in a vital mineral in your diet. Alive, but not really healthy."

Everything changed in 2011 when he decided to train his Labrador retriever, Skyler Rose Raindancer (Sky), to pull him in his wheelchair. Starting on the sidewalks near his home in Woodland, California, Rodney and Sky mushed 30 minutes every day for the first month. Later they moved to the greenbelt multipurpose pathways of nearby Davis and regularly mushed 3-4 miles a visit. "Discovering the long rural pathways in Davis was more than a 'wow' moment. The natural setting reconnected me with nature and was a big part of my mental healing," he says.

Eight years later and 2,500 miles away, in Cleveland, Ohio, Don Wheeler had a similar experience. Pre-injury, Wheeler owned huskies and long dreamed of one day rac-ing a dog sled team. In 2004 he had a motorcycle accident,

sustaining an incomplete spinal cord injury at C6-7. It took him more than a decade to build up his confidence to try mushing as a wheelchair user. In 2019 he joined the Siberian Husky Club of Greater Cleveland for educational purposes and then adopted a 3-year-old husky named Dash. “Mushing with Dash was the closest thing I had felt to riding a motorcycle again. I was hooked,” says Wheeler, who shares his mushing adventures on his Team Dash YouTube channel.

The promise of getting to spend time with dogs and going fast was more than enough to attract Jared Fenstermacher to wheelchair mushing. An avid dog lover and endurance athlete prior to being paralyzed in 2016, Fenstermacher, now a T5 incomplete para, fell hard for his new passion. “Wheelchair mushing has been a natural fit,” he says. “Wheelchair mushing benefits the dogs but also gives me a great workout since mushing requires both balance and arm strength.”

Fenstermacher runs his husky, Titan, alongside his neighbors’ huskies, Maya and Haze, on the streets around his home in Bloomsburg, Pennsylvania. He shares his adventures on social media to show wheelchair mushing’s potential as a novel way to be more physically active and benefit your pets.

DOG TRAINING

When it comes to wheelchair mushing, it all starts with the dogs. You need a dog capable of pulling you, both physically and temperamentally. Huskies and malamutes are the best-known sled dogs, but other working breeds, including shepherds, heelers and Labradors, have been bred to work and follow commands. Higgins, Wheeler and Fenstermacher all had experience with dog training prior to mushing.

Fenstermacher’s dog, Titan, is both his service dog and mushing partner, performing functional tasks like assisting pulls on carpeted areas. Wheeler’s dog, Dash, is also a service dog trained to support him during low blood pressure episodes. Higgins’ dog, Sky, was a family dog with whom Higgins did basic dog training before teaching her how to mush.

The first training step is teaching the dogs to consistently follow verbal commands. Wheeler says that he always starts training in the backyard, “until I’m confident they can consistently follow commands.”

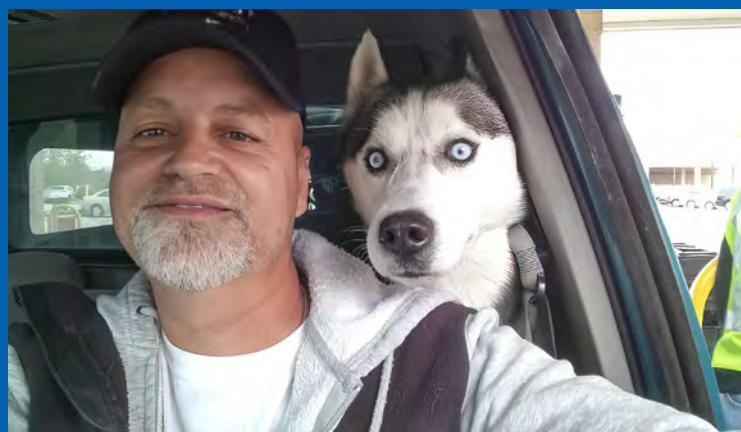
There are about 10 commands to master (see sidebar) before the dog is ready for a harness. Higgins says there are only three difficult things to teach: No smelling, no meet and greet and no chasing wildlife. “If you can teach your dog those three things, the commands and everything else is easy,” he says.

The dogs’ motivation to learn is usually high, so Higgins advises against using treats for training. “The chance to run is reward enough for the dogs,” he says. “Also, you will need hand-use to control the wheelchair, so I always recommend people avoid bringing treats.”

Fenstermacher agrees. He runs with his own dogs and with other local huskies and they are always excited to run. “You can’t push a dog with a rope,” he says. “The dog pulls on his own accord because he likes adventure and exercise.”



Don Wheeler takes his huskies Dash and Gabby to mush on off-road bike trails and other natural paths.



“Mushing with Dash was the closest thing I had felt to riding a motorcycle again. I was hooked.”
–Don Wheeler

GEARING UP

If you’ve ever been out on a stroll and had a squirrel run across your path, you might think you have everything you need to get pulled around by your dog. But animal safety is key, and a few pieces of specialized equipment can make things safer and more enjoyable for everyone. “I’ve met plenty of people who think they are mushing using a collar and leash,” says Wheeler.



THE TRADITIONAL MUSHING COMMANDS ARE:

Hike: Get moving.

Gee: Turn to the right.

Haw: Turn to the left.

Easy: Slow down.

Straight Ahead: Keep going straight.

Whoa: Stop.

On By: Keep moving past another team or distraction like other animals on the trail.

Line Out: This is a command to the lead dog to tighten the gangline and pull the team out straight.

While traditional mushing commands are perfectly acceptable, Rodney, Jared and Don favor using their own commands such as:

Walk On: Start and go straight.

Go Go Go or Let's Go: Go.

Stop: Stop.

Easy: Slow down.

On the road: Transition from sidewalk to road.

Stay: Don't move.

Go left: Move left.

Go right: Move right.

Sit: Sit.

“This actually can hurt the animals due to speed and abrupt start-and-stop aspects.”

A properly fitted dog-harness is essential. All three men recommend Alpine Outfitters.

They offer a quality harness in a variety of styles and sizes at reasonable prices of \$26-\$57. Other essentials include ganglines (think a reinforced leash or towline), gloves, hookups to the wheelchair frame or a waist belt, couplers as needed and, if desired, some type of last-resort control option such as a vibration collar. Each system is customized for the owner, dog and the type of surface being mushed on.

Higgins and Fenstermacher use a FreeWheel to aid speed and control and avoid their front casters digging into bumps, cracks or stray pine cones. Even so, Fenstermacher still takes his fair share of spills. Mushng up to three dogs at a time, he knows his pursuit of speed comes with elevated chances of crashing. “Maya has high prey drive and has pulled me over to the side. It’s not too bad, but I usually get scraped up,” he says.

For Higgins, who mushes with a single dog at slower speeds, the longer wheelbase offered by the FreeWheel makes his chair very stable. “I’ve only crashed three times in 10 years,” he says. “Knowing I had the ability to get back on



Rodney Higgins credits his dog Sky for rekindling his love of nature.

my chair after a crash gave me confidence. Otherwise, I may have never tried.”

Wheeler rolls without a FreeWheel because of compatibility issues, but has only fallen once. “It wasn’t the dogs’ fault. It was my poor choice of terrain,” he says.

HITTING THE TRAIL

Contrary to many perceptions of mushing, you don’t need a snowy wonderland to get out and about. Higgins prefers to mush on multipurpose paved pathways, particularly in natural settings. He likes the safety of being separated from traffic and the chance to be out in nature. Fenstermacher lives in town and would have to drive with the dogs to reach trails or pedestrian pathways. “Transporting them in the truck is a pain, so I typically use the streets,” he says.

Wheeler favors off-road bike trails or other natural paths, but he also mashes on the streets around his neighborhood. If you’re going to mush on unpaved surfaces, larger knobby tires on your rear wheels help with float and traction. In the winter, Wheeler sometimes mashes in the snow, using attachable skis so his front casters don’t dig in and flip him forward.

In addition to more open space and not having to deal with traffic, off-street mushing offers another perk: fewer people. Fenstermacher says he has to go out mushing with a confident mindset because he’ll often get unsolicited critiques from strangers like, “Are you sure that’s not too much for him?” or, “Isn’t it too cold — or hot or wet or late — to be doing that?”

“I’m stubborn and I refuse to let my disability or others’

opinions of my limitations stop me from doing the things I can and want to do,” he says. “My advice to those wanting to try mushing is to get stubborn, set your mind to it and do your thing.”

Like everything else, where to go really depends on your goals and what you have around you. Wheeler likes to go long distances — his longest run is 9 miles — and long, uninterrupted paths are ideal. Fenstermacher often mashes at higher speeds — his fastest mile is under 4 minutes — so for him it’s worth putting up with some traffic and ignorant comments to have plenty of space to move.

For now, Fenstermacher looks forward to mushing in the cooler months. “The husky breed particularly needs a lot of exercise, so in mushing season I try to take other local husky dogs out,” he says. “Someday I’d love to mush every street of Bloomsburg, rotating dogs as I go.”

All three men recommend starting slowly and gradually upping distance, just like a human runner would do. Wheeler has been training his two dogs, Gabby and Dash, to work together as a team and slowly improve their fitness levels. His goal is to do a 20-mile continuous run.

Since losing his longtime mushing partner, Sky, Higgins and his wife are dedicating their time to raising an adopted shelter dog named Jackson. “I’ll need to give Jackson more time and training before deciding whether to try wheelchair mushing,” he says. “It doesn’t work for every dog, but when it does, it’s magical.”

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Photo by Christopher Beauchamp



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A public servant at heart, Ortiz sponsored or co-sponsored 40 bills in his first term.

COLORADO STATE REPRESENTATIVE

DAVID ORTIZ

A FIERCE ADVOCATE

When David Ortiz rolled onto center stage in 2021 as Colorado's first wheelchair user elected to the state legislature, he knew that some people would automatically see him as "the disability" representative. Instead of bemoaning that reality, he went to work.

Building on the skills and insights he'd gathered over a life of service in the military, public and private sectors, he used his first term to establish himself as a legislative force, fighting for the things he believes in and the things his constituents need. No small feat, when you consider that as a disabled, bisexual, Latino veteran, his constituency goes well beyond the House District 38 voters who elected him.

Colorado's legislative leadership recommends first-term representatives try to introduce five bills. Ortiz sponsored or co-sponsored 40. Thirty-five of those passed into law. Eight focused on disability issues, including pioneering legislation expanding options for power wheelchair repair and accessible vehicle rental.

For someone who was wary of being pigeonholed, he has emerged as a fierce advocate for the disability community who is willing to take on anyone or anything he sees impeding it. For these reasons and more, NM is honored to recognize David Ortiz as the 2022 NEW MOBILITY Person of the Year.

BY IAN RUDER

THE BIG DAY

When the Colorado General Assembly is in session, House District 38 Representative David Ortiz starts his morning hygiene routine long before the sun rises. Like any good Army veteran, he's got a process that works and he follows it. As a T10 paraplegic, he leaves two hours to go to the bathroom, get cleaned up, eat, spend some time with his wife, Kate, and head out the door for his 30-minute commute to the Capitol.

In the 10 years since he was paralyzed and sustained a traumatic brain injury in a helicopter crash in Kuwait, he's learned to compensate for the extra time with efficiency and focus. People around him say he can be sweet, funny and goofy, but they struggle to come up with a time they've seen him slow down. Sarah Bennett, his legislative aide, is one of many colleagues who describe him as "driven." "When you're in the Army and you have your mission, you have to complete it," she says. "He definitely feels like he has his mission in the legislature."

That mission was put to the test many times over his first term, but perhaps no day demonstrated Ortiz's approach better than Tuesday, March 22, 2022. Ortiz and his small team had long ago circled the date. Three disability-focused bills Ortiz was sponsoring or co-sponsoring — both of the Right to Repair bills and another that required car rental companies to provide adaptive technology and equal access — were up for debate in front of three different committees. The fate of the bills hinged on the hearings and Ortiz's ability to execute the mission plan his team had assembled over the prior months.

THE TEAM IS EVERYTHING

Much of the hard work for that day had already been done by the time Ortiz arrived at the Capitol and headed into the assembly chambers for the morning. Ortiz prides himself on preparation and teamwork. He carries a small notepad with him everywhere to capture every idea and thought he wants to act on. His short-term memory isn't what it was before the crash, and he doesn't want to forget anything that could help.

Long before March 22, his team had ensured that all the committee meetings for the day would be held in accessible rooms, confirmed participation of all the people testifying

virtually, and gone over the schedule with advocates and allies, some of whom were testifying before multiple committees.

"The team is everything. That's always been the cornerstone of my service," he says. "It was important to make sure we had our advocate allies — like Colorado Cross-Disability Coalition, Disability Law Colorado, as well as others that represent our community — lined up and ready to go and understanding that it's going to be a very packed day."

Brianna Titone is a Colorado state representative who cosponsored two of the March 22 bills with Ortiz, an experience that gave her a deeper appreciation of Ortiz's commitment to and knack for community-building. "He has the ability to tap into different groups of people because of the relationships he has," she says. "He tries to really get the perspective of the people and to really build that relationship with the district."

Even with the strongest relationships, bringing any three bills in front of three different committees in the same afternoon is a logistical nightmare. Adding in a large number of wheelchair users testifying and the hit-and-miss access of



Above: Ortiz made history when he presided over the Colorado House on March 24, 2022. Right: Wheelchair users urge lawmakers to pass the Right to Repair bill on March 22, 2022.



FAMILY VALUES

The values that drove Ortiz's March 22 plan and all of his policy and advocacy work were instilled by his parents at a young age. His mom migrated to the U.S. from Mexico at 16, and his dad served in the Air Force. The family moved around a lot, but Ortiz's parents were consistent in hammering home the importance of service and the need to stand up for those who couldn't fight for themselves. "Giving back was always something that I was raised with and was a tradition in my family," he says. "You take care of community and the people around you, especially those that are weaker or marginalized, and you don't suffer bullies."

Post-college jobs helping Hurricane Katrina victims and working in the Houston mayor's office gave him opportunities to put those values into action. He got firsthand views of the power of policy and the need for leadership in government, but after two years he needed more. "I wanted to serve my country in a more intense way," he says. "Sitting behind a desk all day wasn't it for me."

In 2008 he enlisted in the Army, trading his desk for the cockpit of a Kiowa helicopter. After training, he ended up in Afghanistan on his first deployment. On June 21, 2012, on the way back to base from a combat mission, the engine exploded and the helicopter crashed. Ortiz woke up under a pile of metal, with a brain injury and a T10 SCI.

Just a month past his 30th birthday, Ortiz found himself mired in the Veterans Affairs hospital system. "The Army is really great when it comes to amputees and burns, but when it comes to something more complex, they just farmed me out to the VA because it's cheaper for them. And the VA that I was at in San Antonio was fucking pathetic. It was the worst six months of my life, and you're talking about someone that was in combat."

One of his doctors who happened to be an incomplete quadriplegic told him he needed to get to a facility that specialized in SCI rehab. He settled on Craig Hospital in Colorado, but the Army pushed back. Eventually, after enlisting the media and elected officials to make his case, his transfer was approved. "Craig literally gave me my independence in my life back, and then the adaptive sports programs are what helped me make my life fulfilling again and realize what was possible," he says.

At Craig, Ortiz rediscovered his voice as an advocate and worked to ensure other veterans with SCI had the same opportunity. Eventually one of his former battalion commanders urged him to take the next step. "He was like, 'Hey, you're outgoing, you're a policy wonk, and you have a big mouth. Why don't you advocate and lobby for veterans?'" After three years of doing just that for a handful of organizations, in 2019, Democrats recruited Ortiz to run for office.



A former combat aviator, Ortiz greets a well-wisher on Military Appreciation Day.

the Capitol building only elevated the potential for catastrophe.

Titone says Ortiz's military background is evident in his calmness, whatever the circumstances. "As a pilot in the military, you have to have checklists and plans of what you're going to do," she says. "He knows exactly what he's got to do. And he knows how to execute the plan, because that's part of the dream."

THE BATTLE

All the planning for the big afternoon went into effect when the committee hearings started. One of the two Right to Repair bills was in front of the Public & Behavioral Health & Human Services Committee, the other was in front of the Health & Insurance Committee, and the third bill — concerning equal access for disabled people trying to rent cars — was in front of the Transportation & Local Government Committee. Ortiz raced between rooms to start the testimony, and kept track of each hearing's status via texts from his team.

"The only analogy I can think of is it was like a general in a battle," Ortiz says. "They go where they are most needed at the time, where they feel like the weakest point of the battle was happening for them." But even with the best-laid plans, any good general knows to expect the unexpected. That day it came in the form of industry and corporate representatives having agreed to language in the bills, only to renege in front of committee. On the Right to Repair bills, pushback came from the rehab industry, while on the rental car bill, it came from the car rental industry.

"There was a lot of bait and switch with compromises that were made," says Titone of the Right to Repair hearings. "It was really unfortunate because we made a really good faith effort to try to find common ground, and spent a lot of time and a lot of meetings to try to get it all right. And when we finally had our compromise and asked, 'OK, is everybody good with this?,' they said yes. Then, lo and behold, at the 11th hour, we didn't



Photo by Bear Gutierrez

Ortiz enjoys Colorado's outdoor recreation opportunities, and he works to make sure they are as accessible as possible.

have a compromise and they were trying to go back on it.”

Similar issues emerged in the hearing on the car rental bill. “You could tell the Republican senators that went up there were just regurgitating misinformed sound bites from Enterprise and car rental companies and their lobbyists,” says Ortiz. “They didn’t know what they were talking about. And really, it just made them look like assholes.”

Julie Reiskin, the co-executive director of the Colorado Cross-Disability Coalition, was one of a handful of wheelchair users to testify in favor of the Right to Repair bill. She has been continually impressed by Ortiz’s willingness to stand up for

the disability community in the face of large corporate interests. Reiskin says lobbyists representing providers that make money off the disability community will often go to legislators claiming to represent disabled people, and Ortiz isn’t afraid to challenge that model. “David says, ‘You have a right to lobby for your business interests, but you’re not representing the disability community. We can speak for ourselves,’” Reiskin explains.

Bennett, then an intern, was equally appreciative of her boss’s no B.S. approach. “Hearing someone just shoot straight, and say, ‘No, I’m not putting up with this, I’m not going to appease your demands. We are putting this through to help the disability community,’ was honestly very inspiring.”

Ortiz knows that he can rub people the wrong way, but if that’s the cost of pushing the legislation he believes in, he’s OK with it. “I’m not here for people’s feelings,” he says. “Likewise, I’m not here to be rude, but if you’re running a bill that’s going to negatively impact the disabled community, I’m going to tell you.”

Titone summed up her co-sponsor’s approach: “He says what’s on his mind and he tells you without beating around the bush.”

Thanks to the strong testimony and the work put in ahead of time, all three bills were passed out of committee, in spite of the unexpected last-minute opposition. “I don’t want to say

‘MY TRUE VOCATION’

When former state Sen. Brittany Pettersen asked Ortiz if he had ever considered running for office, he told her he hadn’t. Pettersen, who has since been elected to represent Colorado’s 7th Congressional District in Congress, told him not to answer then and to talk to leaders in his district.

That district, House District 38, had been held by Republicans for the previous decade and was considered a “breeding ground of many of Colorado’s leading GOP candidates,” according to coloradopolitics.com. Still Ortiz, a Democrat, did what Pettersen recommended. He kept hearing the same thing: We need someone like you to serve. “At the end of the day, that’s my true vocation, I like to serve. That’s why I was in the military. That’s why I do a lot of work for nonprofits. So, I said yes and I filed in May of 2019 to run for office.”

Ortiz assembled a large team of volunteers, raised a lot of money and ended up defeating the Republican incumbent by over 10 points.



A ramp and lift were installed in the House chamber for Ortiz’s first term.

that luck had nothing to do with it, but I think everything went really according to plan,” says Ortiz.

However, before anyone could celebrate, word got out that lobbyists were working to kill the bills. “I was very indignant and motivated to make sure that I wasn’t going to let them sink those bills,” says Ortiz. “We had to try to salvage that and make sure we didn’t end up losing votes and not passing the bills. It was too important, and we had to make sure they got passed.”

With the help of the broad coalitions he and his team had built, he reached out to legislators on both sides of the aisle to shore up the votes needed for an eventual floor vote. After over a month of scrambling, all three bills made it to the House floor, all three passed, and the governor signed them into law.

ALL IN FOR THE COMMUNITY

Despite an undeniably successful first term, there is obvious work to be done. The physical accessibility of the Colorado State Capitol provides a perfect metaphor. One of Ortiz’s first matters of business after being elected was securing an accessible office with the space and accommodations he needed. When the process dragged on, Ortiz pushed back. “They thought I was coming in too assertive and too aggressive,” he says. “That was the start of me being like, Oh, they don’t understand that this is not me being an asshole. This is me fighting for my community’s health and access.”

New lifts and floor renovations have improved access, but critical issues remain. “One of the reasons why I’m not running for leadership is because the entire chamber is not accessible yet,” says Ortiz. “How can I be a whip if I can’t get to every single legislator?”

While the progress may be frustratingly slow from Ortiz’s perspective, Reiskin says Ortiz’s impact has already been transformative for disabled people. “As someone who’s been doing this for many years, I’d say his presence at the Capitol is more of a game-changer than anything else he has done. It has created access in a way that we have never had, and quite frankly, could never have gotten without someone like him in there.”

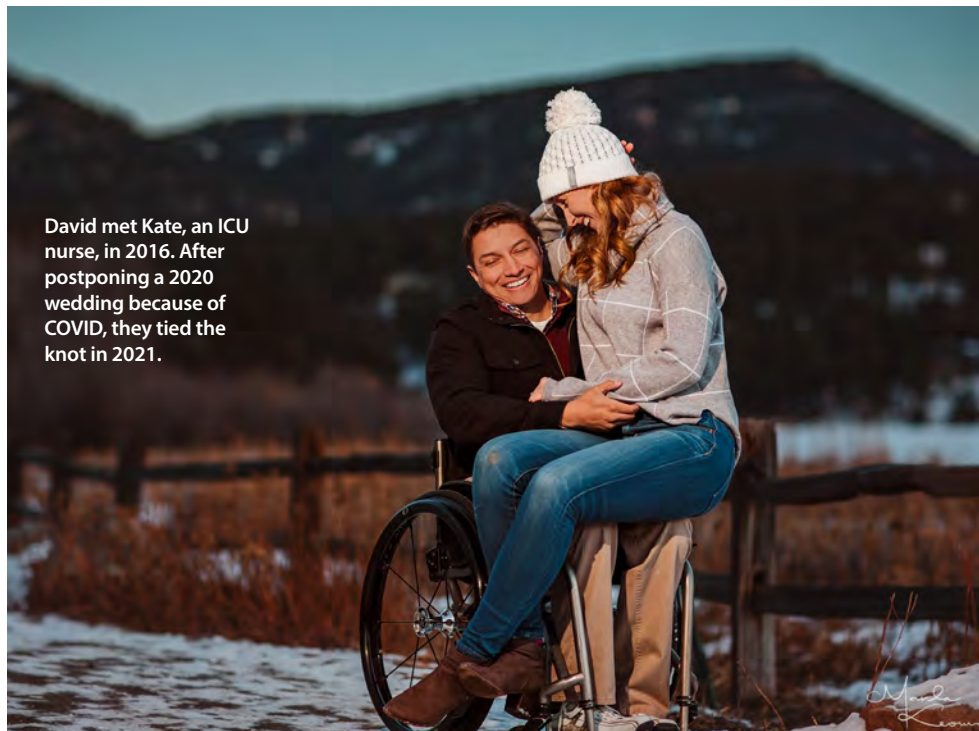
In addition to physical access, Ortiz’s willingness to candidly share details of his day-to-day life have given many of his fellow legislators and the public a better appreciation of what living with a disability is like. “There were some marathon sessions where he stayed up in his chair too long and it resulted in some health problems,” says Reiskin. “He tweeted about it in detail and said, ‘I’m OK, I’m getting good care, and this is part of living with a disability.’”

The physical and mental toll of the job is substantial. During session Ortiz has little time for anything but work. “The stress of this work, and the time that it takes, impacts my health in a very negative way,” he says. He estimates he has made 15-16 trips to the

emergency room since he announced his run in 2019.

On the heels of all of his accomplishments in his first term, Ortiz has abandoned any trepidation about being known for pushing disability issues. Of all the communities he intersects with, he says he feels the most responsibility to the disability community. “He doesn’t distance himself from us,” says Reiskin. “He’s proud of being part of the disability community and he embraces us.”

Ortiz notes that other minority groups have strong caucuses, but there is no disability caucus, and he is the only legislator with a mobility-related disability. “I know how inaccessible the world is, and I’m not giving up on this fight,” he says.



David met Kate, an ICU nurse, in 2016. After postponing a 2020 wedding because of COVID, they tied the knot in 2021.

Photo by Marla Keown

REAL CHANGE

Ortiz’s fight will continue for at least the next two years. In November, he won reelection with over 55% of the vote. He can point to the physical changes in the Capitol and the higher level of awareness around disability issues as signs of progress, but he and his staff are already hard at work on legislation for the coming session. Bennett says to expect a continued push on disability issues. “He tells me he can’t wait to pass a ton of legislation and then hand the bar off to the younger generation. He can’t wait to be a mentor.”

For his part, Ortiz claims to have no interest in running for higher office and says he is perfectly happy representing the people of his district. Reiskin sees a bright future for him whichever way he decides to go, but hopes he stays in public policy and politics because he is so gifted.

Reiskin was so impressed by Ortiz that she incorporated him into the graduate school class on policy she teaches. After playing a recording of him presenting a law, she tells her students, “This is how you do it. This is what real change is.”

—Additional reporting by Joelle Brouner

U.S. REPRESENTATIVE

JAMES LANGEVIN

A PIONEER ROLLS OFF THE HILL

When the people of Rhode Island's 2nd Congressional District elected James Langevin in 2001, they made him the first power wheelchair user and the first quadriplegic in the history of the U.S. House of Representatives. For the past two decades he has been a consistent, effective and outspoken voice for the disability community.

He was the Outstanding Congressional Leadership Award recipient at United Spinal Association's inaugural Roll on Capitol Hill in 2012. And this past year, he received United Spinal's Congressional Lifetime Achievement Award. *NEW MOBILITY* Editor-in-Chief Ian Ruder sat down with Congressman Langevin as he prepared to retire at the end of his term, to discuss his remarkable career and the road ahead.



NEW MOBILITY: Congratulations on 21 years of service as a congressman. As a fellow quadriplegic who understands the added complications and obstacles that come with a spinal cord injury, I have to ask, what has been the secret to doing such a stressful and demanding job for so long?

Rep. Langevin: Just for the record, it's 22 years, but who's counting? (Laughs) Living with a disability, especially being a quadriplegic, is not without significant challenges, as I'm sure you can well appreciate. I really haven't given it much thought in terms of how I've done it. I had this goal in mind — I wanted to run for Congress and serve my community and be the representative who was the voice and the vote for the people of the 2nd Congressional District of Rhode Island — and I never let anything get in my way. I've always had a positive attitude and said, 'I'll figure it out as we go.' It hasn't been without hiccups. There have been times it's been quite challenging being a wheelchair user and serving in Congress, but with a lot of help and a lot of accommodations, I made it.

NM: As the first quad in Congress, and probably the most visible power wheelchair user in



President Joe Biden congratulates Langevin on a distinguished career.

American politics, you've been the face of disability for a lot of people. How do you handle that responsibility? And what advice would you give to others who are trying to be leaders and dealing with the same issues?

RL: I have to say that I've never made disability the sole focus of who I am or what I do. At the same time, I've always recognized the responsibility I've had at various levels of government where I've served to be a voice for those who are facing similar challenges from the disability community. Having

the experience of living with a disability has made me a better policymaker in the area of disability policy. I embrace my disability as part of my identity, but I've never let it entirely define who I am or what I do. That's the advice I would give to anyone that has a disability — you are not defined by your disability. You have interests and hobbies, and passions, just like anybody else. I've always tried to embrace mine, and I encourage others to embrace theirs and, whenever there's opportunity, to leave the ladder down — or the ramp down, if

you will — and allow other people to grow, find their path to success and realize their goals and dreams. I've always felt I have an obligation to do that, and I've always tried to encourage others to do the same.

NM: Of all the conversations and teaching moments about disability you've had with colleagues and elected leaders, is there one interaction or anecdote that stands out?

RL: When we were fighting for the rights of LGBT people, I said I live with a disability and I know what discrimination feels like. I encounter it almost on a daily basis, and I don't like how it makes me feel. I don't want anyone else to feel that same way. I translated my experience into how discrimination might impact others that had nothing to do with disability. It's still discrimination nonetheless, and we need to speak out against it and stamp it out wherever possible.



A young Langevin when he was a state representative.

NM: Since 2001, you've sponsored over 300 bills and co-sponsored almost 4,000, including countless bills focused on disability. What piece of disability-related legislation that you've been involved with are you most proud of? What piece do you feel has had the biggest impact?

RL: One of the most important ones is the Lifespan Respite Care Act. I created The Lifespan Respite Care Program back in 2006, with a Republican colleague of mine. Respite care provides short-term relief for family caregivers, which helps them to continue caring for their loved ones. If the caregiver can't take care of their own health needs — for example, getting to the dentist or the doctor or doing the shopping for the

family — they get burnt out and they can't do the other things that they need for themselves or the family, and everyone suffers, especially the one that needs the care. We wanted to provide a respite care program, and it's been very successful. The estimated annual economic value of uncompensated family caregiving is approximately \$500 billion, if you had to put a dollar figure to it. Supporting family caregivers helps to keep overall health care spending down. I'm very proud of the fact I passed a bill to reauthorize the program recently in 2020.

As far as the bills that have had the biggest impact, I would say the ADA Amendments Act of 2008, which strengthened the ADA after it had been weakened by the courts through several controversial rulings. And the Affordable Care Act that we passed in 2010, because it expanded insurance coverage for people with disabilities and eliminated discrimination based on preexisting conditions. It prohibited the insurance companies from charging higher premiums because of a disability and it also improved access to long-term care support services.

NM: You mentioned the ADA and ADA Amendments Act; 32 years after the ADA was signed into law, what's your quick take on where we are with ADA?

RL: The ADA is a monumental law. It opened up so many doors for people with disabilities, myself included. In fact, I'm confident that I would not be here as a member of Congress if it weren't for the ADA. However, the ADA isn't an end-all solution. It's not just one and done. We can't say we've completed our work. We still need to build on its success and there's so much more that we have to do to take accessibility to all aspects of our society so that people can truly live the American dream and realize the promise of the Olmstead decision: to be able to live in our communities independently.

NM: Is there one disability-related bill that you fought for or sponsored that you didn't pass that you wonder what might have been had it passed into law?

RL: The Air Carrier Access Amendments Act is the one that comes to mind. I've introduced it (every session) since the 115th Congress. We haven't made enough progress toward making air travel accessible yet. I still have my gripes about airline travel — they could and should do more. But we've had some successes with parts of the bill. By way of example, in 2018, we secured language in the Federal Aviation Administration Reauthorization Bill to create an Airline Passengers With Disabilities Bill of Rights, which clearly spells out the fundamental rights of travelers under the Air Carrier Access Act. This Bill of Rights was posted on the DOT website earlier this year, and I'm pleased about that. But there's so much more that we need to do to make air travel accessible. The remaining parts of my bill are focused on updating accessibility standards and holding airlines accountable for violating the rights of travelers with disabilities. The fight isn't over. I am confident that my colleagues will pick up the mantle and strong committee advocacy will eventually get this done.

NM: When you took office back in 2001, you founded the

Bipartisan Disabilities Caucus in hopes of raising Congress' awareness about the challenges facing Americans with disabilities. How would you rate that awareness today and the progress we (the disability community) have made over the last two decades?

RL: Congress was aware of disability long before I arrived in Washington, but the Bipartisan Disabilities Caucus is helping to move the ball further forward. It has served as a forum for education and awareness and helped forge relationships between members of Congress on both sides of the aisle to find common ground on disability issues. I believe Congress' awareness of disability issues is much better now than when I arrived in Washington 22 years ago. But I credit the majority of that progress to the dedicated and tireless advocacy of the disability community. They were the ones that really pushed hard to pass the ADA to begin with, and they continue that advocacy. It's had a profound impact in countless ways. We still have much more work to do to ensure that all people with disabilities have access to the resources and support they need to live independent lives in the communities, to enter the workforce and participate fully in society. Our work is not yet done.

NM: Your old iBot was an iconic presence rolling around the Cap-

itol, and you recently got one of the slick new models. What is it going to take to get Medicare and insurers to recognize the benefits of complex rehab technology and start covering invaluable equipment like the iBot?

RL: Medicare and other insurance policies have not kept pace with the exciting advancements in Complex Rehabilitation Technology, and they're going to need to catch up. To get there, it's going to take persistent advocacy from the disability community and lawmakers. That's why I've been working with United Spinal and other members of the ITEM Coalition to help advance through the requests for Medicare to cover power seat elevation, and power standing systems for power wheelchair users. And I believe that once we succeed with that effort, we have to push it farther. We need to keep pushing

until Medicare, Medicaid and other insurance companies cover all forms of Complex Rehabilitation Technology so that the people with disabilities can live more fulfilling and independent lives in their communities. Technology is game-changing — when you can afford it and use it. We have to make sure that it is affordable and covered.

NM: There was a 21-year period after you were paralyzed before you joined Congress, and now you've served in Congress for 22 years. What are your plans for the next 20 years? What are you most looking forward to?

RL: I'm still working on what my next chapter will be. Right now, the plan is to come home and take my time to decompress a little bit. I'll be pursuing a role in academia and there'll be other

things that I'll be involved with. I want to do something that's meaningful and challenging. I'll be working on determining what those things will be over the course of the next several months. Being a member of Congress has been all-consuming — it can be a dizzying pace sometimes. I am so fortunate to have such an amazing staff, and I'm going to miss having them around me and working with me every day.

NM: What advice do you have for fellow wheelchair users who are interested in running for office?

RL: Just do it. Start by being involved in your community, pursuing things that you have a passion for and interest in. That's what I did, I developed an interest in government politics. I started that way and one thing led to another. It's important to serve as a role model wherever possible and open up doors of opportunities and break down barriers for others with disabilities so that they, too, can pave their own way to success and realize their own goals and dreams.

NM



Is Franklin allowed on Langevin's new iBot (above)? Maybe not.





It took Kenn Perry 23 years to find a martial arts teacher willing to train him as a wheelchair user. He's been paying it forward as a teacher for 30 years.

ROLLING WITH THE PUNCHES: Self-Defense for Wheelchair Users

BY DEBORAH RUBIN FIELDS
AND IAN RUDER

Imagine you're hanging out by the pool in your wheelchair with a friend, and a group of thugs emerges from the bushes, knocks out your friend and rushes your chair. What do you do?

Double amputee Ted Vollrath found himself in exactly this situation and he didn't hesitate. He knocked down the closest attacker with two quick punches, grabbed a ninja star from his spokes and zipped it across the pool, right into the jugular of another assailant who was reaching for a gun. Vollrath then finished off the remaining thugs with an array of punches and body attacks, eventually dragging two of them into the pool and subduing them.

If that sounds slightly (or extremely) fanciful, rest assured, Vollrath — reportedly the first wheelchair user to receive a black belt in karate — did do all these things ... but he did them as the eponymous title character in the 1978 grindhouse classic “Mr. No Legs.” Without the benefit of Hollywood magic, however, the prospect of

defending yourself as a wheelchair user can be quite daunting. What are the best tactics to protect yourself? Can a wheelchair user actually stave off attackers? And if so, how?

Prevention and De-Escalation

For 23 years, Kenn Perry struggled to find the answer to an even simpler question: Where does one go to learn adaptive self-defense? Perry, a polio survivor who uses crutches and a wheelchair, finally found a kenpo karate teacher willing to instruct him — and most importantly, he learned to explain why he could not perform an exercise and how to work with instructors to adapt the moves.

Today, he holds black belts in kenpo and small circle jujitsu. He founded the Willow Foundation for Adaptive Martial Arts and is a member of the Adaptive Martial Arts Association. In his 30-plus years teaching students of all abilities, he has been an outspoken advocate for adaptive self-defense and martial arts.

While Perry has never faced a situation like Mr. No Legs, he did meet Vollrath at a self-defense conference, and he has used his skills to physically defend himself. His best advice for fellow wheelchair users is to never let dangerous situations get that far. Use common sense — don't roll alone at night, avoid sketchy situations, and keep your head on a swivel.

"If you're doing self-defense right, it's very much mental," says Perry. "You're hoping that before it gets too physical, you've already been able to de-escalate the situation or get out of the way. Your ultimate goal should be gaining good control of your chair, or whatever apparatus you use, and increasing your situational awareness so you can see challenges coming before they get there."

Awareness is also at the heart of Molly Hale's self-defense instruction. She has been practicing Aikido for 38 years — 11 as a nondisabled student and 27 as a C5-6 wheelchair user. She is the U.S. representative for the Disability Working Group of the International Aikido Federation. With a fifth-degree black belt, she and her husband are opening a dojo in Northern California.

"In a martial practice, you learn a 360-degree awareness," she says. "So not only are you aware of what's in front, but also what's behind. We call it collecting the backside. Wheelers need to gather their 'backsides,' and engage in bringing energy from their back through the front of the body."

Learning to control breathing is a big part of this expanded awareness. "If one is holding one's breath or seizing up, it can cancel out effectiveness," she says. "Lack of sufficient oxygen creates a panic in the brain, clouding thinking and response."

Controlling your voice is perhaps even more important in conflict management. Erik Kondo, a T4-5 paraplegic with a third-degree black belt in small circle jujitsu, urges students to practice speaking and body language in front of a mirror. "The most effective technique to learn is how to use your voice to set boundaries and to send a message that you will not be easily victimized. Using your voice in a powerful manner requires practice. For many people, setting firm boundaries doesn't come naturally."

When Conflict Is Inevitable

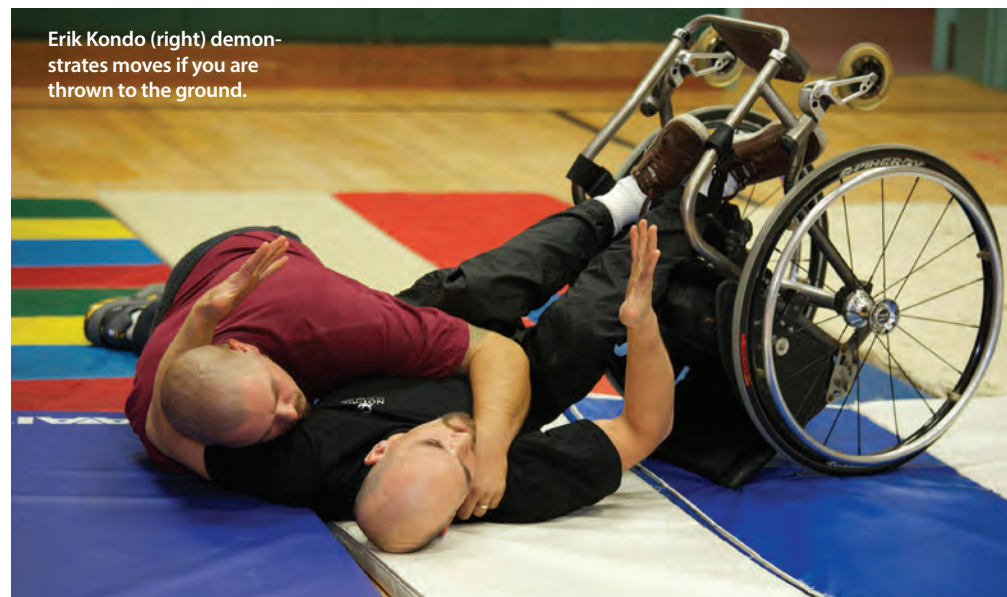
Sadly, sometimes awareness and voice are not enough. "A highly motivated attacker will not be deterred by your voice and body language alone," Kondo says. "Such a person will likely use violence to get what he or she wants." Kondo founded his nonprofit Not-Me! Inc. to promote self-defense education to help wheelchair users and others in exactly those situations.

Kondo stresses that people should be cognizant of the differences between the martial arts and self-defense. To explain the differences, he refers to David Erath's *The Ultimate Guide to Unarmed Self Defense*, which notes that many forms of martial arts "were not made for self-defense in the first place; most provide no education or understanding of real violence. Many martial arts techniques will not work against a fully resisting,

suggestion that wheelchair users should grab a frontal attacker's hair or clothing and take a quick push backward to disrupt the attacker's balance and cause them to fall forward.

"Assuming the attacker has broken a strong verbal boundary and appears to be ready to physically attack or is in the process of grabbing, the wheelchair user would have to use one arm to reach up and grab the attacker and pull back on one wheel with the other arm to go backwards," he explains. "This is a very weak movement. There is no power. Most likely the attacker would just counter-grab and pull the wheelchair user out of the wheelchair."

Kondo says a common and effective violent attack against a wheelchair user is to knock the person out of the wheelchair, either by pulling the person from the front, pushing the wheelchair over from the side, or knocking the person backwards with a pull from behind or a



Erik Kondo (right) demonstrates moves if you are thrown to the ground.

uncooperative opponent. In addition, most styles lack realistic training with and against modern weapons."

For Kondo, realistic training means being prepared for the unexpected and understanding what actually works and what only works in theory or against a compliant training partner. He takes issue with a lot of traditional instruction that doesn't account for the variables that occur during real-world attacks.

As an example, he questions the practicality of another adaptive instructor's

push from the front. He urges wheelers to focus on minimizing negative consequences by knowing how to fall without sustaining injury and how to protect the head once on the ground.

"You must know how to use your arms and hands in such a manner as to both protect against continued attacks while simultaneously striking back and making as much noise as possible," he says. "In the event of a violent assault, fighting-back methods could include eye gouges, biting, clawing, ear ripping,

nose and eardrum penetration, neck and throat attacks, along with head and groin strikes. The overall strategy is to convince the attacker to willingly disengage from you by causing as much pain and injury as possible, while minimizing your own chance of serious injury.”

Trust Your Body and Skills

Perry urges students to think outside the box about what tools are available. “You

have to understand that you have things that able-bodied people don’t think of that can be used very effectively,” he says. “If you can quickly remove the armrests off your chair, that becomes a club, and carbon fiber and aluminum and steel is a lot harder than bone. You smack a guy in the arm or a leg with that and you can cause a lot of damage very quickly.”

Manual wheelchair users can also use their footrests to undercut an attacker’s balance. Perry recommends maintain-

ing a 45-degree angle to your attacker. “If they’re coming in on a 45, you’ve taken away a lot of vital targets that they might want to strike, and you still have some ability to attack some of their vital areas. It also sets you up for an escape route. You know that if somebody’s coming into you on a 45, you can hit them and move them in one direction and you take off in the other direction.”

For power wheelchair users, Perry says the key is to avoid a victim mentality. “Your mindset has to be different,” says Perry. “If you’re thinking because you’re sitting in a chair and can’t move your arms that you are highly vulnerable, you’re forgetting that you’re sitting in a 300-pound tank. When you hit your joystick, you’re on top of the attacker before he knows it, inflicting pain.”

Hale emphasizes that what self-defense looks like for you will likely be different than what it looks like for anyone else. “Keep an open mind, and honor and trust the movement you have,” she says. “Don’t expect what you do to look like any classical martial art, because it’s all adaptive.”

Unlike 35 years ago, when Perry struggled to find an instructor willing to teach him, now many teachers are willing to work with students of all abilities. Perry encourages anyone who wants to learn more to find an instructor who communicates well and is willing to push them.

“When you’re in a dangerous situation, you need to have trained past your comfort zone. You need somebody that’s going to tell you, ‘That’s not good enough,’” he says. “If you find the right teacher, you’ll come up with approaches that are appropriate that you can make work.”

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Dating in my 40s as a Wheelchair User

By Sylvia Longmire

So, can you still . . . do it?

As crude as it sounds, this is the most common question women wheelchair users get when they enter the dating pool. As if dating in 2022 wasn't hard enough already – especially when you're in your late 40s like me – people with disabilities who are brave enough to put themselves out there in the search of romance face an entirely different set of challenges than those of nondisabled singles.

My situation is further complicated by the fact I wasn't born disabled, and only started dating as a full-time wheelchair user after my divorce seven years ago. In my 20s, I never had a hard time meeting men at bars or social events. I was attractive, in great physical

shape, outgoing, and led a very active social life with friends. At the time, I didn't want to get married or have children, so I wasn't looking for anything serious. Online dating existed, but it wasn't nearly as popular as it is today. In any case, I didn't need it.

Fast forward to 2015, when I became newly single. I had been diagnosed with multiple sclerosis 10 years earlier and was now a full-time wheelchair user. I could stand with some help and had full upper body function, but I could no longer walk at all. I was still attractive, but not as fit as I used to be because now my options for exercise were limited. Still, after taking the appropriate amount of time to heal from my divorce, I decided to give dating a try after over a decade of being off the market.



A New World

The return to dating came with a long list of anxiety-inducing challenges. Just like for nondisabled singles, there are two main routes for people with disabilities to look for a romantic partner — in person and online — and each way has its pros and cons. Personally, I prefer meeting potential dates in person. That way, there's no question about the fact that I use a wheelchair — men get a sneak preview of what I physically can and cannot do (in a G-rated capacity), and they have an opportunity to get to know me beyond just the chair.

However, the biggest obstacle to meeting potential partners in person is going out and getting into places where you would, you know, meet potential partners. Much of my social life revolves around the live music scene in Orlando, and dive bars aren't exactly known for their wheelchair accessibility. Wheeling around tables and stools, inaccessible bathrooms, and touchy-feely drunk patrons isn't my idea of a good time. Almost every time I go to a local bar to hear live music, an inebriated man much larger than me is either leaning on my chair, trying to lean on me, or is on the brink of falling on top of me. While I get an inordinate amount of attention from men when I go out for a live music event, much of it isn't necessarily pleasant.

A male friend once told me that people often treat me like I'm a pet — and as a single woman in a wheelchair in social spaces, I'm certainly regarded as a novelty of sorts. In bars, both men and women tend to come up and touch me without permission. On a recent cruise, a woman approached me during a silent disco, kissed me on the cheek and hugged me without even saying hello first. On another cruise, a guest entertainer had a hard time keeping his hands to himself, despite having a wife back home.

I've had better luck with friends of friends, or people whom I meet in a group setting, but even that isn't a guar-

antee against a bad situation. Several months ago, I had an acquaintance offer to do me a favor with a home repair. I had known him for a couple of years from the live music scene, but we had never had an extensive conversation. We went out on a few dates, and things seemed promising, until I decided to do a cursory background check of public criminal records. It turned out that three weeks before our first date, he had been arrested for domestic battery of his ex-girlfriend, who had broken up with him only a few days earlier.

No App for This

A lot of wheelchair users opt for the online dating experience, also known as the ninth circle of hell. Truth be told, my online dating experience has been horrific. I make sure my wheelchair features prominently in my primary profile photo on every platform. I have a good mix of full-body photos in my wheelchair and close-ups of my face, so when men swipe right on me, I'm assuming they know what's up. The hardest part for me after matching with somebody is to get a good conversation going.

The first challenge is getting past ... let's call them "unfortunate" comments and questions. One man asked me if I could pull him in a wagon behind my chair. The most common first question I get has something to do with my ability, or perceived lack thereof, to have sex.

Next is the curse of multitasking. I've had men confuse their conversations with me because they were messaging another woman at the same time, which gets uncomfortable when they tell me how much fun they had hanging out with me the night before — even though we've never met. One told me he wasn't into texting or online dating, right after he asked me through an online dating app for my phone number so he could text me.

Even if we're able to engage in great conversation over sev-

The Devotee Factor

One of my most viewed YouTube travel videos is of me demonstrating the difficulty I had in simply transferring from my power chair to a very high hotel room bed. Before you get any crazy ideas, know that I was fully clothed!

I credit the popularity of that video to devotee viewers. These are typically men who have a kink or fixation on a woman's disability as a source of sexual gratification. In some cases, this fetish involves watching a disabled woman struggle.

Sometimes devotees are hard to spot. Other times, you get an introductory message through online dating apps like I did a few years ago from a man who said he couldn't wait to take care of me, help me put on my clothes, feed me, brush my hair, and ... paint my toenails. In many cases, these guys may be harmless, but it's wise to stay aware and safe.

eral days, that doesn't always bode well. A few years ago, I was really hitting it off with a senior firefighter of a local battalion. That is, until I figured out his full name, Googled him, and found out he had been arrested for domestic assault. Then there was the guy I was having a pretty profound conversation with, who suddenly started to get way too sexual in his texts and asked if he could take a pause from texting so he could go masturbate.

Then there are the personal moments that are just plain awkward. Several years ago, I was rolling around downtown Warsaw, the capital of Poland, when an American man came up to me. He said, "Hey, are you on Tinder? I think I saw your profile last night. Sophia or something, right?" Of course, it was me. There probably aren't that many women who look like me with travel photos in an electric scooter on Tinder, and certainly not within whatever mile radius his app was set to. But there I was, telling him no, he must have me mistaken for somebody else.

Rolling Forward

By now, I'm sure you're wondering what my success rate has been with both dating methods. Because I'm a travel writer, I

THE FIRST CHALLENGE IS GETTING PAST ... LET'S CALL THEM 'UNFORTUNATE' COMMENTS AND QUESTIONS. ONE MAN ASKED ME IF I COULD PULL HIM IN A WAGON BEHIND MY CHAIR.

//

spent a few years not dating because I was always out of town, and I didn't date at all during the pandemic. However, I have been on several pleasant dates with men I met through online dating. They never made it past the first date because the chemistry just wasn't there, although they were genuinely nice people. They had a few shy questions about my MS and my wheelchair, but that only came after a considerable amount of conversation. The two men I have dated for any significant length of time since my divorce are people I had either worked with or knew through mutual friends, and this is still how I feel safest.

Dating at an older age is tough, whether or not you have a disability. Being a wheelchair user adds extra obstacles in the minds of others. They worry if down the road they're going to have to take care of you. If they'll be able to have sex with you. If you'll be able to go out on "normal" dates. The answers to these questions are going to vary from person to person, of course. But the good news is that there are awesome men — and women — out there whose interest in a person goes beyond simply the way you get from point A to point B. Only you'll have to sit through some awkward dates and head-tilting conversations to find them.

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The Flap

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BY THE ROLLIN' RNS

The dreaded pressure sore — a major challenge to maintaining quality of life and a problem that can occur no matter how vigilant you are. Whether your sore quickly gets out of hand or simply isn't healing fast enough despite treatment, there may come a time when your wound care team suggests "flap surgery." We are here to explain what this means and how you should proceed based on the knowledge and experience of others who have been through this.

Well before considering flap surgery, there are many wound care treatment options worth exploring, including wet to dry dressings, an Unna boot (wrap), wound vacs, ointments, creams and more. But when these treatment options aren't successful or take too long to heal a wound, is when flap surgery starts being discussed.

In flap surgery, the surgeon removes all the dead and diseased tissue, a procedure called debridement, and then replaces it with a "flap" of healthy tissue, along with an intact blood supply from a nearby part of the body to promote healing. Patients who develop stage 3 and 4 pressure injuries with a prolonged chronic and complex wound are the usual candidates for flap surgery.

We spoke with three individuals who are all too familiar with flap surgery: Jim Vacik, 61, a C6-7 complete quad since 1979; Dustin Matthews, 38, a C3 quad since age 2 from a spinal stroke; and Erica Davis, 41, a T2-T11 paraplegic from a spinal hemorrhage in 2005.



Erica Davis's flap surgery journey started with a small scrape.

ERICA DAVIS: FINALLY GETTING IT RIGHT

After accidentally falling to the floor in November 2021, Erica Davis had to scoot across the carpet to get to a chair that she used to pull herself up. "I was wearing boxer-type shorts and they rolled up, giving me direct contact with the carpet, so I got a small carpet burn," she says. "Just a small scrape is how it all started." Even though she was treated by wound care nurses at home, the wound quickly worsened. Two prior

skin grafts in the area from a burn in 2009 didn't help the healing. After six weeks of oral antibiotics and home health nurses, she was admitted into the hospital in January near where she lives in Carlsbad, California.

An MRI showed something going on in her hip bone, either inflammation or infection, so she had a peripherally inserted central catheter or PICC line inserted to deliver IV antibiotics. Knowing the wound would not heal if there was a bone infection (osteomyelitis), she took on the task of

interviewing doctors and discussing their approaches before she made up her mind as to which approach was best for her busy lifestyle. “One surgeon wanted to be more aggressive with flap surgery, but three other doctors were against it. I was just waiting for them to figure things out and give me my options so we could get the show on the road and back to healing.” She was discharged to her home in mid-February after the PICC line was removed.

While she was recovering at home with wound care nurses coming in three times a week to change the vacuum-assisted dressing called a wound vac, two more infections developed. The last infection needed another IV antibiotic, but she no longer had the PICC line. She ended up going into the ER with fever and chills. “They took an MRI of my hip that had the osteomyelitis, and results showed there was still some infection left, which is why I kept getting infections even though the wound was very slowly healing.”

After careful consideration, Davis selected a surgeon from the three physicians she had consulted. “I chose the

surgeon that seemed to have my best outcome in his plans.” In all, she was treated with not only oral and IV antibiotics, but also a wound vac, hyperbaric oxygen, debridement surgery, and finally, muscle flap surgery. She says it all helped, but killing the bone infection was critical to success.

Her surgical team performed flap surgery by pulling tissue from her upper gluteus muscle back to the wound area and stitching it in place. From surgery, she went directly to a Clinitron sand bed, a specialty bed that promotes healing. “It’s like a mix between a waterbed, quicksand and a cloud. It’s so weird. It’s constantly moving and it’s nice and warm.”

Importance of Post-Op Recovery Time

After three long weeks in the hospital lying in the Clinitron bed after surgery, Davis was finally discharged home, where she started an even longer process of strict bed rest. “I was not allowed to put any pressure whatsoever on my right tush as my muscle flap continues to heal.” Having done her homework, she lobbied to get approval for a Dolphin pressure-redistributing bed, one of the best in-home therapy beds.

Her health care team came up with a post-op schedule for her: complete bed rest for six weeks with no sitting, before adding five minutes of sitting time every day until she reached two hours. That took 24 days. After that, the protocol called for a five-minute rest after every two hours of sitting — forever. “I will have to be more careful with my tush now that it’s had a few surgeries, but I’m looking forward to getting back out there again.”

Davis is careful to point out her takeaways from the ordeal. “I didn’t really start to make real progress until I had an infectious diseases doctor and a plastic surgeon involved as well.” Reconstructive plastic surgeons are best for flap sur-



After an intensive recovery period, Jim Vacik — pictured at Red Rocks Amphitheater — was able to return to his active lifestyle.

gery. “The plastic surgeon really stressed how important it is to do regular pressure relief. Muscle can die in two hours without blood flow, fat takes four, and skin dies in six hours.”

Davis is now back to teaching a workout class one day per week. “I’m all healed up on the outside, but I was told it can take up to a year to heal up completely on the inside. I can’t wait to get back to teaching my workout class full time. I want to get back to my people.”

JIM VACIK: PROPER NUTRITION AND STAYING VIGILANT

Jim Vacik refers to his flap surgery experience as an adventure. Beginning in 2009, he started having bouts of osteomyelitis, which required antibiotics, like Davis. The bone infection created a sore under his skin that worked its way out, resulting in sepsis and hospitalization. “At that time, I was 30 years post-SCI. It was my first sitting sore, in the right ischial. A little drainage started, and I noticed it in my pants,” he says. “I felt something. It was difficult to actually look at since I’m a C6-7, but it felt hot and moist.” Very quickly it progressed into fever and chills, and by that time it had tunneled out. “I had no idea it was a bone infection.” A nurse practitioner at Craig Hospital’s outpatient clinic looked

Protein Needed for Wound Healing — More Is Better

The National Pressure Ulcer Advisory Panel “recommends a global protein intake for pressure ulcer healing of 1.25 to 1.5 g/kg of body weight per day. For patients with Stage III/IV pressure ulcers, the proposed level is 1.5 to 2.0 g/kg, depending on the size of the pressure ulcer and the total protein loss from draining wounds. In a study, the group receiving higher protein (1.8 g protein per kg body weight) demonstrated nearly a two-fold greater rate of healing than those randomized to lower protein intake (1.2 g protein per kg body weight).”

Taken from ncbi.nlm.nih.gov/pmc/articles/PMC5930532

at it and sent him straight to the ER at nearby Swedish Medical Center, where he was seen by an infectious diseases doctor and a plastic surgeon.

First, they debrided the wound area and put him on antibiotics, leaving the wound open and on a wound vac. He continued on the IV treatment for months to kill the infection until he was ready for flap surgery. “A long time before then, maybe 20 years prior, I had a sore in that same place, but it seemed minor. I did have other problems with osteo not in that area.” They shaved down his ischial tuberosity and removed some bone. The doctor could see what was there, and having seen hundreds of similar wounds, said an MRI was not needed.

“While I was healing, I was on a high protein diet tailored to the number of calories that I needed for optimum wound healing, along with a steroid regimen similar to what bodybuilders do, also to enhance healing.” He was admitted to the ER around St. Patrick’s Day and discharged three months later around the Fourth of July.

Vacik’s post-op schedule was similar to Davis’s. He had to lie completely flat on an air mattress with no more than 6 degrees of head elevation for six weeks, and turn using a logroll technique every two hours. After six weeks, when the wound was declared healed, his physical therapy program started with some gentle stretching and range of motion. He was allowed to sit up for 10 minutes and immediately went back to bed for a skin check. The next day it was 15 minutes and back to bed. The following day it was 15 minutes first thing in the morning, then back to bed, then another 15 minutes later in the afternoon and back to bed.

Each day the sitting time was increased by five minutes, then 10, then 20, then in half-hour increments, as his skin tolerated it. “The goal was to get to eight hours

Dustin Matthews feels fortunate to have avoided flap surgery.

minimum of sitting time with no skin issues. I was also doing weight shifts (for pressure relief) every 20 minutes for two minutes.”

DUSTIN MATTHEWS: WHEN FLAP SURGERY CAN BE AVOIDED

With lots of patience, a wound vac, and several wound debridements, Dustin Matthews healed a 2009 pressure sore in nine months with no discussion of a surgical flap. But in 2019, a sore opened up in the same butt cheek. “My wound care doctor at this time believed in nothing but flap surgeries, but he never shared his plan with me,” he says. “He performed the first debridement and thankfully didn’t think the wound was ready for the flap that day. In recovery, he mentioned the flap and I freaked out.

“I had read a lot about flaps and I preferred to heal otherwise. My biggest concern was lying flat and having that cause lung issues.” With a C3 SCI, he worried that his lungs would not be able to take extended time lying flat. “Recovery is too hard, and that would force me to stop living my life.” Based on these concerns, and the advice of his home health nurse, Matthews decided against surgery. “My home health nurse had seen flaps fail numerous times, and my bond with her is great. I’d trust her in anything.”

His doctor kept insisting on performing a flap, so he ended up leaving against medical advice.

Matthews found a

new wound clinic and now says his wound is completely healed. So how was it treated successfully without flap surgery? “I never did have an MRI, either the first one or this one, because I have metal in my back, but with this second wound it became clear I had an infection, so the doctor scraped it and biopsied it. I did IV antibiotics through home health and it cleared up pretty fast.”

The doctor did something new as well, using platelet-rich plasma therapy along with a wound vac. “The wound went clear to the bone. It did so well and made progress every doctor visit. Now I am healthy and happy. Flap free.”

Dr. Bruce Ruben, a wound care specialist who built his own completely wheelchair-accessible wound care clinic in Michigan and is known for successfully treating nonhealing wounds, believes in the healing power of the body when everything is done right. “In this case, it sounds like the doctor did everything right,” he says. “I have had moderate success with PRP therapy, but a pressure-free wound properly debrided, with proper nutrition, good circulation, no edema and no infection can heal on its own with proper management.”

Bottom line, we have spoken to many in the SCI population and a high percentage of those who have had flap surgery would do it again. But as we have researched, and by talking with others, it is a major commitment in post-op care and a major responsibility to “baby” the site. Getting up too soon, staying up too long, or allowing too much pressure could cause the surgical site to reopen. Starting all over again with an open wound adds the risk of infection. Also, moving in the bed can cause shearing and reopening the site. Proactive healing following flap surgery is labor-intensive for many months afterward. **MM**

—Additional reporting by Tim Gilmer

RESOURCES

- Wound Source, woundsource.com/blog/pressure-injuries-and-flap-surgery
- Dolphin Bed, joerns.com/products/dolphin-fis



MEMBER AWARDS *gala*

a #StrongWheeled Success

BY SHANNON KELLY

United Spinal Association’s yearlong #StrongWheeled Together campaign culminated in November with its first-ever Member Awards Gala, a virtual celebration of the strength of the SCI/D community. With awards, musical performances and more, the gala highlighted United Spinal’s efforts to empower wheelchair users to live the lives they choose, and to raise public awareness about the benefits of diversity, equity and inclusion in helping people with disabilities discover greater independence.

“Our #StrongWheeled Together campaign is a tribute to the collective power of United Spinal’s members and grassroots advocacy leaders. Together we are building a better future for people with spinal cord injuries and all wheelchair users while honoring our past,” said event emcee and Ms. Wheelchair America 2020, Hilary Muehlberger.

The gala celebrated a new generation of leaders with a night of entertainment and education while commemorating the historic figures who helped pave the way. United Spinal CEO Vincenzo Piscopo presented Judy Heumann with the Lifetime Impact Award for her decades of tireless advocacy.

“When I look back at everything I have accomplished, I find

that none of it would have been possible without the roots Judy Heumann laid down through her incredible advocacy. Presenting Judy with the Lifetime Impact Award was incredibly exciting, as well as humbling,” said Piscopo. “Her wisdom is incomparable. She shared a wealth of knowledge and has an incredible warmth.”

The gala also announced the winners of the #StrongWheeled Together Awards, each of whom received \$5,000 grants for their leadership in the areas of Entrepreneurship and Innovation, Performing Arts, Sports and Recreation, Visual Arts and Writing, and Youth Leadership.

Fifteen finalists were selected among a diverse pool of nominees from around the nation. Those finalists crafted videos about their lives and achievements that were published

on United Spinal’s YouTube channel. The award winners received the most likes on YouTube in each category.

“We created our #StrongWheeled Together Awards to raise awareness of the gifts and talents of our community’s artists, athletes, innovators and leaders. It is our powerful way to support their impactful work. And it demonstrates that we are #StrongWheeled Together in our greater fight for recognition, equality, justice and inclusion,” said Piscopo.

To watch the gala, sign up for membership with United Spinal at unitedspinal.org, where you can also find information on peer support and becoming an advocate or a member of its chapter network.

And the #StrongWheeled Together Award Goes to ...

Entrepreneurship and Innovation: Erik Kondo

Erik Kondo is advancing innovation and creativity in the field of adaptive mobility. He has pioneered the concept of “wheelchairboarding” as a method of adapting existing mobility devices for enjoyable and high-performance mobility for wheelchair users.

“Winning this award provides me the opportunity to promote two areas that I am passionate about: encouraging do-it-yourself innovations and the need to advance entrepreneurship for people with spinal cord injury/disease,” said Kondo. “I plan to use the funds to build and host websites for select people with spinal cord injuries and disorders to help them with their enterprises. I will also use the funds to help people in Nigeria with SCI/D start a small business so they can sustain themselves.”



Kondo

Performing Arts: Dominick Evans

Dominick Evans is a disabled and nonbinary transgender director, screenwriter and Hollywood consultant. He directed the 2021 music video for James Ian’s song “Spaces,” capturing the way people in the Spinal Muscular Atrophy community live their lives and occupy their own unique “spaces.”

He plans to put the grant money toward his organization, FilmDis, which advocates for authentic representation and



Hilary Muehlberger hit her mark as MC.



Vincenzo Piscopo presented Judy Heumann a Lifetime Impact Award.

inclusion of disabled people in front of and behind the lens. “We are using the funds to hire someone to help us with our FilmDis study into disability representation on television. We now have a data analyst who’s going to help us compile our latest study, which will be released at the beginning of 2023.”

Evans is developing television pilots and hopes to be the first disabled person to be the showrunner of a television show from their home. “I was able to direct a music video that way and I believe I can show Hollywood just what the disabled community is capable of when they are accommodated.”

Sports and Recreation: Antonio Martin

Detroit native Antonio Martin’s goal was always to play in the NFL, but when he became paralyzed from a gunshot wound in 2012, he had to rethink his plan. He decided to help other talented football players from his hometown play professional football, even though he no longer could, so he started his business, Bros 2 Pros Sporting Agency & Mentoring.

Martin also joined Team USA Paralympic Powerlifting. He has traveled all over the world to compete in the sport and holds the American record in his weight class for the last three years, lifting 502 pounds.

“Winning this award means a lot to me because it’s my first award since being disabled. This award has inspired me to continue to compete at the highest level and do more for the disabled community,” said Martin. “I plan on using this grant money on my next competition so I will be able to compete at the 2024 Paralympic Games. I have also started a spinal cord injury meetup to help individuals with disabilities to continue to be active and social.”

Visual Arts and Writing: Yesenia Torres

Since becoming paralyzed seven years ago, Yesenia Torres has dedicated herself to serving the disability community by advocating for changes in legislation and peer mentoring. She is a community leader at the Colombian Consulate, a board member at the Brooklyn Center for Independence of the Disabled, a council member of New York State Independent Living Council and the accessibility outreach coordinator at the New York City

Taxi and Limousine Commission.

Her first book, *Destinada a Renacer*, documents the hard passages of her life to encourage people who are going through difficulties. She is finishing the second book from the trilogy, *Against the Horizon*, and is excited about the final book. “I will use the grant money to pay for my editor expenses, book illustration design, publishing and translation into English,” she said.



Torres

Youth Leadership: Anna Sarol

Anna Sarol is a coach, adaptive athlete, keynote speaker, social media blogger and disability advocate. She uses her Instagram page to educate others on spinal cord injury and to advocate for inclusion and equity. “There’s a lot of time, effort and care that goes into each individual content that I upload,” says Sarol. “Despite what one might see as a 30-second video, I know it took me 5-6 hours to produce. All of it is worth it, knowing that I am doing my part to make the world a better place. Winning this award reminds me that I’m not only making a positive impact, but a long-lasting one.”



Sarol

“I am a huge advocate for prioritizing shoulder health as a wheelchair user. I understand the chronic pain we can often experience, and I would love to help others alleviate this trouble. As part of my plan, I will use the grant money to purchase muscle therapy guns for other wheelchair users to use whenever their bodies need them.” The therapy guns deliver percussive massage for muscle soreness, pain and recovery.

The Music

The gala was also packed with performances by musicians from the disability community, including:

- Hip-hop duo **4 Wheel City**, in a fun, celebratory performance. These two United Spinal members perform with famous rap stars like Snoop Dogg, and yet they always find time to speak at schools and provide peer support.
- Recording artist **Kebra Moore**, whose song “He’ll Make a Way” was featured on the soundtrack of *Becoming Barack: Evolution of a Leader*.
- 2020 American Idol contestant **Marna Michele**, who was coached by Katy Perry and Luke Bryan to sing Lady Gaga’s “Million Reasons.”



PRODUCTS

By Michael Franz

TESTING THE EVOLUTION HOME GYM



After 21 years as a quad, I struggle to find new ways to exercise that feel worthwhile. Doing the same exercises on the same equipment for years makes it easy to hit plateaus and become discouraged about making progress. The Evolution Home Gym is a new piece of exercise equipment that combines resistance bands with a sturdy and versatile platform so wheelchair users and others with disabilities can perform exercises in new and different ways. After a few weeks with the Evolution, I could feel muscles burning that haven't burned in a long time.

Simplicity Evolved

The Evolution's simple yet effective design consists of a 3-by-3-foot platform with height-adjustable posts on the corners. The posts have holes where you can place hooks to anchor resistance bands. The Evolution comes with five sets of resistance bands with up to 170 pounds of resistance, eight hooks and locking pins to anchor the resistance bands, two pairs of handles, a pair of wrist/ankle straps and an assistance strap that is useful when extra support is needed. It also comes with a pair of bars that can be attached to the tops of the

posts to create a set of parallel bars.

Delivered mostly preassembled in a single 77-pound box, it only takes a few minutes to finish setting up the Evolution. The posts on the corners come preattached and folded down but need to be set in the upright position and secured with a bolt, for which an Allen wrench is included. Assembly does require being able to reach the ground and manipulate the Allen wrench, so assistance may be required depending on your level of function.

The Evolution allows users with differing levels of function and strength to complete exercises that would otherwise require several pieces of equipment. In my experience as a wheelchair user, the worst part about using resistance bands is finding someone or something to anchor them. The Evolution eliminates this problem as it provides a steady base and many options for attaching the resistance bands. The resistance bands come in 5-, 10-, 25- and 35-pound resistances and can be used individually or together.

Exercises can be completed either on the Evolution's platform or outside its frame. While on the platform, you can do seated exercises like chest presses, shoulder presses and front shoulder raises. You can also utilize the parallel bars for tricep dips or to work on assisted standing exercises. From outside the frame, which is where I did most of the exercises while testing the Evolution, you can

do rowing exercises, shrugs and curls, among many other options.

The handles for the resistance bands worked well for me with my Active Hands grip aids. You can also use the parallel bars from outside the frame to do sit-to-stand exercises from a wheelchair. I was able to do almost all the exercises on the Evolution that I would normally do with the weight equipment I use at home or at physical therapy. The Evolution website has a video library of exercises for wheelchair users as well as nondisabled people. I found the video library very helpful, both for finding ideas of what to do and how to properly set up the Evolution for different exercises.

Some Assistance Needed

Quads and people with limited hand function, beware: There are some design decisions that could make it difficult to use independently. First, the platform of the Evolution is 2.5 inches high. In order to get on the platform, the user needs to pop a wheelie and pull themselves up using the posts or have somebody bump them up onto the platform. I have spoken with representatives of the company, and they hope to add an option for a small ramp in future generations of the Evolution.

The other shortcoming of the Evolution is that it will be difficult for users with limited hand function to adjust the height of the posts and to secure the hooks and locking pins. In order to adjust the height of the

“I found the video library very helpful, both for finding ideas of what to do and how to properly set up the Evolution for different exercises.”

posts, you need to twist and pull a knob to unlock the post and simultaneously move the post up or down to the desired height. To secure the hooks and locking pins, you need to put the hooks through the holes in the posts and secure them by threading what is essentially a large bobby

pin through a hole in the stem. I was not able to do it on my own. Of course, this is not an issue if you will have assistance, but it is worth considering if you're looking for a piece of equipment that can be used independently.

The Evolution is a great piece of equipment for wheelchair users looking to enhance their workout regimen. I enjoyed using it enough that I would consider purchasing one myself. The Evolution is also well suited for gyms and physical therapy clinics looking to add adaptive equipment. The Evolution is available for \$679.99 with free shipping in the U.S. For more information, visit the Evolution website, evolutionvn.com.



The handles for the resistance bands worked well with the author's Active Hands grip aids.

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OUTDOOR TRACKS

By Kary Wright

ACCESSIBLE SAILING: THE UNLIKELY SAILOR

I've always loved the water. As a kid I explored it with floaties, and then as I got older, canoes, rowboats, powerboats, water-skiing and scuba diving. As an adult, a fortuitous flight over a tropical island added fuel to my dreams when I saw people jumping off several sailboats anchored in a circle in a lagoon.

I phoned my brother to brainstorm how two brothers from the Great White North could possibly make sailing part of our lifestyle. We talked money, time and location. Over some beers, we formed a plan to make our aquatic dream a reality.

Around a year later, my brother and I were driving and talking about our plan when we got into the accident that made me a quadriplegic and gave my brother a severe head injury. We crossed sailing off the to-do list, penciled it onto the lengthy can't-do list, and forgot about it for a long time afterward.

Over the years, I've had a couple of sailboat rides, but I never had the opportunity of controlling one. I purchased a radio-controlled sailboat back in my radio-controlled-aircraft days, and spent hours learning the basics, including how to trim the sails for different wind speeds and angles. It was interesting and fun, but real onboard sailing remained on the can't-do list.

In early spring this year, I remembered hearing about the Disabled



"Super Dave" (left) joined Wright when he sailed an adaptive Martin 16 with instruction from the Disabled Sailing Association of Alberta.

Sailing Association of Alberta and sent an email to see if they were back in operation after being shut down by the pandemic. I was thrilled to get a reply saying they were.

I called my buddy Dave and told him the sailing club in Calgary had boats designed for disabled people. "Do you want to learn to sail?" I asked. Knowing how much he loves the outdoors and water sports, I already knew his answer.

"You bet, sounds like an adven-

ture!" he said. We booked a boat.

The day arrived and we started on the 2 1/2-hour drive early in the morning, allowing extra time to scout out the area and check over the boat to see how I could control it. The boat is a Martin 16, a 16-foot sloop designed specifically for sailors with disabilities by Don Martin of Vancouver, British Columbia. It has an adjustable molded seat that holds even us quadriplegics safely in place — in my case akin to making an

octopus sit up — and a joystick for control. All lines are routed to the cockpit so it can be completely controlled from the seat.

The boat is made mostly from fiberglass, with a double hull filled with foam to make it unsinkable even when fully flooded, and a 300-pound bulb keel that makes it untippable. It is very safe and has optional power assist.

Dave and I arrived at the club an hour early. The staff greeted us, and we introduced ourselves. The place was operated by a handful of college-aged kids. We went over my disability, what adaptations I'd need and what my goals were. We determined that I would need the power-assist system installed, and that I could use a joystick for control. We checked the joystick, and they allowed us to replace the ball on it with the taller one from my wheelchair.

For higher-level quads they have a mouth-controlled sip-and-puff system allowing full rudder and sail control. We were blown away by the staff's friendly attitude and savvy working with disabled people. They understood transfers and balance issues — they even reminded me to put my seat cushion in the boat when I forgot. The treatment and attention to detail was second to none.

Two Daves and a Dude

One of the staff informed us our instructor was named Dave, making our crew: myself, Super Dave (my buddy) and Sailor Dave. Super Dave and I went out for a walk while the staff installed the electric control system in the boat. When we arrived back at my assigned time, everything was ready to go. Super Dave had a life jacket and sling on me in seconds, and with the help of the staff, I was in the boat in no time. I tested the joystick, left and right for steering, back



Wright uses a joystick to control all lines from the cockpit.

“By the end of the afternoon, I was able to approach the dock heading into the wind and just kiss it while pulling up parallel.”

and forth to tighten and loosen the sails. The staff pushed us away from the dock, the wind turned us around and away we went.

“So do you want help or advice from me, or just to learn on your own?” asked Sailor Dave.

“We want to learn as much as we can,” I responded. “Tell us everything we’re doing wrong.”

“We want to get to the point where we can take the boats without instructors,” added Super Dave.

Sailor Dave gave us our first orders, directing us to head for a distant oil derrick and to “stay on target no matter what the wind does.” He had me practice following a course, staying in straight lines in different winds. I learned to steer the course with the rudder and tighten and loosen the sails to get the most power out of them. When going against the

wind, or “tacking,” you need the sails tight. When running with the wind, you let the winch out to loosen the sails. You can still travel forward in a headwind about 45 degrees off the bow, but any less and you are in “irons,” a no-go zone where your sails develop little to no thrust.

Sailor Dave had me practice tacking upwind in a zigzag pattern, being careful to turn quickly through irons so I wouldn't stop and lose control of my path. We also practiced docking to a buoy out in the lake. We approached from a few boat-lengths downwind and turned directly into the wind toward the buoy, trying to time it so the boat stopped just as it touched it. After a few tries everything became much easier. By the end of the afternoon, I was able to approach the dock heading into the wind and just kiss it while pulling up parallel.

Now, I'm totally hooked on sailing. I'm passing the cold winter months using a sailing simulator called Sailaway to keep learning and honing my skills. I can't thank the great crew at the Disabled Sailing Association of Alberta enough, and I can't wait to go back.



IN THE MEDIA

By Teal Sherer

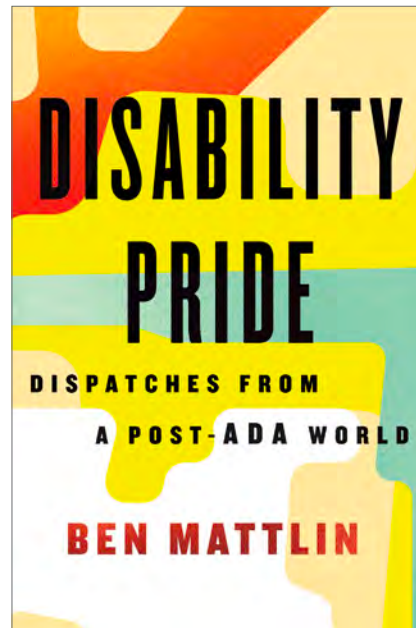
DISABILITY PRIDE: AN EXCERPT AND Q&A WITH BEN MATTLIN

In the opening to *Disability Pride: Dispatches from a Post-ADA World*, Ben Mattlin notes that when he was born with spinal muscular atrophy in 1962, the condition was practically a death sentence. Sixty years later, Mattlin and thousands of others with SMA and other disabilities are not only alive, but part of a vibrant disability culture. Mattlin, a longtime contributor to *NEW MOBILITY*, wrote *Disability Pride* to better understand how disability culture evolved, where it sits today and where it might be going next.

More than three decades since the passage of the ADA, a new generation of disabled people has come of age. In this context, Mattlin explores a wide range of topics, including how attitudes toward disability have changed, the rise of disability activism and the movement's shortcomings — particularly the poor acknowledgment of nonwhite and LGBTQIA+ advocates in the struggle for disability justice. Chapters on neurodiversity, systemic ableism in healthcare, the right-to-die movement and the struggle for deinstitutionalization provide a well-rounded read for anyone looking to deepen their perspective on longstanding issues that the community faces to this day.

EXCERPT: What is Pride — and Why Does it Matter?

For many people, disability pride remains a slippery, subjective concept; it connotes different things to different folks at different times. Pride in our accomplishments? Pride in our identity? Is it like gay/queer pride? Black pride? This lack of specificity may be surprising considering it's not really a new concept to the movement. In the early 1990s, Ed Roberts reflected that before he could go about trying to change the world, he had to alter his attitude about himself as a ventilator- and wheelchair-using polio survivor. He had to become proud of who and what he



was. Around the same time, the disabled writer Laura Hershey published a poem called “You Get Proud by Practicing” that became a kind of anthem, helping people understand how to achieve a healthy self-acceptance. It spoke directly to the shame and embarrassment many disabled people feel about their “broken bodies” or lack of a spouse or money or a job.

But what are the limits and the benefits of this post-ADA identification with disability pride? Eli Clare, a Vermont-based author, essayist and poet who describes himself as “white, disabled, and genderqueer,” writes in an essay called “Shame and Pride” that pride is sometimes used by marginalized communities as an act of resistance. “We’ve rejected the idea that our body-minds are broken.

We’ve learned lessons from the Black Power movement of the 1960s and the slogan ‘Black Is Beautiful.’ We’ve rallied around the value of pride,” writes Clare.

Emily Ladau, author of *Demystifying Disability: What to Know, What to Say, and How to Be an Ally*, says that disability pride is “not an isolated thing. It’s more like a shared cultural identity.” Born after the ADA became law, she is a past winner of the Paul G. Hearne emerging Leader award for up-and-comers in the disability movement. She uses a wheelchair because she has Larsen syndrome, a genetic condition that can cause dislocations of the joints and other hand and foot abnormalities.

Ladau cohosts *The Accessible Stall* podcast — a (mostly) monthly production where she and her cohost debate and explore a variety of current issues — and, for a number of years, Ladau edited *Rooted in Rights*, a blog that highlights authentic, progressive disability perspectives “through an intersectional lens,” or, as Ladau says, it “showcases perspectives that don’t always get the mainstream attention they deserve.”

Ladau’s mother and uncle also have Larsen syndrome, which she says was important for giving her role models when she

Q&A with the Author

Teal Sherer: As someone who writes about disability representation in media, I appreciate that the inclusion of wheelchair users in advertisements, on TV shows, and on Broadway inspired you to write the book. Can you tell us what you saw?

Ben Mattlin: It really was about five years ago when model and actor Jillian Mercado was on a big billboard in Times Square for the skin care brand Olay. Then, one after another, I began to see visibly disabled people representing cosmetic companies and high fashion on glossy magazine covers. Around the same time, there was the show *Speechless*, and Ali Stroker won the Tony. All of a sudden, disabled people were breaking the barriers in Hollywood, on Broadway and in high fashion and I thought, wow, what's going on? After the ADA was passed 32 years ago, I got married and we had kids, and I lost touch with the disability community. I realized a generation has come of age, with these rights, protections and expectations of being able to participate in society.

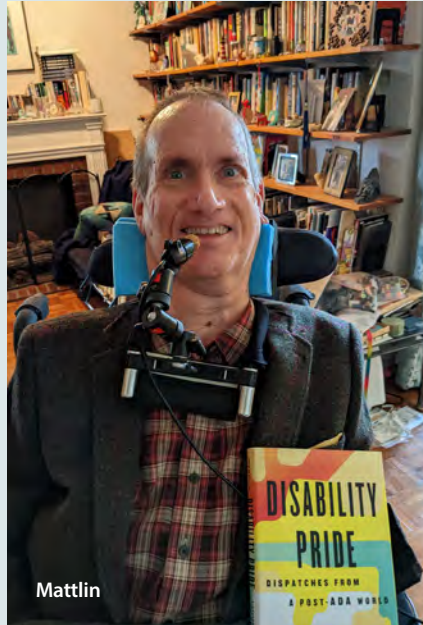
TS: *Disability Pride* is not only the title of the book — you have also dedicated a chapter to it, and it's a thread throughout. Is there anything you learned about disability pride that you didn't know going into it?

BM: I thought disability pride was about not feeling ashamed. That it was about loving yourself and self-esteem. I realized by the end of writing the book, that there was another aspect. Once you get to know more about the breadth and depth of the disability community — all that it does and has always done, often without any recognition and a lot of it erased from history — you almost can't help feeling proud to be to be part of that club. So, that was something kind of profound.

TS: In the introduction, you write: "I am not trying to repre-

was growing up. That's rare. As the scholar Jennifer Natalya Fink observes, disabled children are often relegated to an other status, their disabilities regarded as personal traumas they and their families must cope with, rather than ordinary experiences. "Despite the fact that one-fifth of all the planet's people are formally recognized as disabled, meaning that more or less everyone else is related to a person with a disability, we continue to construct our sense of family and its lineage in such a way that we are stunned, shocked and traumatized by the incredibly common, collective and familial experience of disability," writes Fink.

Authentic disabled role models can be crucial for helping disabled kids — and newly disabled adults — build pride. In mainstream media, there aren't many, and the few who do exist are



sent the entirety of crippdom. As a white, heterosexual, cisgender man, I couldn't if I tried." With that awareness, how did you approach researching and writing the book?

BM: I wanted to be as broad and inclusive as I could be. To kind of keep myself out of it and to amplify other people's voices or their words or however they express themselves. I put on my reporter hat. The hardest pieces to write were the two chapters in the middle. The ones on neurodiversity and intersectionality — communities of color, queer and disabled, and so forth. I am not part of those groups, though I am an ally. At first,

I felt a little awkward. Like, should I not be doing this at all? But I couldn't exclude them either. These are important parts of the disability community. I tried not to speak for them but rather designated space for members of those communities to relate their own perspectives.

TS: In addition to *Disability Pride*, you have written two other books — *Miracle Boy Grows Up* and *In Sickness and in Health*. You have also written for publications like *The New York Times*, *The Washington Post* and *Los Angeles Times*. What advice do you have for aspiring writers?

BM: The best advice I ever got when I was starting out was to write and write and write. How else can anybody know what you are capable of? For the first draft, throw everything you know into it. Don't self-edit. Just get it all in there. When you revise, then you cut out the bad stuff and polish up the good stuff. I liked getting to know other writers and reached out to some of my writing heroes — most were accommodating and friendly. It helped me feel connected to the writing community, and then later if I was looking for blurbs or referrals to agents or whatever, it was useful to have made those connections.

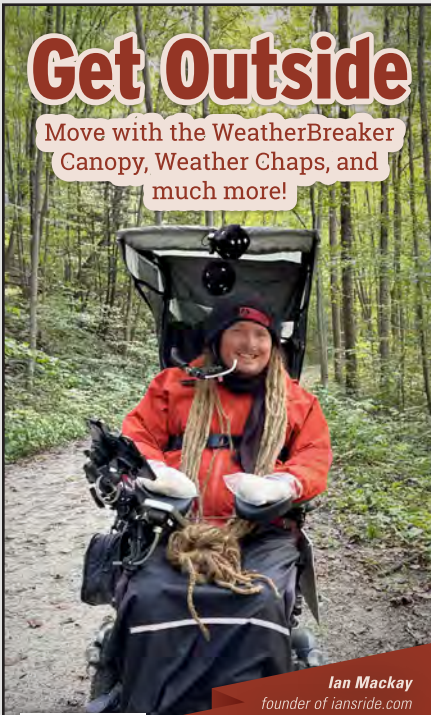
far outnumbered by nondisabled icons, which can be counterproductive for disability pride, reinforcing unrealistic expectations of attractiveness and acceptability.

Surprisingly, Ladau says her personal convictions about disability pride solidified when she got to know more people with different types of disabilities. "It was really when I started to find myself surrounded by a lot of other disabled people, when I chose to surround myself with the disability community," she says. "By doing so, I understood I wasn't alone. That's when I was able to foster this stronger sense of identity and pride."

Excerpted from Disability Pride: Dispatches from a Post-ADA World by Ben Mattlin (Beacon Press, 2022). Reprinted with permission from Beacon Press.

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The Inaccessible Childcare Conundrum (January 17)

Many daycares are based in private homes and — despite being subject to the ADA — they often remain inaccessible to wheelchair-using parents. Seth McBride shares the distressing reality of a recent childcare search for his 17-month-old daughter and asks why the U.S. won't do more to support working parents.

Gear Guide: Casters and Forks (February 1)

You might not think much about casters until you happen on a rogue pinecone and wind up sprawled on the sidewalk. Our latest Gear Guide catalogs all the casters and forks currently on the market so you can keep rolling smoothly.

Taking Advantage of an ABL Account (February 14)

ABLE accounts are tax-advantaged investment accounts that let you save for disability-related expenses without having to worry about Social Security and Medicaid's restrictive asset limits. We share tips on how to maximize these programs, whether or not you're receiving disability benefits.

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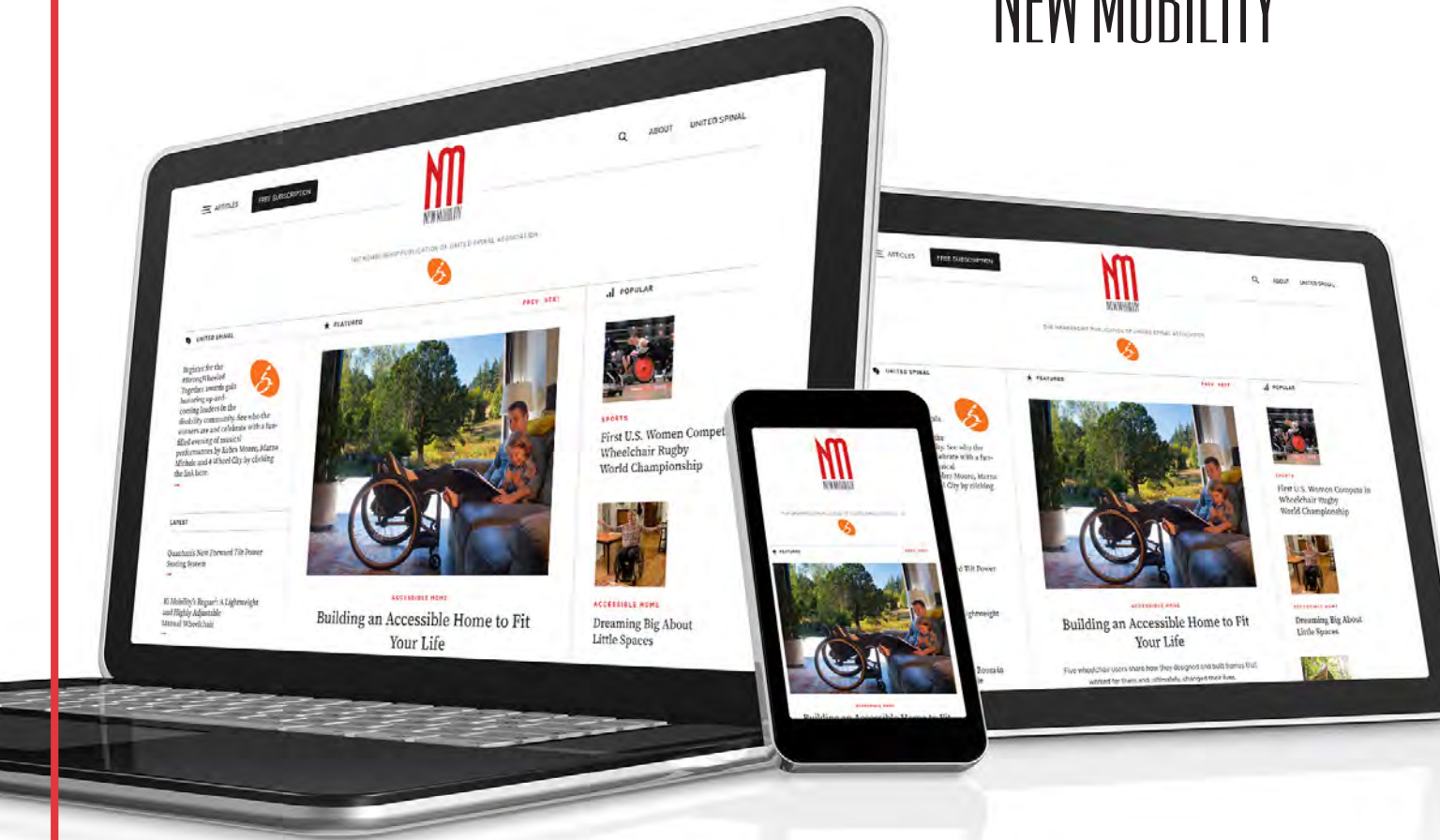


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Chicago
June 23-25, 2023

Houston
August 4-6, 2023

Phoenix
Sept. 8-10, 2023

Ft. Lauderdale
October 13-15, 2023

Dallas
Dec. 1-3, 2023

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