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NEW MOBILITY



THE MEMBERSHIP PUBLICATION
OF UNITED SPINAL ASSOCIATION

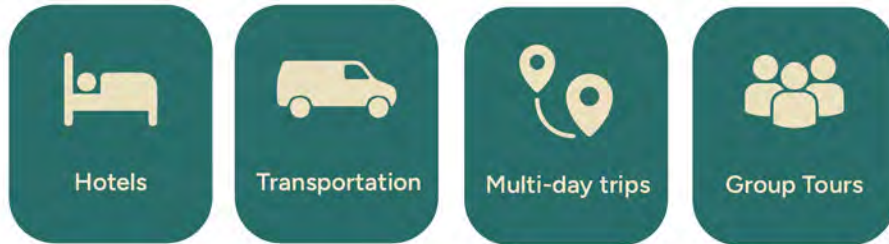
**Person of the Year:
Accessible Travel
Advocate
John Morris**



Making travel accessible

Wheel the World is the expert solution to find and book accessible hotels, multi-day trips, and group tours. Founded by Alvaro Silberstein, a C5 quad, we understand the importance of accessibility. With hundreds of accessible hotels on our website to choose from, you'll know all the accessibility details before you go including bed height, door width, bathroom details, and more.

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“

Wheel the World and Essential Costa Rica has helped so many people including myself be able to secure a vacation where you have accessible transportation and lodging.

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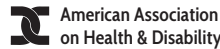
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COVER STORY

PERSON OF THE YEAR **24**

Most people know John Morris from his industry-leading accessible travel site, wheelchairtravel.org, but behind the scenes he has emerged as one of our community's most effective advocates for accessible air travel. IAN RUDER shares the different approach that Morris has embraced and how he is leading the fight for a more accessible future.

PLUS: Rising Stars: SWTCon Award Winners.

Cover and Contents Photos by Kyle Klein

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KATE MATELAN has the coats, bags, layers and accessories to keep you looking great in your wheelchair, no matter the winter weather.

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Painting is more than a hobby for the talented artists of the Association of Mouth and Foot Painting Artists. CHERYL ANGELELLI explains how the MFPA empowers its members to make real money.

40 FROM INDIA WITH LOVE

Sustaining a spinal cord injury while traveling in India exposed Jonathan Sigworth to the realities of disability in a developing country. TIM GILMER reports on how Sigworth is working to offer wheelchair users worldwide more pathways to independence.

44 POTENTIALLY PANAMA?

Intrigued by the possibility of saving money on care and costs of living, LILLY LONGSHORE took a trip to Panama to see what life abroad would look like as an aging quad. Here's what she found.

47 ADAPTIVE PANTS REVIEWED

Three wheelchair users test adaptive jeans that recently hit the market.

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BULLY PULPIT

By Ian Ruder



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ME AND MY ALGORITHM

Every time a targeted ad pops up on my phone or computer, I'm torn between being repulsed and fascinated. My intellectual side rages against living in a world where every electronic device doubles as an artificial intelligence-fueled spy devoted to knowing me better than I know myself. But then I see an ad for a *Die Hard* Nakatomi Tower advent calendar or tickets to see the *Star Wars* burlesque show, and my eyes light up.

Instead of worrying about how technology seems to be infringing on our private spaces and thoughts, I've decided to embrace it. I love my algorithm and want nothing more than to understand it. I'll talk within range of my phone about something obscure I'm interested in, just to see if it my algorithm is listening. Whenever an ad pops up or something is recommended, I try to determine why.

Sometimes the rationale is simple. *Die Hard* is one of my favorite movies, and I've purchased advent calendars — hence the Nakatomi Tower advent calendar.

Sometimes the suggestions are more nuanced. I'd never have guessed I'd enjoy watching videos of people clearing storm drains or washing exceedingly dirty carpets, but YouTube had me pegged based on my love of lawn mowing videos.

And, yes, sometimes the algorithm makes no sense. You won't find me buying sheer "ice silk underpants with 3D pouch and ventholes" no matter how many times Facebook tries to sell them to me.

Regardless, my algorithm is infinitely entertaining and — ice silk underpants aside — surprisingly useful in a true capitalist/consumer way. It has led me to some unique gifts and purchases and some memorable concerts and shows I might have missed.

Recently, my obsession with my algorithm collided with another of my "favorite" pastimes: filling out medical registration questionnaires. When you've clicked through as many of these forms as I have, you begin to wonder if they serve an ulterior agenda. Are they trying to discredit me? I can see the computer

saying, "Last time this guy said he had three kidney stone surgeries. This time he only mentioned one. Flag him!"

But I had a different idea filling one out while I was thinking about my algorithm. What if there was a medical algorithm? An algorithm built on the hundreds of questionnaires, test results and after-office visits I've accumulated that tried to keep me healthy instead of selling me things I probably don't need.

Sure, it could suggest equipment that worked for others with similar function and needs, but it could do so much more. It could help find the best experts to treat your needs, or maybe even supplant the need for experts. By comparing all your data with others around the world and throughout history, it could predict and analyze your health needs with accuracy that doctors could only dream of.

I started thinking about all the data that could fuel my algorithm, and the possibilities seemed revolutionary. I was getting excited.

Then an email from 23andMe popped into my inbox. It reminded me how leery I am about sharing my health info with third-party vendors. Images of Mark Zuckerberg and Elon Musk and the people behind the current algorithms started floating in my head. I could see my utopian solution morphing into a dystopian nightmare.

Tracking my internet history and eavesdropping on my daily conversations to sell me superfluous stuff is one thing, but having access to every microscopic data point of my medical history is a whole other level of creepy.

As it dawned on me that someone smarter than me is already building, or has built, something similar to what I envisioned, I stopped thinking about how a medical algorithm could improve my life and started worrying about whether we should be working to stop such an entity. It's probably too late for the latter, but brainstorming about how we regulate and implement such a powerful tool seems essential. Here's hoping my algorithm senses my interest in being involved and steers me in the right direction.



BEHIND THE STORIES

With Ian Ruder



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

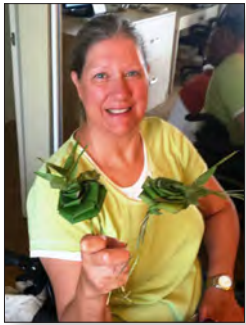
FEATURED WEB PARTNER:

Spin the Globe is an award-winning travel blog and site for accessible trip planning and disability resources.
spintheglobe.net

We liked **Kate Matelan's** 2022 "A Wheelchair User's Guide to Dressing Well" so much, we brought her back for our definitive guide to winter and fall clothing. She credits her mom for teaching her to embrace fashion. "She's always been super fashionable," says Matelan, "and we love figuring out what to wear together." When it comes to her personal style, Matelan says she likes "to mix basics with other funky pieces and styles." That same description could apply to Matelan's writing, as her fun prose has made her a memorable, longtime NM contributor. Matelan currently works as a senior copywriter for meal kit service HelloFresh.



When you get as many pitches for accessible travel stories as we do, it's refreshing when an email comes in with an idea we haven't seen before. **Lilly Longshore** managed to surprise me with her pitch for "Potentially Panama," a look at accessibility in Panama from the eyes of an aging wheelchair user considering moving abroad for more affordable living and care. The fact that her pitch was built on a 2021 NM story about ex-pats was icing on the cake. "I'm not tethered to living in America, and I wanted to explore other opportunities and see if there was something out there that might work," says Longshore.



I've used this space before to rave about how much our staff enjoys **Greg Moomjy's** writing, so you can imagine how excited I am to have him on board as one of a handful of new regular contributors we'll be rolling out in 2024. He approached us about the idea over a year ago and has patiently worked with our team to figure out the details of a recurring column. "Since I began writing for New MOBILITY, I've enjoyed exploring the many facets of what my disability means to me," says Moomjy. "Hopefully, with this column I can share my experiences and give advice to those that need it."



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.



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SHARE

“It feels like she is your own personal champion.”

NOVEMBER-DECEMBER 2023

Alana Nichols: Juggling Adaptive Sports, Advocacy, Motherhood and Media

Your Own Personal Champion: I met Alana in 2018 after I found myself on the Tibetan plateau organizing a wheelchair basketball tournament inspired by a little girl who needed more disabled role models in her life. Alana flew out to Tibet and made the tournament happen. Alana was the first disabled person I saw in the media that I wanted to be. Before meeting her, I was a little nervous how this incredibly accomplished athlete would relate to a 10-year-old with no interest in basketball. But as soon as Alana arrived in Tibet, I was in awe of her ability to genuinely connect with people on all levels. Alana has this endless capacity to recognize people's strengths and accomplishments regardless of their situation. Whether you're getting a new powerchair, skiing down a mountain on tethers or filling out a CAF grant, it feels like she is your own personal champion.

Cecelia Black

Via email

A New Hands-Free Option to Control Your Wheelchair: munevo DRIVE

A Needed Alternative: Wow. Just wow. Thanks for such a complete analysis of the product and how reasonable it will be for the actual people who will be using it. This sounds like a real alternative for those who have been using other more difficult systems. How much will it cost and will it be covered by insurance?

Deborah Gregson

Newmobility.com

Editor: Nina Rattenbury of munevo suggests interested parties get in touch with

their local vendor or assistive technology professional for specifics. She says “insurance can cover it” and notes that Veterans Affairs will cover the cost.

Profit by Renting Your Accessible Properties

Good Info: Such an informative and well-written article. The increased inventory on accessible homes is a true need, and this article covers so many of the benefits of that investment.

Adam

Newmobility.com

WEB FIRST CONTENT

No Limbits Adaptive Pants: Reviewed

Pondering Pants: I have been buying IZ Adaptive clothing for years. They have a new pant called Game Changers that have no back pockets and no seam up the middle on the back. These features help eliminate the risk of pressure sores for seated individuals. The downside with IZ products is a higher price, sizing inconsistency and unavailability, and the length of time to receive your order. Even with these challenges I still like my IZ Adaptive clothing. And, if the items are not available, you can always call or send an email to see if they can make what you are looking for. If you place a large enough order, they may do custom production on an order for you.

I also tried the JCPenney's adaptive women's jeans and ended up returning them. They have Velcro on both sides seams, which was challenging. I was afraid the rough Velcro side could damage skin and it was hard to open and close. As you described the challenges with the zipper sides on these jeans it reminded me of the challenges with



the Penny's jeans. I also hated that the Penny's jeans sat up to bra line in front and about butt crack in the back. I am a para with full hand function and these pants were a problem to get on — I can't imagine how a quad with limited hand function would manage. Nothing is ever easy for us.

Susan

Newmobility.com

Editor: See page 47 to read this article in print.

Wheelchair Users' Guide to Fall and Winter Clothing and Accessories

Leather Works: My leather bags and boots last for years. I pair a cotton T-shirt with wool sweater and scarves. Always works. I live in Minnesota — it gets COLD here. I have proper snow boots that have lasted for years. Totally worth the money.

Debi Smith

Newmobility.com

Another Vote for Leather: I lost my insulated leather mittens last year. Big loss for me because they gripped so well on my rims and they were REALLY warm. Insulated thicker leather gloves or mittens are hard to find nowadays.

Tuffy

Newmobility.com

Editor: See page 16 to read this article in print.



Dear Readers,

In keeping with good journalistic practice, I'm not going to bury the lead: I'm writing to ask you to support NEW MOBILITY financially. As we kick off 2024, we are launching a new subscription model that we believe will best position NM to continue providing the authentic, one-of-a-kind content we have reliably delivered for the past 35 years.

I never take asking for money lightly — especially from our community — so I want to make the case for your support.

If you are reading this, you are one of our loyal print readers. The obituary for print content has been written countless times over the past two decades, but the format's survival is testament to the fact that for many of us there is something profoundly special about being able to enjoy content in a hands-on way.

I love reading our archives online, but there is something about paging through the latest issue and seeing the articles laid out with sidebars, photos and, yes, even ads, that no internet browser has yet been able to replicate. In my dream world, we would provide free print and online access to everyone in our community who wants it. Unfortunately, as has been well documented elsewhere, the cost of print continues to rise. This is forcing even the largest news and media publications to reconsider their business models and making that dream even more difficult for a niche publication like NEW MOBILITY.

Thanks to the generosity of United Spinal Association, we've come close to achieving that dream over the past few years. The organization appreciates the financial obstacles so many of our disabled readers face. It has covered the added printing costs and agreed to provide a free print or online subscription to members. When you consider that membership is free, this means anyone who has wanted a print copy has been able to get one.

Under the new subscription model, all readers will maintain free access to the online edition of NEW MOBILITY, and new United Spinal members can still choose to receive a year of print issues for free. The main change is that we are asking members who want a print copy after that first year to subscribe for the low member rate of \$10 per year. The nonmember rate is \$14.95 per year.

For some perspective on what a good deal that is, consider that NEW MOBILITY retailed for \$5 per issue back in 1989 when it was published quarterly. In our current era of inflation, \$1.67 per issue has to be one of the better deals out there.

Spending decisions these days are tougher than ever. Whether it's online fundraisers to pay for needed medical equipment, bills refused by insurance, or the inescapable costs of day-to-day life, our money seems to be stretched thinner than at any point in recent memory.

If the emails and comments I see are any indication, you — our readers — appreciate and enjoy NEW MOBILITY. I encourage you to use this opportunity to show your support by subscribing if you have the means to do so. Or, if you have the resources, please consider sponsoring a print subscription, or multiple print subscriptions, for other community members.

Since its inception in 1989, NEW MOBILITY has survived the rapidly changing media world by delivering authentic, unique content created by the mobility disability community for the mobility disability community. With your help and financial support, we are excited to charge forward into our next 35 years.

Sincerely,
Ian Ruder
Editor-in-Chief
NEW MOBILITY



newmobility.com/subscribe

Hairless Casters?

Bowhead Corp.'s new Sevens casters feature a unique hollow-wheel design intended to eliminate one of most common annoyances of wheelchair casters: collecting hair between the caster and fork.



The hollow caster uses a large stainless-steel bearing that Bowhead says is more durable, less prone to rust and has a higher load capacity than typical wheelchair caster bearings. Christian Bagg, the wheelchair user who founded Bowhead, says the Sevens were designed for long-term use. "A big feature of the Bowhead Sevens is the modularity and the main-

tainability. What this means is each component is replaceable or maintainable. Some parts like the tire are consumables. We'd rather have you change just the tire than replace the whole casters," he says.

For more info, including pricing and where to buy, go to bowhead-corp.com/casterwheels.



Less Grumbling at the Gas Station

The fuelService mobile app aims to make getting gasoline as a wheelchair user less of a pain. The app provides a list of nearby fuel stations from its network of over 8,000 participating stations in the U.S. You can choose a station and tap "Ask for Assistance." Then fuelService contacts the station. After a few seconds, the app lets you know if the station's employees are available to help in the next 30 minutes. If they aren't, you can quickly try another station. Once you receive a confirmation, you can drive to the station with confidence. Upon arrival, you simply enter your pump number and notify the station through the app.

If you want to give it a try, the app is free to download on the App Store and Google Play, or you can go to get.fuelService.org.

WATCH

NEARLY FOUR YEARS AFTER THE START OF THE COVID-19 PANDEMIC, A NEW DOCUMENTARY OPENS THE DOORS TO THE APPALLING CONDITIONS FACED BY A GROUP OF WORKING-AGE WHEELCHAIR USERS AT THE GOVERNMENT-RUN COLER REHABILITATION AND NURSING CARE CENTER IN NEW YORK CITY.

FIRE THROUGH DRY GRASS WAS PRODUCED BY THE WHEELCHAIR USERS WHO LIVED THROUGH THOSE CONDITIONS, THE REALITY POETS, A GROUP OF



SON ON THE POWER OF COMMUNITY ORGANIZING. WATCH THE FULL DOCUMENTARY AT PBS.ORG/POV/FILMS/FIRETHROUGHDRYGRASS. AND YOU CAN READ MORE ABOUT THE REALITY POETS AT NEWMOBILITY.COM/2021-PEOPLE-OF-THE-YEAR-THE-REALITY-POETS.

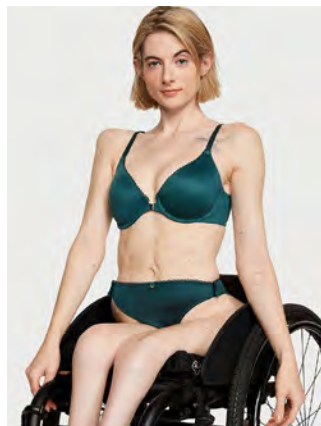


The fuelService app may make it easier to get assistance at gas stations.

Victoria's Secret Releases First Adaptive Line

Victoria's Secret and PINK have launched their first adaptive collection of bras and panties featuring magnetic closures, front strap adjusters and sensory-friendly fabric.

Wheelchair user and model Bri Scalesse stars in the Victoria Secret's Adaptive campaign. "Being a face for Victoria Secret's Adaptive campaign is an ode to my younger self who never saw a body like hers represented by an intimates apparel brand," she says. View the line at victoriasecret.com/us/vs/bras/adaptive.



Project Pope Chair

Paul de Livron makes wooden wheelchairs that are unlike — and more beautiful than — any wheelchair we've ever seen. He creates his chairs using pre-programmed machine-cutting to slice wood into layers, which he glues together and sands by hand to make a perfectly fitted creation of flowing curves. After seeing Pope Francis on TV being pushed around in a clunky hospital chair, de Livron decided the pontiff needed a chair more befitting his status as the most famous wheelchair user in the world.

The chair that de Livron made for Pope Francis is full of symbolic details. The wood for the frame is sourced from both Russian and Ukrainian forests, and the footplate is cut with the shape of a dove, symbol of peace. The armrests are made from charred ceiling beams recovered from Notre Dame Cathedral, and a geometry-inspired cross on the backrest is a nod to Francis' past as a scientist.

De Livron delivered the one-of-a-kind chair last fall. Check out more of his work on Instagram @pauldelivron.

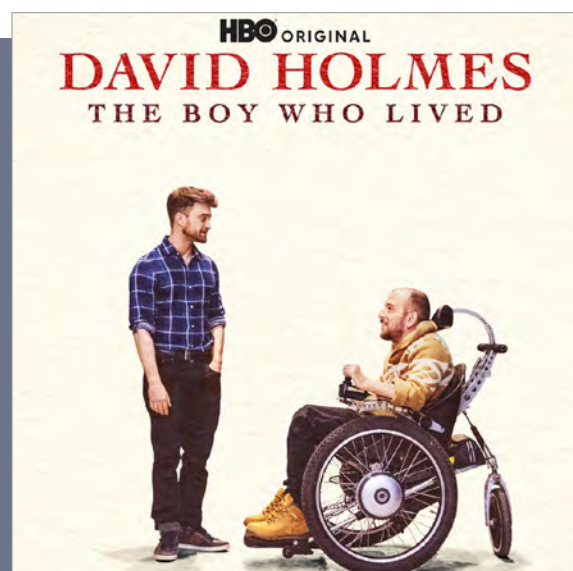


THE BOY WHO LIVED, A DOCUMENTARY PRODUCED BY HARRY POTTER ACTOR DANIEL RADCLIFFE, TRACKS THE LIFE OF HIS GOOD FRIEND AND STUNT DOUBLE, DAVID HOLMES, WHO WAS PARALYZED IN AN ACCIDENT WHILE FILMING *HARRY POTTER AND THE DEADLY HALLOWS*. THE FILM INCLUDES A LOT OF HARRY POTTER FUN, ONE VERY INTERESTING BRITISH-MADE WHEELCHAIR, AND WHAT APPEARS TO BE A LIGHT TOUCH ON THE TYPICAL "UNIMAGINABLE TRAGEDY" ANGLE

THAT PLAGUES MOST MAINSTREAM DOCUMENTARIES ABOUT WHEELCHAIR USERS.

AS HOLMES SAYS IN THE TRAILER, "BEFORE MY ACCIDENT, EVERYTHING WAS ABOUT BEING COOL AND BEING A STUNTMAN. NOW, IT'S ABOUT BEING PRESENT. I HAVE SO MUCH LOVE IN MY LIFE. ... I'M INCREDIBLY LUCKY."

THE BOY WHO LIVED DEBUTED ON HBO, AND YOU CAN STREAM IT NOW ON MAX.



By Shannon Kelly

United Spinal in the White House

United Spinal Association was honored to be represented at a range of recent events hosted at the White House, including a celebration of the 50th anniversary of the Rehabilitation Act of 1973 and the 33rd anniversary of the Americans with Disabilities Act. The event also recognized recent accomplishments including:

- The National Institutes of Health now officially designates people with disabilities as a population with health disparities.
- The Department of Justice issued a proposed rule to add more specific requirements about web- and mobile-application accessibility.
- The Department of Health and Human Services announced its plan to strengthen Section 504 of the Rehabilitation Act. The rule changes are hoped to improve access to medical equipment.



From left: Influencers Squirmly and Grubs, United Spinal board member Charisma Sydnor, Cole Sydnor, President Joe Biden.

“We were incredibly honored to be invited to attend a ceremony at the White House celebrating the anniversaries of the Rehabilitation Act and the Americans with Disabilities Act,” says influencer and United Spinal board member Charisma Sydnor. “When we all started our YouTube channels, we never expected to be amongst such fierce advocates and incredible change-makers. Let’s continue the fight to make our nation a more accessible and inclusive place for all!”



Meet United Spinal's Newest Board Members

United Spinal welcomes six new board members. The cohort represents a younger, more demographically and professionally diverse group while remaining disability-led.

Robert Barbieri: Barbieri is a family member of a wheelchair user and is passionate about working on behalf of our community. He has dedicated his successful business career to the tech sector, and currently serves as managing director of the business consulting firm New Port Partners.

Christopher Connolly: Connolly is a resident physician at and graduate of University of Michigan, holding both an MBA and MD. He is a former intern of Sen. Tammy Duckworth and an active advocate for our community living with quadriplegia.

Ana Torres-Davis: Torres-Davis is senior attorney at the National Council on Disability, having previously worked at the Department of Housing and Urban Development and the AARP Foundation.

Ali Ingersoll: Ingersoll is a seasoned nonprofit and diversity, equity and inclusion professional, a dedicated United Spinal member, Ms. Wheelchair America 2023, and a writer.

Carol Salas: Salas is the director of the Puerto Rico University Center for Excellence in Developmental Disabilities, newly elected president of the Association of the University Centers on Disabilities, and former staff member on the National Council on Disability.

Charisma Sydnor: Sydnor is one-half of superstar YouTube duo Cole & Charisma. Along with being an influencer, she was also once a rehabilitation tech, and has an M.A. in occupational therapy.

Meet New Member Cory Nadell

C1-C7 SCI, Age 42 from Fairmont, West Virginia

Why did you join United Spinal?

Instantaneously and without warning, my physical abilities literally hit reset, and fear and despair flooded every moment and thought. Finding United Spinal's website with its array of knowledge and community of people was a great comfort to me. The vast amount of information still has me clicking links on the site.

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

My rickety, base model Tracer EX2 wheelchair has been my life blood for the last two years. My goal for 2024 is to start using a walker or rollator as my main mode of mobility.

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

I would make sure that wheelchair users have the ability to safely, comfortably traverse the main roads of towns big enough to have a post office.

Pittsburgh Chapter Helps with Annual Wash & Tune-Up

As most health insurances only approve mobility devices every five years, wheelchair maintenance is imperative. The University of Pittsburgh Medical Center Rehabilitation Institute hosted its 11th annual Wash & Tune-Up event to help keep users' chairs rolling the way they should. Volunteers washed, performed minor repairs and evaluated potential problems on the wheelchairs. United Spinal's Pittsburgh Chapter was one of the 20 organizations involved in this event that served over 50 wheelchair users.

"Aside from just aesthetics, having a clean chair is really important for hygiene. When you're cleaning it, you can get all of the hair that gets caught up in the wheels so you

have a smoother push and you're not putting as much strain on your shoulders and elbows," says Chris Mielo, communications manager for services organization Achieva and a wheelchair user himself.

Get involved with United Spinal's chapter network: unitespinal.org/support/chapter-network.



The UP Wash & Tune-Up was a hit.

Tech and Health Care Equity Take Center Stage at SWTCon

United Spinal's StrongWheeled Together Conference held in Las Vegas in October offered opportunities for connection, learning and action for over 100 wheelchair users, students, clinicians and partners across various industries.

Two main focuses of the conference included the importance of accessible technology and making the health care system more equitable for the disability community.

Matthew Castelluccio, the organization's vice president of community support, facilitated a session with clinicians about bridging the gap between the medical model and community model. "This session was focused on the community needs of our patients and how medical professionals can be equipped with resources to address these needs. The medical professional should focus on the whole person and all aspects of their life," he says.

Members of the disability community discussed their experiences being discharged from in-patient care through the initial phase of being home. They shared what resources were available to them and where they turned for support. This panel allowed clinicians to learn from the lived experienced of wheelchair users firsthand and ignited a thoughtful discussion.

Panelists also discussed the barriers that the disability community faces when it comes to receiving medical care. They began the early stages of crafting a comprehensive health care toolkit that includes:

- Information and tips on self-advocacy for community members.
- Information for health care professionals on how to provide equitable care.
- Tools for health care professionals to gauge the accessibility of the office environment and provide telehealth services for their patients with physical disabilities.

The conference allowed students and partners to learn from the disability community about barriers they face while using technology, and the opportunities for using technology to improve health equity.

The breakout sessions brought together leaders in technology who are working to use their products to enhance independence for wheelchair users. "Even though many of our tech partners are aware of and working toward the development of assistive technology for wheelchair users, their eyes were opened to new ways to use their products and to barriers the disability community faces that they hadn't realized until after interacting so closely with the wheelchair users in attendance," says Louis Linebarger, the director of United Spinal's Tech Access Initiative.

SWTCon was a great success but just the beginning, according to United Spinal CEO Vincenzo Piscopo. "Our community is powerful, and I am more convinced than ever that when we are StrongWheeled Together, our ability to impact change gets exponentially bigger," he says.

DAY IN
THE LIFE



CAPTAIN TYLER TURNER

At the peak of summer tourism season in Depoe Bay, Oregon, you don't need to search far to find Capt. Tyler Turner. Long before the sun's first rays reach the small inlet that US Harbors magazine named the "Best Harbor in the U.S.," Turner stations himself on the Surfrider, his 50-foot boat, to prepare for another day helping one of the region's most popular charter services.

Turner, 35, grew up on the bay and learned the ropes from his father, Capt. Jeurgen "J.T." Turner. His road to captaining his own boat took a detour in 2008 when he broke his sternum in a motorcycle accident, sustaining a T4 spinal cord injury. He dedicated the next five years to rehab, mas-

tering his knee-ankle-foot orthotic braces and, as a paraplegic, figuring out how to do all the tasks required of a captain. It took over two years of appeals to convince the Coast Guard, but in 2013 he satisfied their demands and went on to earn his merchant mariner master license.

Today, Turner spends 200-225 days a year on the water, with most excursions clocking in at 6-12 hours. When he's not on the water, he's helping his wife manage the charter booking service and the candy shop they own, and spending time with his two young daughters. Here's how Turner describes a typical day leading his most popular outing, a five-hour bottom-fishing expedition.

3:30 a.m. I have to be down at the boat by 5:30. Everything takes a little longer as a para, so I make sure to leave myself enough time to drink some coffee, go to the bathroom and stretch. After I'm done stretching, I put on my KAFO [braces]. Mine are all carbon fiber and stainless steel because everything else corrodes when you're out on the water as much as I am. Once I'm all set, I'll throw my wheelchair in my Dodge Charger and head for the dock.

5:30 a.m. To get my license as a wheelchair user, the Coast Guard stipulated that I work with a two-man crew. By the time I arrive, [the crew has] already prepped the boat and is ready to help me down the gangway. With the tide constantly changing, the ramp can be flat or super steep. I learned it's better to back [my way] down early on, when my foot plate got caught going down forwards and threw me out of my chair.

After my injury my dad cut doors on the side of his boat's hull to make it easier to board in a wheelchair, and I've done the same. Most of the local captains have followed suit, which is really cool. Once I get to the cabin, I stand up with my braces and pull myself up to the bridge. My crew stashes my chair below and boards that day's passengers.

6 a.m. We'll drop crab pots on the way to wherever we're going fishing, and then hit the open seas looking

for whatever is on that day's agenda: rockfish, lingcod, cabezon, albacore tuna, halibut ... you name it. While we're out there I'm standing in the bridge, watching the sonar fish-finder and communicating with the passengers and crew. I used to stand the whole time, for 6-12 hours, but after getting a wound on my foot last year, I put in a seat. I'm trying to sit more. When time's up, or when we catch our limit, we'll pick up the crab pots and head home.

12 p.m. After cleaning the boat and taking notes on the excursion, I usu-

ally make a pit stop at our charter service office just to see what's going on and say hi to my wife. She's the brains behind the business and the candy shop, but I try to help out with behind-the-scenes stuff.

1 p.m. The first thing I do when I get home is take off my braces. During peak season, I know I'm going to be spending too much time standing in them already. In the comfort of my chair in my home, I can tend to business chores. I might be talking to distributors for the candy store,

setting up an appointment to get ice, or ordering supplies for the boat, depending on the day. I wear a lot of different hats.

4 p.m. Any time my two daughters are around, I try to spend with them. The toughest part of this job is that the busiest season coincides with when our kids are out of school.

5:30 p.m. We have two freezers full of fish at the house, and as you might guess, we eat a lot of seafood. My wife and I alternate cooking, but we all love a good egg-panko-breaded white

fish, panfried all crispy. After dinner, we'll all get out and roll around the neighborhood before maybe settling in for a movie or game.

9:30 p.m. I get zombie status where I literally almost fall asleep just sitting in my chair. It's a grind, and I try to rest as much as I can and take care of my body. It's important to have fun though, so we'll try to do little minivacations or a vacation in the wintertime. Otherwise why work so hard, right?

EQUIPMENT I CAN'T LIVE WITHOUT: My custom carbon fiber KAFOs.

FAVORITE SPOTS ON THE OREGON COAST FOR FISHING: Depoe Bay, Pacific City.

WHY I ENJOY TAKING WHEELCHAIR USERS OUT ON THE WATER: I love to share the experience of being out there for a few hours and leaving your worries behind.



GEAR HACKS

By Kary Wright

TINKER TIME

Life is all about identifying things that turn your crank and taking steps to make those things happen. Your gut will tell you what feels right, and then somehow the world/life/universe/God has a way of helping you figure out how to manifest your vision. Big projects and exciting adventures are great, but sometimes little projects can be just as satisfying. Over the years I have learned that I love to solve problems — and quadriplegia comes with a multitude of things to problem-solve. Often the solutions pop into my head about 2 a.m., and once they do, going back to sleep is not an option.

Learning to make computerized projects has been a dream of mine for a long time but until recently has been out of my realm of expertise. The advent of Arduinos, cheap microcomputers about the size of a stick of gum, has changed that. Now anyone can make themselves a design and programming expert.

In my last column I wrote about designing and building an Arduino-controlled device that flushes out my bladder and will hopefully stave off urinary tract infections. While building it, I got to incorporate some 3D design and printing, some computer programming, and for a few fun days, some tinkering around with a friend. The whole experience was so satisfying that I came away searching for more things to design.

Here are three more fun projects my buddies and I have been working on.

Tinker 1: Quad Watering System

I love watching things grow, but asking someone to water a bunch of plants takes away from my enjoyment. As a quadriplegic, though, my handling a watering-can around the computer equipment of my office might make for great entertainment to others, but to me has the potential to be extremely expensive.

The hamster in my head was running at full speed one night trying to devise a watering system I could control independently. In the morning I scoured Google and YouTube for ideas, eventually settling on a system that would sense the moisture of the soil and engage a small pump to water if the moisture drops below the desired setting. Then it would wait a minute for the water to soak in before resuming the soil test.

I found plans online and the parts were readily available for about \$20 plus 25 cents worth of 3D filament to make a box for the electronics. With my friend Dave helping to tinker and solder, the project came together perfectly.



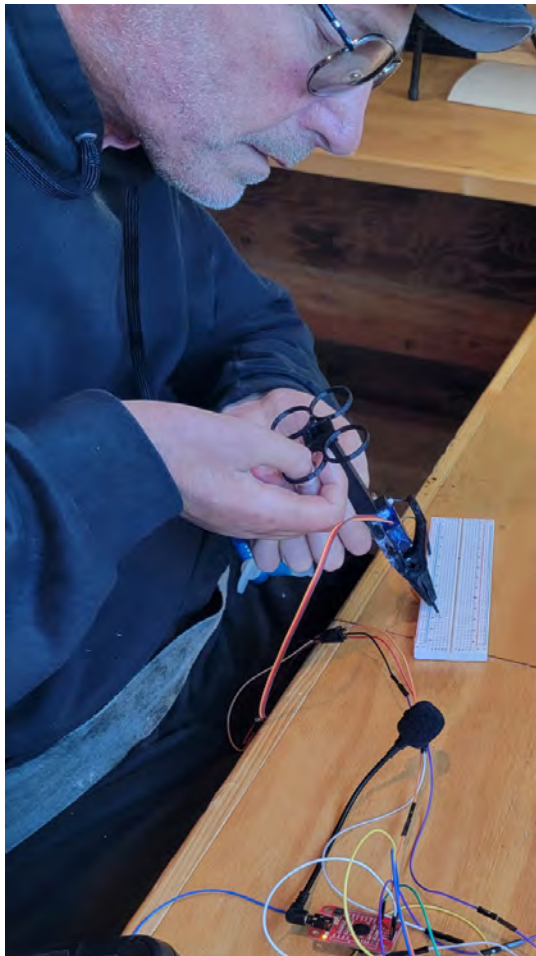
As my guinea pig, I used a spider plant that my wife, Terry, feared was dead. It loved the regular, moderate watering, and quickly sprang back to life. Terry has since moved more plants into my office for “intensive care,” and I’ve modified the system to water five plants at once. I’ve also ordered parts to make a few more of these units. It’s so invigorating to have it come together and work perfectly. This system has become like a test bed, and could easily be ramped up to maintain a remote garden from a water barrel or whatever else you can dream up.

Tinker 2: Voice-Activated Pliers

Building the watering system reminded me of how frustrating it can be fiddling with teeny, tiny wires and other small pieces with my quad hands. I said to myself, “Self, if you only had voice-activated pliers, then you could.”

It seemed fortuitous that the Arduino boards I was learning about can accept voice commands. I called my fellow quad-buddy Landon to pick his brain about how voice-activated projects work. He sent a picture of a small module he’d built that lets him use his voice to control a microcomputer. I purchased the material to build the same setup he has.

While I waited for delivery, my late-night hamster started running again. I watched a few videos — how I learn everything



Left: \$20 and some online plans were all Kary Wright needed for a hands-free watering system. Above: Voice-activated pliers at work. Right: Friend Dave tests the tricked-out Hoyer lift.



nowadays — and began to realize the potential of this system. My plan was to design and 3D-print some pliers that I could pick up with my quad hands and open and close using voice commands. The microcomputer module Landon shared with me would control the pliers.

Waiting for the voice board and servos was agony, but by the time they arrived, the design was printed, and putting everything together only took a day or so. Now I can pick up and plug the tiny wires into microcomputers, servos and other electrical components. I can also design, build, program and test new electronics projects with no outside help. This provides a new level of independence for me and has me thinking about what it would take to build a longer, larger voice-activated grabber that those of us with limited dexterity could control by voice.

Tinker 3: A Better Lift and Battery

A few years ago, I found a great deal on a portable patient lift with a “new” battery included. Excited about how much easier the lift would make travel and transferring into vehicles, I pur-

chased it. I got it home, charged it up to test it and ... nada. The battery was dead. I bought a new battery for about \$100, did not use the lift for a year, charged it, and again it was toast. A little venting session with Landon revealed that he has three of these lifts and not one has a battery that will last.

But what if there was a readily available solution that was much cheaper? Landon pointed out that my DeWalt weed trimmer uses a battery with virtually the same voltage — and I already had several of those around the house.

The hamster sped up and my mind started racing. A quick Amazon order later and a \$20 DeWalt battery adapter was on its way. Dave and I brainstormed a controller that would enable my attendant to operate the lift with one hand and handle a patient with the other. Dave suggested a remote winch-controller that would do just that.

We easily found a suitable model online and ordered it. After an afternoon of tinkering, we successfully bypassed all the electronics and hooked up to the actuator directly. Dave tested its strength by sitting on the lift’s horizontal bar and riding it up and down. Now the Hoyer lift works perfectly with a remote winch-controller and 20-volt quick-change battery.



FUNCTIONAL FASHION

A Wheelchair User's Guide to Winter Clothing and Accessories

BY KATE MATELAN

From down-feather coats and heavier seasonal wear to layers and accessories, this is your cool-weather guide to reshaping “What can I wear?” into “What do I want to wear?”

Whether your fall and winter are harsh, or just kind of cool, dressing as a wheelchair user means new layers, lengths and, quite frankly, more time. Reclaim extra dressing time by building your fall and winter wardrobe with adaptive wear, self-modified gear and carefully

selected mainstream garb. It can be done!

This breakdown of styles, fits and fabrics will take some of the work out of searching for functional fall and winter fashions, and includes my personal tips from 20-plus years of dressing as a wheelchair user. My No. 1 recommendation: Pick cozy gear this time of year, but always check that it allows for movement. Bend, push and move your upper body — whatever you can do to make sure the clothing won't hold you back.

COATS

With summer in the past, it's time to get ready for the long haul of fall and winter. First step: Breaking out the fall or winter coat for the frigid, blustery season. But let me guess — you haven't been able to find a coat that's the right length or has the most accessible closures, right?

I know the drill. But thanks to my manual wheelchair thrashing many a coat, I've racked up plenty of shopping practice over the years. Through trial and a whole lot of error, I've found the hits and misses when giving a new jacket a test run.

Style

You want to look stellar while still wearing a coat style that's functional. If the coat is supposed to extend well past your knees, then don't even consider it. The excess fabric from these styles has nowhere to go when you're sitting, and gets in the way of moving comfortably.

The solution? Opt for styles that are cut shorter or fan out easily at the hips without too much fabric. Bomber and motorcycle jackets are usually shorter styles. Look at

peacoats as well, although you'll find some manufacturers make them too long or too rigid. Ski jackets are a long shot but can work, especially adapted varieties. I find down-feather puffer jackets to be an excellent style, but they don't always dress up a nice outfit. Take a look at slim-line puffer jackets found at almost any department or outerwear store — they rank high in my jacket choice for warmth, style and all of the reasons below.

Depending on your hand function, closures can be a deal-breaker. As a low-level quad, buttons and zippers can be difficult, but give me snaps or a belt that ties and I'm golden. Some coat styles have several types of closures in one — maybe toggle loops and snaps — so always investigate before you put the jacket in the "no" pile.

If all else fails, I have three go-to options for making the coat work. If you can't find a closure that fits your function, make sure you invest in a very warm coat and a thick, cozy scarf to fill in the unclosed jacket. Another option is a pullover jacket that eliminates the closure problem altogether. Or if you're the creative type and your jacket style permits, have the skilled hands of a seamstress sew in Velcro closures.



Above, left: Capes like this one from IZ Adaptive are easy to put on. This page: Kinetic Balance offers adaptive jeans, jackets, bags and more.



Power wheelchair user Fazila Ikram wears a pea coat by IZ Adaptive.

Length

Short to midlength jackets are the sweet spot, but there is an exception: adaptive coats.

I stand by my Adaptations By Adrian rain cape for wet days in fall and spring, and rotate in the fleece-lined winter cape for colder, snowy and sleety days. These longer adaptive coats cover arms, legs, and chair parts, and keep you dry. Honestly, the cape is a bit more functional than fashionable, but it is a game-changer. I layer the cape over my winter coat for full body- and chair-coverage.

Other adaptive coat styles also offer added length and take into consideration the seated frame. Check out Tommy Hilfiger Adaptive, IZ Adaptive and online at Target or Kohl's for other lengths and styles made especially for us.

Fabric and Color

Choosing fabric this time of year is key. Mix delicate fabrics with slush, mud, snow, sleet and ice-melt, and you've got a big problem. Throw in a chair or other mobility equipment, and you're lugging around a lot of that fall and winter mess.

When you're hunting for the new coat, think about the effects of the elements — most likely the cuffs and bottom of the jacket will be seeing the worst of it. You want a fabric that will wick away the water and/or dry quickly. That's another reason I love the quilted puffer jacket. Wool coats are great for warmth and provide a decent coat life, but they can absorb a bit of slush on the ends of the sleeves. If leather's your choice, always make sure it's treated, or vegan, and beware of it getting eaten up when moving at high speed.

The cleaning tag really gets me: It's that moment of panic

when I decide if I can bring home another “dry-clean only” item. Sometimes you can get away with dry cleaning a jacket twice in fall and winter, but it depends on how hard you wear your clothing and how brutal the elements are that season. Just remember: When your coat is at the cleaners, you need to have a backup. I try to save last year’s coat for those dire moments.

If you get that pesky pilling on your jacket from it rubbing on your chair, buy a garment groomer at the local drugstore. Some of these tools look like plastic combs while others resemble a scratchy Styrofoam square.

As for color, bright colors rock, but they often show all the dirt and wear on a coat. Although you may find it blah, a black, brown or gray jacket is probably your best bet for giving the appearance of being clean and well-maintained. Plus, dark winter coats are much more versatile with your outfits.

Kate’s Top Five Coat Tips:

- 1. Try on the coat with your heaviest clothing.** The jacket needs to fit comfortably with the max amount of clothing. Move around and you’ll know right away if it’s the one.
- 2. You get what you pay for.** Choosing a coat that’s well made and from a trusted brand is worth the investment when it comes to style and durability.
- 3. Reclaim your old jacket.** If the outside of a well-loved coat is still in decent shape but the inside isn’t, simply replace the lining.
- 4. Protect clothing under your coat ... at all costs.** Keep slush far away from your clothes by pushing up your sleeves underneath the jacket.
- 5. Solid colors aren’t boring.** Add a bold pop of color with a scarf or gloves, and you’ve upgraded your solid jacket in an instant.

BAGS

Changing weather conditions are typical this time of year. And so is lugging around more personal and medical items in our bags. Between rubbing against dirty wheels and chair frames and getting caught on every other wheelchair part imaginable, our carryalls endure a lot of wear and tear. Finding one that also fits on your chair without falling off, and opens and closes appropriately, means filling a long list of demands.

Those “wheelchair bags” from chair manufacturers might be designed to fit over the back of your chair, but they often aren’t winning any style points in my book. Believe me, other options do exist. What you ought to have is a swanky, sporty or funky bag that’ll make a statement yet still be functional.

Style

You’ve got a lot of options: backpack, satchel, drawstring, messenger, tote, etc. They all have their pros and cons, but none stick out as an absolute miss. You do, however, need to see how they fit on your chair, and figure out what’s the easiest to get on and off throughout the day.

A major style decider is how each opens and allows you to access the interior of the bag. For example, backpacks



Nina Tame bought this jacket second-hand. “I prefer cropped jackets, as they sit nicely when I’m in my chair,” she says.



Ffora’s Active Bag has a hard outer shell.



Jansport's adaptive backpack comes in six different colors.

unzip completely, letting you reach in at any angle, while a messenger only allows access from the top. You'll want a style that matches how you or a companion can best get to whatever is inside. Plus, the type of bag needs to fit your style — it's more than a bag, it's something that screams, "This is all me!"

Zippers, snaps and Velcro are all typical bag closures. You can always play around with keychains and other key rings to make zippers more convenient. Be sure that the closure style actually shuts your bag and protects all valuables. Since it'll be hanging on the back of your chair, you want to make sure someone can't rummage into your bag or that something can't tumble out.

Keep your eye out for an easy-to-access side or outside pocket too. Fall and winter weather can get grimy, making it crucial to have quick access to wipes, winter gloves and a junk towel to wipe down wheels.

Size

Your choice of bag size is dependent upon what you intend to pack and the style of your chair. It also depends on what

weather conditions you might encounter through the day. Leave room for bulkier items and extra accessories. You want enough room to get your goods in and out, but not so much that it creates a black hole for your meds or car keys.

The biggest factor is the configuration of your chair — be sure the size of the bag fits on your ride snugly without inhibiting any wheeling or getting prodded by wheelchair parts. You want it to be secure so you don't innocently lose your belongings and someone can't snatch it off the back of your chair. Move around with the bag to see if it drags on the ground or gets twisted when you push or pop a wheelie.

Fabric and Color

Durability and washability are the top two musts for any bag fabric. I use my bags to carry around my personal life and my cath life, so there are a lot of fluids involved. If my lubricant explodes, I don't want to have to dry-clean my bag and wonder if that spot might be there long-term.

Avoid leather and suede since those textiles probably won't handle a lot of chair rubbing, spills or seasonal weather

elements as well as other fabrics. A nylon backpack works best. It's durable and washable, so you can count on it to maintain its strength and be cleaned in a flash. If you're caught in wet weather, a nylon bag can dry off quickly. Another option is a clothlike tote for dependability, but be cautious of a soaking precipitation, since moisture may linger. No matter the fabric, make sure the straps on your bag are sturdy and sewn in well; they'll take a lot of stress hanging on your chair.

Darker colors rule when it comes to masking the wear and tear your bag will endure from fall and winter wheeling and being dropped or dragged on all kinds of surfaces. However, solids are a bit of a bland option. To upgrade something plain, add buttons, screen printing, customization, etc., for personal flair, but don't go overboard or start bedazzling your bag to no end. Too many extras can tangle up in your chair.

If you want to ditch the solids, try a printed bag that incorporates bold colors with a darker undertone — for example, a pattern of orange, green and tan with a brown undertone. The brown will keep your backpack from looking too dirty or scuffed while still maintaining that pop of color. You may be toting your bag to an important meeting or get-together — keep that in mind when picking a print.

Kate's Top Five Bag Tips:

- 1. Consider the weight.** A full bag might throw off the balance of your chair or add excessive weight to your wheeling.
- 2. Add some security.** If you're rocking handlebars, buy some rubber chair-leg protectors and squeeze them on the end of your bars to keep your bag in place.
- 3. Cross the straps.** Try crisscrossing the straps to make a tote fit on the back of your chair without too much bulge.
- 4. Leave your name and number.** Keep a business card or note in your bag in case you accidentally lose it. Some items in our bags are mission-critical.
- 5. Go for storage spots.** Pockets on the inside and out are great for cellphones and other items that you need readily accessible.

Bring it.



FEELDOM
Premium Adaptive Gear

FeeldomLife.com




Erča Bartošová enjoys the snow. The upside of mittens? Easy to put on.



Angela Rockwood shows that with the right accessories, style and staying warm can go hand in hand.

LAYERS

Love it or hate it, fall and winter are all about layers. Multiple shirts, sweaters, jackets, fashion scarves, socks, leggings and pants are part of the wardrobe. As a wheelchair user, that equates to longer dressing minutes, pressure sore considerations, movement conundrums and, honestly, grumpiness — for me at least. I'm all about the quicker and easier dressing during the warm weather.

But it doesn't have to be doom and gloom. And there are good reasons for layering up when it's cold outside. Keeping your body warm, especially where you can't feel and circulation might not be tiptop, is important. Protecting

yourself when going out to dinner or a holiday party is smart, but it doesn't mean you have to let go of fashion for function.

Style

Layers are ideal for warmth but can also be a real pain in the ass when it comes to care or body-temp fluctuations. Look for fits that aren't an absolute struggle to get on or off, solo or not. Or, plan your layered look by what type of care you may need that day or who will be with you.

Before adding a new layered piece to your wardrobe, ask yourself, "Will this be an absolute pain to wear? Can it fit under or over another item? Will it work under my coat?" It seems simple, but being realistic is super-important. You want ease and versatility in your fashion.

Length and Size

Go long. Cover your arms and legs. Ankles too. Exposure to fall and winter temps has other consequences, plus so many of us can't control our temps anyways.

With atrophied bodies comes a range of leg- and arm-sizes. As a petite female with atrophied legs and muscular arms, I oftentimes buy kids regular-size bottom layers and adult petite-size top layers. If I'm wearing two pairs of pants, my base layer may be a kids size and the second layer an adult size.

Mix and match lengths and sizes to get the coverage, fit and layering ability that makes sense for you. I build out my top layers from least coverage to most coverage, aka cami, T-shirt, cozy sweater, chunky cable scarf. For my bottom layers, I go opposite, keeping most coverage from hip to ankle as my first layer and then adding socks and boots over top. I lock in the warmth at my legs, the coldest part of me, and give myself the ability to disrobe my top if I get hot.

Fabric and Color

Thin, warm fabrics are a wheelchair user's best friend: less bunching and more cozy. Combining these fabrics together, and in the right order, makes or breaks the day. Start with thinner fabrics close to your skin and build out from there. Reminder: Bulky doesn't necessarily equal warm. Nor does it always lend itself to flexibility.

Gravitate toward mixed-material shirts, blazers and other clothing. These allow for easy layering and pushing, with a finished look in the front and stretchy material on the back.

I recommend Under Armour ColdGear or a similar, technology-focused thin underlayer. Dual-layer fabric with a warm underlayer and wicking components checks all the boxes for skin contact. Put these must-haves under shirts and pants for added warmth, or wear solo around the house. My

advice: Start with a tried-and-true black set, then branch out into colors and patterns. Many styles are designed so that they can be your whole outfit too.

Thin, thermal sock fabrics are also crucial. Fit into sneakers, boots and other shoes without stress and strain — that's where these winter staples save the day. Stock up on solid shades for the utmost versatility, but don't shy away from bright and colorful or whimsical socks. With exposed socks back in fashion — at least right now — and fall and winter boots covering up most of the fabric, there are no color rules.

Embrace fall colors, wintry shades, and everything in between. Incorporate patterns, prints, sparkles and whatever else feels right. Fall and winter tend to have richer, darker hues which, honestly, help hide dirt and debris.

ACCESSORIES

Gloves, hats, scarves! The trifecta fends off the chill and supplements coat styles and other layers this time of year. They're my go-to for cold fall mornings and crisp afternoons or the all-day freeze-fest in the middle of winter.

Accessories can help to avoid bulky sweaters or itchy pullovers and more restrictive layers, without sacrificing warmth. Can't layer too much clothing because of skin issues? Need easier and faster access for care down there? Running out of time before heading out the door? Many accessories solve these dilemmas and more while providing a weather-appropriate outfit with style.

Style

As a manual wheelchair user, fall and winter gloves are the hardest part of my outdoor garb. The need for traction on wet, slippery terrain is key, which lends itself to fingerless gloves — however, ice-melt and frigid temps don't mix well with exposed fingers.

Both fingerless or fully covered finger gloves with traction beads on the underside are viable options. The stress test: Try on the gloves and see if they pull between your fingers when maneuvering. If so, it's a hard "no" on the style. Don't dismiss adaptive ski-glove styles with side zippers and other easy in/out or on/off features.

Hats and scarves are an

To stay comfortable in winter, author Kate Matelan relies on layers. Here she's wearing Under Armour cold gear leggings and long sleeve shirt, mixed media t-shirt, faux leather (washable) moto jacket, silk thermal socks, faux leather booties, and scarf.



absolute must in fall and winter. Experiment with different styles — think short, long, wraparound, tied or bucket, flapped, beanie or trapper. The biggest style consideration for scarves is how they fit when sitting. Avoid anything that might get tangled in wheels, wheelchair backs, or other layers. And with multiple ways to style or tie scarf-shapes, a long scarf may work perfectly if you cross or wrap it around.

Fabric and Color

Most fashion gloves are cotton- or fleece-based and absorb rain and snow easily, making for soggy hands. Look for water-resistant or quick-dry fabrics, or cover up cotton with your all-weather wheelchair push-gloves. Outerwear companies and outdoor-focused businesses often have fabrics more suited to chair users.

Gravitate toward more neutral glove colors with an emphasis on gray shades for winter use. Gloves may have the most contact with sloppy snow or white ice-melt residue. Darker shades or colors are often the easiest-to-maintain option. But let's say it: If you like it, buy it. Favorite color is light pink? Do it. Just be ready for extra cleaning or more dirt to show.

Go semiwild with hats and scarves. Basic-colored jackets and neutral gloves don't provide a lot of pop. Scarves and hats have less contact with your chair, and the fabric and color show off your personality. Ensure the fabrics don't irritate your skin, give you brush burn when moving, or absorb too much moisture if wearing outdoors.

Kate's Top Five Accessory Tips:

- 1. Invest in a water-resistant hat with ear flaps.** Stay warm and dry without your hat flying off. Plus, head and ear coverage is key to maintaining body temp.
- 2. Buy a short, thick infinity scarf.** This style covers your exposed neck when your coat is fully or almost fully closed.
- 3. Have multiple types of gloves on hand.** Pun intended. Your below-zero glove choice might be different than your apple-picking day glove. Be ready for anything.
- 4. Beware of open-weave scarves.** Zippers, earrings and other jewelry tangle up in these oh-so-cute options. When you're speeding around in the cold, you don't want to stop in the snow for this snafu.
- 5. Organize your accessories.** Scarf hangers and holders, and baskets or boxes, hold accessories for easy grab-on-the-go.

2023 PERSON OF THE YEAR:

JOHN MORRIS

BY IAN RUDER

HIS PASSION FOR FLYING HAS DRIVEN HIM TO BECOME AN EFFECTIVE LEADER IN THE FIGHT FOR ACCESSIBLE AIR TRAVEL.

In the 10 years since he founded wheelchairtravel.org, John Morris has racked up well over a million miles flying around the world and has watched airlines total his power wheelchair four times. He's lost track of how many times his chair has been damaged and won't even guess how many times his rights as a traveler have been stepped on.

But none of that has dampened his love for flying. Listening to him talk about everything from airports, to specific planes, to the overall experience of air travel, it becomes clear that for Morris, flying is more than a business or a pastime: It's a passion. "I've loved travel all my life," he says. "Taking off and landing are my two favorite experiences in the world, even better than a roller coaster."

Understanding Morris' deep-seated passion for his subject is key to grasping why he's emerged as one of the most thoughtful and effective leaders in the fight for a more accessible future for air travel, where everyone can safely enjoy flying, regardless of their physical function.

Morris remembers how easy and enjoyable traveling was before the 2012 car accident that led to the amputation of his right hand and both legs. "I have a perspective on the tremendous freedom that I had in traveling and exploring the world. I don't think that any of that freedom should be restricted," he says. "At the end of the day, it's more than frustration. It's part anger at the status quo persisting for so long, and it's also this realization that no one is coming here to defend me — I have to do it myself."

Morris started doing that by creating one of the most widely read accessible-travel newsletters and one of the best sites for disabled travelers and industry professionals; and in 2023, a year after almost rolling away from his travel platform, he has taken his advocacy to a new level. In a year which saw some of the first real signs of progress on improving accessible air travel, he was a constant force for change behind the scenes, in front of cameras and on social media. For his continued vigilance and dedication to serving the disability community, we are proud to honor him as the 2023 NEW MOBILITY Person of the Year.



Photo by Kyle Klein/Meet Boston



With well-over 100 flights per year, Morris has built relationships with airport and airline staff all over the world.

Finding Hope at 35,000 Feet

Lying in a hospital bed after being severely injured in a car accident and explosion in 2012, a 23-year-old John Morris wondered whether his life as a frequent traveler had come to an end. Prior to the accident, he had racked up hundreds of thousands of air travel miles, flying so frequently he was on a first-name basis with many airport staff. As a student and later as a high school teacher, he cut down on airfare costs by planning elaborate multides- tination routes that earned him loyalty bonuses and discounts.

After his accident, with third- and fourth-degree burns covering 30% of his body, and multiple surgeries and possible amputations looming, that all seemed in jeopardy. “I was led to believe in the hospital that travel was going to be off-limits and that my own lifestyle was not going to be attainable,” he says. “I just wasn’t fed any real hope.”

It took getting back in the air to rediscover that hope. After spending much of his first post-accident year in the hospital, Morris decided for amputating both legs below the knees. He already had his right hand amputated, and realized a dramatic reduction in pain, so he hoped this step would further reduce his pain levels.

A few weeks later in January 2014, with his legs still bandaged, and not having been in public other than to church, Morris rolled onto a cross-country flight from Florida to California with his sister to watch his beloved Florida State Seminoles play for the college football national championship. “I was sitting on an airplane before I even went to a restaurant as a wheelchair user. Medically, maybe I should not have taken the trip, but I just I had to,” he says.

Morris’ Seminoles won, but more importantly the trip gave him confidence that his life as a traveler did not have to end. Within weeks he was back on planes, visiting friends through-

out the Northeast, and in April, gazing from atop the Great Wall of China. By year’s end, he had been on over 150 flights. “You couldn’t stop me once I got going,” he says. “It was unbelievable. Looking back, I’ve never had a better year in my life.”

At the time of his accident, Morris was teaching high school history and even considered joining the seminary, but now he’d found a new calling. Recognizing the need for more and better accessible travel information, Morris registered the domain wheelchairtravel.org in September 2014 and started posting content the following January. “The more I traveled, the more I realized I could potentially make a difference in the accessible travel world,” he says.

A Platform Is Born

Building wheelchairtravel.org into one of the web’s best roadmaps for traveling with a disability didn’t happen overnight. From the beginning, Morris set a

high standard with well-written reviews and stories that went beyond glossy promotional content. While Morris covered many of the fancy and often expensive destinations other travel writers and influencers did, he also made a point of being up front about costs and prioritized the nitty-gritty details that might make or break a trip for someone with specific needs. “I try to provide answers to the questions that I had when I first started traveling with a disability, practical information about traveling by air and finding a hotel,” he says.

Through good and bad experiences, he realized that understanding your rights as a disabled traveler is just as important — if not more — than knowing the bed height and door width. “I had heard of the Americans with Disabilities Act but didn’t really know much about it, and I certainly had never heard of the Air Carrier Access Act. But I read those and I read through the regulations, and that inspired me to get the word out,” he says. “People need to know that these rights exist. I want

people to understand the rights that you have to accessibility and equal access.”

Morris started a regular newsletter in 2015, devoting ample space to covering industry news and government policy that affected disabled travelers. His candor and insight gave him a broad appeal that went beyond disabled travelers. “If you go down the email list on my site, you’ll find every airline domain name listed in the contacts, and hotels and aircraft manufacturers and Airbus and Boeing — they’re all in there. I haven’t put them there. They’ve signed up themselves,” he says.

The same people signing up for Morris’ newsletter started offering him speaking and consulting opportunities. After a long career in the travel industry, Jake Steinman learned about Morris while planning to launch a new organization promoting accessible travel. Steinman saw a need to educate travel leaders about disability, and identified Morris as the perfect person for the job. “I think he’s the brightest person in the industry that I’ve met,” Steinman says.

“He’s not just book smart, but he’s got good judgment. He’s a thought leader.” Steinman was so impressed, he recruited Morris to be one of the original advisory board members of his industry accessibility group, TravelAbility.

Steinman compares Morris to a utility infielder in baseball, saying, “I can assign him to anything and I know he will do it well and he’s fine with it.” One of those assignments was being a panelist for a first-of-its-kind accessible-travel summit in 2018. Most of the attendees were nondisabled travel-industry leaders. “When they see somebody like him, what he’s accomplished and how often he’s traveled, they’re just gobsmacked,” says Steinman.

Pandemic Problems

Morris funded his initial post-accident travels with money from a small settlement and financial support from friends and family, but eventually needed to figure out a way to sustainably monetize his efforts. To save on

Egypt is one of the many fun destinations Morris has reviewed for accessibility on wheelchairtravel.org.





Airline industry conferences give Morris an opportunity to advocate for accessibility.

have prevented power wheelchair users from flying on American Airlines got picked up by national media and led to American apologizing and reversing the policy. In July 2022, he popped back into the headlines after American destroyed two of his wheelchairs in a span of 17 days.

Both of those 2022 flights occurred while Morris was moving to Boston. He'd signed a lease and accepted a job as the senior manager of culture and inclusion for a large online furniture retailer. The job seemed a good blend of Morris' passions for employment and disability equity, and he was slated to start in August. But a week before his start date, the company rescinded the offer, citing tough economic times. "I wasn't sure how to react," says Morris. "I felt like an unmoored boat, just floating out in the ocean with no coastline in sight and no directional navigation aids. It was scary."

Steinman commiserated with Morris as he planned his next steps. "I think

costs and continue generating content, he started doing more press trips paid for by destinations, and took on more speaking engagements and opportunities to train business partners. Then 2020 rolled around.

"The pandemic shut all that down," he says. "I really did not know how much longer I could sustain things. I

decided to go back to school at University of Florida and get my MBA. I wasn't going to abandon the website, but I decided the majority of the time and my 9 to 5 couldn't be the travel industry anymore, it had to be a real corporate job."

In the interim, Morris continued to make headlines. In November 2020, his coverage of a policy change that would



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he sort of felt defeated,” says Steinman. “It was just so unfair.”

While Morris searched for similar jobs, he began investing more time again in wheelchairtravel.org. By the end of 2022 and about four months of fruitless searching, his perspective had changed. “I started to think my preference is to fail in this job search,” he says.

With traffic on his website exceeding pre-pandemic levels, and plenty of opportunities that he had put aside during the time away, Morris recommitted to making his travel work a sustainable, full-time gig. “I felt as though there was a lot of work left unfinished,” he says. “It was nice to be presented with the opportunity to continue that work on a full-time basis and to remain focused on it.”

The Industry

By the end of the pandemic, accessible air travel had emerged as one of the hottest topics in disability. Countless stories of damaged wheelchairs and trampled rights swept social media,



All Wheels Up Founder Michele Erwin (left) appreciates Morris’s levelheaded approach to advocacy. “The industry feels that they can learn from him,” she says.

prompting national media outlets to pick up more than the occasional story. Morris’ reporting and advocacy ideally positioned him to reap the benefits from the uptick in interest.

To spur change, Morris long ago made the decision to prioritize his advocacy ef-

forts on the people designing, building and managing the planes, instead of the government officials who crafted policies affecting accessible travel.

“I feel like I have a better chance of being successful with industry than with government,” he says. “With industry, I

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have a lot of credibility. They may not like what I say, and I certainly put people on the spot, but they know where to find me and they know I am honest.”

In 2023, Morris attended five of the industry’s key events and showcases, often finding himself the only wheelchair user or disability advocate in attendance. “I’ve got to decide what cape

I’m wearing at different moments,” he says. “Media is not generally welcome at those events, so there’s sort of an understanding that I’m not there to cover the event as a journalist, but to attend as an advocate.”

As much as Morris loves to break an important story, he has bigger goals. “I would rather spend the money and

get no financial return on going to an industry conference and maybe put something in someone’s mind that comes to fruition in terms of a new accessibility feature five years down the line,” he says. “There’s a huge range of barriers that exist, and it’s going to take a long time to overcome them all, but the only way it’s going to happen is with allies on the inside.”

Michele Erwin, founder of All Wheels Up, the organization leading the fight to allow wheelchair users to fly in their wheelchairs, has crossed paths and worked with Morris on and off over the last five years. “There are not a lot of other people doing what he does, and actually, I think it’d be fair to say, there isn’t anybody else doing it like him,” she says. “Instead of going to Congress and trying to force change on the industry, he seeks the industry players out and meets them in their sandbox, saying, ‘Let’s have a conversation.’”

One of the events Morris attended was the Aircraft Cabin Innovation Summit in Atlanta. The conference is usually attended by senior executives in the aircraft cabin interiors industry who are working to improve passenger experiences. Monica Wick, CEO of RedCabin, the company that organizes the summits, says Morris’ insights have been invaluable. “It’s fair to say John has changed the way the industry thinks about this challenge,” she says. “His ceaseless campaigning and contributions to RedCabin will help change the future dynamic for flying in a wheelchair.”

Whether he’s speaking about accessibility on a panel or simply chatting up a fellow attendee, Morris has a skill for getting others to see things from a different perspective. “He definitely draws you in when he’s speaking,” says Erwin. “You want to listen to what he has to say, and you never feel like you’re being spoken at or preached to. The industry feels that they can learn from him and he’s not up there pounding some sort of soapbox drum.”

His industry-whispering paid off last June when he got to be the first wheelchair user to publicly demon-

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strate Delta Air Lines' first-ever on-plane wheelchair securement prototype at the Aircraft Interiors Expo in Hamburg, Germany. Such a system has been the holy grail to many wheelchair users for a long time. Morris has covered numerous rumored versions of the idea across the industry in the past 5-7 years, and has been a strong supporter both publicly and behind closed doors. Thanks to an industry friend, he got a late heads-up that Delta planned to unveil the system at AIX. Morris hadn't planned on attending but immediately reached out and got on the schedule. "I was thrilled to see it," he says. "I think that really is the solution that so many people have been waiting on for decades."

Demanding Accountability

Even with the excitement, Morris knows implementation of a working system remains years away and is far from guaran-



Morris still finds time to enjoy the destinations he visits.

teed. He also knows that until solutions like a securement system are in place and airlines are held accountable, disabled passengers will continue to be treated as second-class citizens. Knowing these harsh realities motivates him to keep shining light on the often-dark circumstances that disabled travelers face.

Morris was one of the first people, if not the first, to report on the lawsuit

brought against United Airlines by the family of wheelchair user Nathaniel "N.J." Foster Jr., who went into a coma after an incident while being wheeled off a plane. Morris flew to San Francisco in August 2023 to report on the trial.

"No matter who was at fault, we can't have a situation where someone gets on an airplane, and before they're off the airplane, they are brain-dead because of a



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The group's facilitators are Matt Castelluccio, a dad with a spinal cord injury of twin 10-year-old boys; Lesly St. Louis, a dad with spina bifida of a 5-month-old daughter; and Erin Gilder, a mom with a spinal cord injury of two teenage boys aged 16 and 18.



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loss of oxygen,” he says. “No other passenger on that airplane walked off with an injury of any kind. Something terrible happened there. It should not have happened.”

After one day of trial, United settled for \$30 million with no admission of guilt. Morris is committed to using the platform that he has built to hold the airlines accountable and bring about a future where no one else has to go through what the Fosters experienced.

“We’ve got to solve for the problems that are facing travelers right now. It can’t be, ‘Well, let’s put investment on hold for 30 years, while we wait for wheelchair spaces to be installed and widely available,’” he says. At the top of Morris’ list are improving accessibility training and accountability for airline staff, and getting airlines to collect and share more data about their planes and how they handle mobility devices.

Business and Pleasure

To help realize those goals, Morris is committed to further growing his platform and methods of engagement. On the strictly travel side, he is expanding his group travel offerings. He had sold out a series of accessible tours of Portugal in 2020, but had to cancel because of the pandemic. He’s also looking to monetize his writing. With over 27,000 subscribers signed up for his free newsletter, Morris decided to start posting paywall-protected content regularly on Substack. “I feel like if I continue doing good work the support will increase, and then perhaps Substack can really become a key pillar of my business model. It’s already growing in importance,” he says.

He’s also taking on more consulting opportunities with destination management organizations like Meet Boston, working to educate travel insiders about authentic representation and the true value of accessibility. “I’m trying to make sure that disabled people are incorporated into that marketing,” he says, “not just on the surface level of including disabled people in the photo media that they use, but in actually developing resources.”



When Morris is not busy with all those endeavors, he’ll likely be responding to the multitude of emails his readers send. He runs wheelchairtravel.org by himself. He estimates he spends two hours every day personally responding to reader emails, and seems genuine when saying he wishes he had more time to get through his backlog. The same

passion he shows for traveling, drives his work as a reporter and an advocate.

It takes a certain personality and perspective to watch your wheelchair damaged and broken repeatedly and still show up at the gate every day with a smile. John Morris has that unique blend, and the disability community is fortunate to have him.

MI

RISING STARS: SWTCon Award Winners

In October, United Spinal Association honored six up-and-comers making their mark in the disability community. Today's leaders and tomorrow's changemakers, they are already making a difference in the lives of other wheelchair users.



High school senior Anja Herrman (second from right) was one of the youngest award winners of the night.

WRITING AWARD: Anja Herrman

When Anja Herrman says her life has been “a complete mess,” it’s the kind of thing you might expect a typical 17-year-old to say, except Herrman is not your typical 17-year-old and her “mess” is one that many would envy.

On Oct. 11, Herrman was in Washington, D.C., for the first “Girls Leading Change” celebration at the White House. First Lady Jill Biden recognized her as one of 15 young women “leading change and shaping a brighter future.”

A week later found Herrman 2,500 miles away in Las Vegas, at United Spinal Association’s first StrongWheeled Together Conference to receive the StrongWheeled Together Award for Writing. The award was based on published works and her competition essay, “I’m A Disabled Teen. My Wheelchair Needs to Grow with Me as I Wheel Towards Independence.”

“There has been a lot of, ‘Oh my god, what is happening’ moments recently,” Herrman says. “Then you add looming deadlines for college applications on top of that.”

Staying at the Paris Las Vegas Hotel & Casino proved to be a nice respite, besides a good opportu-

nity to practice her French. She particularly enjoyed rolling around the hotel and running into all of the SWTCon attendees using wheelchairs. “Just being in a room with so many other wheelchair users was so much fun. It’s not something I’m used to,” she says. “It was great to be able to share those moments with the other awardees — it made the honor even more special. I’m very grateful.”

SPORTS AND RECREATION AWARD: Arthur Renowitzky

Living in California’s Bay Area, Arthur Renowitzky didn’t have far to travel to receive the StrongWheeled Together Award for Sports and Recreation, but arriving at United Spinal’s largest annual meetup in Las Vegas still felt like

being in a whole new world. “This was my first event with United Spinal in person, and I was blown away by the whole experience,” says Renowitzky. “The awards night, the conference — it was great. And just being able to connect with everybody, ... having coffee with folks and engaging in stories, I’m real appreciative.”

Renowitzky earned the



Arthur Renowitzky accepts his award for his work in adaptive sports.

award for his work on and off the basketball court. He plays guard for the Golden State Road Warriors, who won this year's championship in the National Wheelchair Basketball Association. He also serves as the executive director and co-founder of the Life Goes On Foundation, a nonprofit he started in 2007, using sports to support gun violence survivors and young people with spinal cord injuries.

For Renowitzky, SWTCon was a chance to connect with people in the disability community outside his usual adaptive-sports orbit. He sees the community-building as a valuable means to grow the impact of Life Goes On. He is working on a documentary about his basketball team and adaptive sports, and is expanding his nonprofit's outreach. While SWTCon was his first experience with United Spinal, he's sure it won't be his last. "I want to continue to be a part of it," he says.

PERFORMING ARTS AWARD: King Khazm

King Khazm took time out of his busy touring schedule to accept the StrongWheeled Together Award for Performing Arts for his work as a hip-hop artist and community organizer. Based in Seattle, Khazm has toured around the world, including Dubai, Guatemala and everywhere in between, raising awareness about disability and empowering the community through music, art and community service.

In addition to touring, King Khazm has worked with countless artists as a producer, including Afu-Ra, Def-I, Eli Almic and Gabriel Teodros. He is also involved with many organizations in the community as a board member of the Here and Now Project, a Seattle disability commissioner, and as executive director of hip-hop organization 206 Zulu.

He enjoyed spending the weekend connecting with other wheelchair users at SWTCon in Las Vegas. "Receiving this award and having an opportunity to connect with other wheelchair users

who have managed to excel in their endeavors and life paths is a momentous and incredibly inspiring occasion," he says.

He describes his journey as a disabled musician as challenging yet gratifying. "Being a wheelchair user poses additional logistical and financial constraints when it comes to touring. Things rarely go as planned, even when hotels, planes and venues confirm their accommodations," he says.

Sure enough, on the way to Las Vegas, King Khazm lost a charger to a medical device. "Flexibility and creative problem-solving are instrumental in successful operations," he says. His final remarks summed up the spirit of SWTCon perfectly. "People with different abilities do exist. We are real. We have aspirations. We can thrive. And we are indeed StrongWheeled!"

VISUAL ARTS AWARD: Xi Nan



Xi Nan has been recognized internationally for her art.

Being selected for the StrongWheeled Together Award for Visual Arts is the latest in a long line of achievements and honors for Xi Nan. Born and raised in Jilin, China, Xi now is a full-time

ceramist, sculptor and advocate in New York, dedicating her career to helping people with disabilities.

She took second award in the 2011 Emerging Artists with Disabilities exhibition at the Smithsonian Institute, and her work has been exhibited at shows around the U.S. and the world, including the 2018 National Council on Education for the Ceramic Arts in Pittsburgh and the 2022 Venice Art Biennial in Italy.

She was honored to be selected as one of the SWTCon award winners. "I am very grateful for this recognition from United Spinal, and I think this is a great opportunity to be connected and share our ideas and thoughts," says Xi. "This platform is great for artists with disabilities to be recognized and to shine our abilities and to break through our limitations."

When not sculpting or making ceramics, she is also a paraclimber and a somatic healing facilitator. She offers one-on-one coaching sessions in spiritual healing, artistic healing, disability empowerment and energy/chakra realignments.

ENTREPRENEURSHIP AND INNOVATION AWARD: Ryan Gebauer

Ryan Gebauer got his first taste of being an entrepreneur when he was an elementary school kid selling odds and ends on the front lawn of his boyhood home. He progressed to mastering the school lunch trade and then pursued business as



Performing artist King Khazm says, "Flexibility and creative problem-solving are instrumental in successful operations."

an undergraduate and graduate student. He started his first business, an online traffic school, at the age of 29. Eventually he settled into a successful career as a real estate broker and instructor, culminating in the 2015 launch of his own brokerage dedicated to helping people with disabilities and seniors. "I've always had a business mindset," he says.

In recognition of that mindset and his work advancing accessibility in the field of real estate, Gebauer, 45, received the StrongWheeled Together Award for Entrepreneurship and Innovation at SWTCon. He has had people from across the disability spectrum reach out to him for advice and relishes helping others find their way into the field.

He has adapted to the recent downturn in the real estate market by focusing more of his time on teaching continuing-education classes for fellow agents. His work in continuing education has given him the view that bureaucracy and regional requirements often stand in the way of common sense, especially in improving accessibility. "I would love to work with United Spinal on developing a class to teach real estate agents about disability," he says.

Though unable to attend SWTCon in person, Gebauer felt honored to be recognized. "I'm excited to keep working to innovate and educate around accessibility," he says.

Ryan Gebauer has been an entrepreneur his whole life but has really made his mark as an accessible real estate broker.



Giana Bisnett organized an inclusive emergency evacuation plan for her school.

YOUTH LEADERSHIP AWARD: Giana Bisnett

Giana Bisnett has made more of a difference in the community before the age of 18 than most people do in a lifetime. The high school sophomore found her voice as an advocate through the Disability EmpowHer Network, which offers women and girls the opportunity to lead and succeed. She attended the organization's yearly camping trip in the Adirondacks last year where they learned life skills, survival skills and team building.

The girls were challenged to create a yearlong project related to disability. Bisnett chose to work with her school district to purchase evacuation chairs. "For my entire school career, I have had to go into a safe room or stay at the top of a stairwell in my wheelchair during fire drills or emergencies. Neither felt safe," she explains.

Bisnett created a plan, reached out to school officials to share it and ultimately convinced district officials to purchase evacuation chairs for every school. After the plan was approved, she spoke in front of the school board about her project. "It felt amazing to experience the process from idea to fruition. The best part is that this chair can save lives — I hope to see it in every school throughout the country," she says.

Bisnett was not able to attend SWTCon to accept her award, but hinted that this won't be the last time we hear from her. "Winning this award feels incredible and will propel me toward my future as I use my voice to be a change-maker," she says.



Mariam Paré says it took her 10 years to master mouth-painting.

INDEPENDENCE T H R O U G H

ART

The Association of Mouth
and Foot Painting Artists

BY CHERYL ANGELELLI

Mariam Paré always knew she wanted to be an artist. In 1996, she was on the path to achieving her dream, enrolled as a 20-year-old art major at the College of DuPage in Glen Ellyn, Illinois, when she was shot in a random act of gun violence. The bullet struck her in the neck, instantly rendering the tools of her trade — her hands — useless. “In the beginning, I thought my life was over. I thought as a quadriplegic, I’d be lucky if I could feed myself,” she says, “so painting was not even on my radar.”

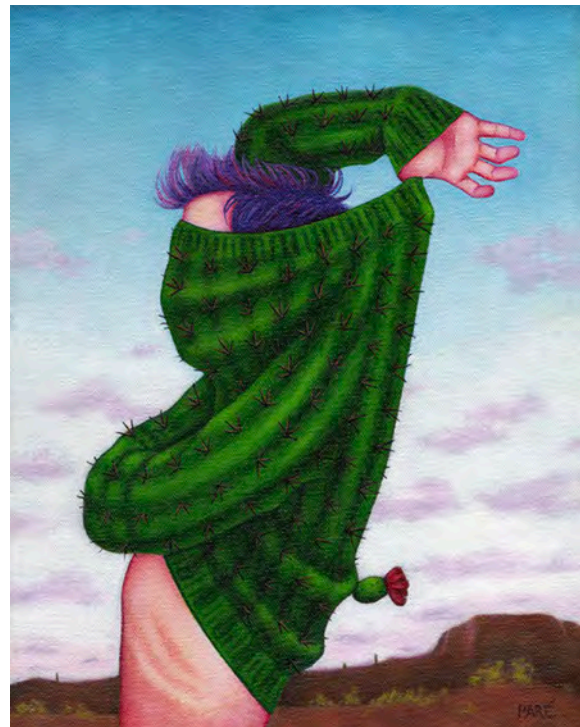
It wasn’t until she held a pencil in her mouth to write her name that Paré could begin to reimagine her life as an artist. “I was surprised,” she says. “My signature looked the same as I would have written it with my hand, and that made me think, OK, I just might be able to paint as well with my mouth, too.”

Paré reenrolled in college soon after her injury. She says learning to paint by mouth was like starting all over again. “I knew how to paint, I had that knowledge in my brain — it was just translating it with this new way of outputting my ideas,” she says. “It took about



From the Heavy series by Mariam Paré

“I thought I’d be lucky if I could feed myself, so painting was not even on the table.”



Cactus Sweater by Mariam Paré

10 years before I could look at one of my paintings and say, “You can’t even tell I did that with my mouth.”

It was a chance encounter with a stranger at the Chicago Abilities Expo that set Paré’s life on a trajectory she couldn’t have imagined. While displaying her artwork at the expo, she was approached by a fellow mouth painter who told her about the Association of Mouth and Foot Painting Artists, and encouraged her to apply.

“I thought, holy cow, there is this whole association of artists who paint in this weird way that I do. I was like, sign me up,” she says. She submitted a portfolio of her best work, and in 2005 was accepted as a student member in MFPA.

Painting with Purpose

Also known as the Association of Mouth and Foot Painting Artists of the World, MFPA is made up of nearly 800 artists from 72 countries who share one thing in common — they all love to paint, and due to disability, they hold a paint brush with their teeth or toes.

The association is also unique because it is a for-profit business founded and run by the artists themselves. Only a small number of nondisabled employees are hired to handle some of the administrative duties.

MFPA artists submit thousands of new works of art to the association each year. The artwork remains the property of the artists, but the right of reproduction is transferred to MFPA, which works with publishing houses around the world to sell the art in the form of greeting cards, calendars, prints, illustrated books and other items. More than 90% of the profits go to the artists in the association.

MFPA was founded in 1957 by German painter Erich Stegmann and a small group of disabled artists from eight European countries. A polio survivor, Stegmann grew up without the use of his arms and built a highly successful career in Germany by painting with a mouth-held brush. It was his vision to create a worldwide organization that would allow mouth and foot painters to attain self-respect, creative fulfillment and financial security.

“As human beings we strive to be seen and heard. MFPA uplifts and provides those opportunities for a section of society that has been systemically marginalized,” says Kate Adams, MFPA artist liaison for North America. “The association gives artists the freedom to create, freedom to exist and participate in society, freedom to give back and give value.”

From the onset, Stegmann was adamant that he did not want the association or the artists themselves to be viewed as a charity or with pity. To this day, MFPA’s motto remains “Self-Help, Not Charity,” and the association does not qualify for charitable assistance. “We don’t want people thinking we’re painting for any other reason than we are artists. Love our art for what it is. Yes, you can be amazed by how we make it, but that’s it — we want the work to stand for itself. No pity,” says Paré.

There are three artist levels within the association: student, associate and full member. Students receive a three-year scholarship that comes with a monthly stipend earmarked to help them improve their standard of painting. Funds can be used for things such as materials, private art tutors or transportation to get to art class. As the student improves, the scholarship amount increases. Students can continue to reapply after the scholarship term ends.

Classes and supplies such as oil paint can be expensive, since many of the artists have a limited income or rely on government aid. “The scholarships help lessen some of that burden,” says Adams.

When a student has reached a standard judged by the full

members of the association to be equivalent to that of a nondisabled artist, associate or full membership is granted. Associate members receive a monthly income and full members receive an income for life, regardless of whether the progression of their disability or health makes it impossible for them to keep contributing works of art to the association to be sold.

Other association benefits include the opportunity to meet, network and learn from one another at conferences, exhibitions and other events. “That kind of camaraderie is huge,” says Paré. “There is nothing online, no books, no teachers who can share techniques that are very specific to mouth and foot painting; that only comes

from getting to speak with other mouth and foot painters who actually get it. For example, I was having trouble reaching the top of the canvas painting by mouth, until another mouth artist shared a trick to flip the canvas upside down and paint half of it upside down.”

MFPA Artists in the U.S.

MFPA has been operating in the U.S. since 1961. There are currently 43 student artists, two associate members and four full members working in the U.S.

**POTENTIAL
ARTISTS**

MFPA is always looking for new artists, whether you’re already painting at a high standard or seeking to develop your artistic skills. To qualify, you must be unable to paint with your hands due to a disability.

Applicants are reviewed by the association to determine the artist’s capability, which governs the level of financial support deemed necessary to develop the artist. For more information about applying, email kvmarch@mfpausa.com.

To learn more about MFPA or to purchase work produced by their artists, visit mfpausa.com.

Prior to becoming a quadriplegic at the age of 18, Frank Espinosa, 51, of Whittier, California, never picked up a paintbrush or took an art class. As part of his personal healing and rehabilitation, he began sketching with his mouth and progressed to painting.

“It was really hard at first trying to control the brush with my mouth,” he says. “In the beginning my art looked like a 2-year-old painted it.” With time and mentorship from an MFPA full member who lived nearby, Espinosa began to flourish. He was accepted into MFPA in 2014 as a student, and continues to receive scholarships to hone his skills. “Being a painter and part of MFPA has given me a sense of purpose and a positive way of living. It’s also given me a goal to learn as much as I can, so I can try to become a full member.”

It’s a goal Paré herself recently achieved. After being accepted by MFPA as a student in 2005, she made full member in 2023. Now 47, her life as a full-time artist in Naperville, Illinois, is a busy one. When she isn’t painting all day, she is thinking about her next project. “I can daydream about ideas forever, that’s almost my favorite part . . . thinking about the emotion I want to provoke, what I want my art to say,” says Paré. “That is the greatest gift I get from my art, successfully conveying an emotion or an idea that moves somebody.”

Painting is her first love, but now she has branched out into video, photography and digital art. “More recently, I have been making art about being a gunshot survivor or having a disability. I’m learning a lot about myself, and being able to express myself that way has been cathartic,” she says. “I think that is kind of where my future art is headed.”

She keeps busy with commercial projects too, thanks to the doors MFPA has opened and the exposure it has given her work. She has participated in international exhibitions at exclusive museums all over the world, and hosted accessible art workshops across the U.S. and Canada for children of all abilities. Another career highlight was presenting actor Pierce Brosnan with a portrait he commissioned from her after learning about MFPA. She also recently closed a deal with LIFEWTR, the premium bottled water brand, to be a part of their “Life Unseen” campaign to amplify the unique work and perspectives of diverse creatives.

“Thanks to MFPA, I get to say I accomplished my goal of becoming a professional artist,” she says, “and I get to earn a living doing something I love.”



Frank Espinosa’s technique has come a long way since his early days as a mouth painter.

“It was really hard at first trying to control the brush with my mouth. In the beginning my art looked like a 2-year-old painted it.”

FRANK ESPINOSA



City Shadows by Mariam Paré



JONATHAN SIGWORTH

BUILDING A GLOBAL COMMUNITY

BY TIM GILMER

In his award-winning 2009 documentary, *More Than Walking*, Jonathan Sigworth addresses a large group of quadriplegic men in Pune, India. Sigworth, a C7 quad, was paralyzed in a bicycle accident in India in 2006 when he was 19 and returned to educate and inspire his fellow quads. “What we are really trying to promote,” he says, “is using your disability as your greatest strength.” Sigworth sees the men as future mentors who can become “a resource to quadriplegics in other places in India.” He wants them to turn their worst nightmares into becoming an army of teachers and helpers, but for many of them, his speech is the first time they’ve been told they can live independently.

A large percentage of people with spinal cord injuries in developing or low-resource regions live in poor economic conditions with unstructured medical systems and few SCI facilities. Rather than wait for these countries to catch up, Sigworth has dedicated himself to helping bridge this gap. In 2016, he founded *More Than Walking*, a nonprofit that provides rehabilitation guidance to health care providers and acute and chronic SCI survivors on a global level through online video courses and support efforts.

All of his efforts are built around his understanding that people with spinal cord injuries and disorders are stronger together. “If we can embrace ourselves as part of the global disabled community, we really can make a huge difference,” he says, “because we are the most diverse, the most marginalized group on the planet.”

THE BEGINNINGS

In the acute stage of his SCI, prior to starting his nonprofit, Sigworth returned to the U.S. to rehab at Gaylord Hospital in his home state of Connecticut. Injured during his gap year after high school, Sigworth started his undergraduate degree the following year at nearby Wesleyan University. He was still learning to be independent, doing outpatient therapy and rebuilding his strength. “I was thrown into college classes and having to dictate papers instead of type them,” he says. “It was really a struggle to adapt, being the only wheelchair user on a campus that was very hilly.”

Sigworth applied to Wesleyan’s prestigious film program, but didn’t get in. “I really wanted to major in film, so I took a year off to make my own documentary,” he says. Sigworth transferred to Dartmouth after hearing about the school’s generous funding for undergraduate film students. “I wanted to use that funding to go back to India to continue doing various cool projects like the documentary and other things,” he says.

Sigworth had been returning to India every winter break since his injury. He relished seeing the friends he’d made there and spreading the word about independent living and his other new passion: quad rugby.

Going back and forth between India and university was like rolling in two different worlds. In India, he acted as a role model, implementing fun and interesting programs, teaching skills he had learned, and working on his film. “I was meeting people who had never met someone of my level of injury or anyone with a spinal cord injury who was independent,” he says. “In India, you roll down the middle of the street and everyone stares at you because there are very few wheelchair users that you see out on the streets that are making it.”

A DARK TIME LEADS TO HOPE

Back at Dartmouth during the school year, he felt isolated, and grew depressed. “Here I am at a very good college, chronically depressed, and yet I knew that my friends on the other side of the world did not have access to the resources I had,” he says. “What was I going to do with the opportunities I had? Was I making the most of that? That question was constantly in the back of my head and the social isolation was still very real, very jarring.”

Without access to wheelchair rugby, and with many of his friends in wheelchairs halfway around the world, Sigworth realized what he was missing. “I think the real source of my depression was I just got disconnected from the spinal cord injured community,” he says.

Sigworth saw the same thing happening with a friend in India. “Samir lived in a village where there were no other wheelchair users around. I ended up being able to bring him an extra wheelchair that was very similar to mine. I stayed in touch with him, but he was also depressed and he had some health issues,” he says. “While I was at Dartmouth dealing with my chronic depression, he ended up dying of a stomach

ulcer. And he had reached out to me in his depression. But I just couldn’t connect or feel that I could help.”

Understandably, he describes it as a really dark time. “I never tried to kill myself, but there was a night when I went out in the late fall in the parking lot outside of my dormitory, looked down where the end of the parking lot sloped into a small gully full of trees, and I wondered. What would it be like to just let go of my wheels and let myself roll?” he says.

His experiences reinforced the importance of staying connected to your peer community. “When you don’t, you can have everything else in the world going well for you and you can still feel alone,” he says. “I never want to be in that state again. I never want others to feel that they are disconnected and feel that they have nothing to offer.”

CONNECTING COMMUNITY

When he graduated and returned to India in the fall of 2013, Sigworth’s priorities were clear. He started a transitional living program called Empowering Spinal Cord Injured Persons, at first living with two other quads on the ground floor of a three-story house. Mindful of the need for social interaction, he invited people in the neighborhood and people on the wheelchair rugby team from the hospital to come to a dance party in the living room of his apartment. “I was the DJ playing Bollywood dance hits on my Spotify account for a group of people we hadn’t met who were now partying with the people who were part of the transitional living program,” he says.

Sigworth advocated to change rules limiting caregiving at this year’s Roll on Capitol Hill.



For some this was their first experience living on their own outside of their family home. “Now they were on a dance floor having a great time with international tourists into the wee hours of the morning,” he says. “I think this really speaks to a kind of openness that should be more present in our society, but that you most often find on a dance floor.” In the process of establishing ESCIP, Sigworth learned that SCI survivors in developing countries spend an average of seven years before getting any kind of independent living training.

Soon after establishing ESCIP, Sigworth connected with the woman who would help him launch More Than Walking and eventually become his wife. Nearly 10,000 miles away, Jessica Bello Capote was working as a physical therapist in Cali, Colombia. In November 2013, when looking for tools to help a patient, she found Sigworth’s instructional videos on YouTube and reached out to connect.

Sigworth traveled to Colombia in 2014 and met Bello Capote in person for the first time. She introduced Sigworth to her friends and her work. “I could see he liked to tell people his story. He already had the idea for More Than Walking and he wanted it to be more international through the internet,” she says. “He was very fun, interesting, smart and we had similar priorities. I could see he cared about people. He was a good person who cared, always being helpful.”

They married in 2016, and worked together to start MTW. “It was all his idea,” she says. “He was the one directing it. In the first three years, when I had more time [before a busy PT career], I supported him by giving my perspective from treating people with SCI.” Now many of MTW’s teaching videos feature not only SCI survivors demonstrating their skills, but also input from the physical therapy perspective as well, so PTs and PT students everywhere can also learn about SCI.

PRIORITIES AND THE FUTURE

Today, Sigworth is not only making more how-to videos but also plans to create video courses that spread independent living skills and needed information on important topics for the disability community via webinars, podcasts, etc. “I think the biggest issues are access to basic rehabilitation, equipment, and basic benefits like government support. These are global issues. And access to active rehabilitation. Even in the States, people may not be learning some of the basic independent living skills that they should be. And this situation is mirrored in developing countries like India and Nigeria and places where there are no specialized spinal cord injury hospitals,” he says.

Rules that severely limit caregiving hours are especially damaging. “If you need caregivers 24-7, most states require



Sigworth with his wife, Jessica Bello Capote.



Sigworth with quad ESCIP House residents Joseph (left) and Gajendra (right).



Sigworth spreads the word about the benefits of wheelchair rugby in India.

PRACTICAL RESOURCES FROM MORE THAN WALKING:

The website for Sigworth's nonprofit, More Than Walking, has a variety of resources to help wheelchair users learn new skills and connect with others in the community. There is an archive of demonstration videos showing how wheelchair users do everyday tasks like transferring, getting dressed, driving, managing bowel and bladder, and a whole lot more. Visit: morethanwalking.com/demonstrations. The easiest way to navigate is via the categories on the right-hand side of the webpage.

You can also go to morethanwalking.com/connect.html to connect with a peer mentor, submit your own videos or join More Than Walking's SCI peer support group on Facebook.

that you remain poor. You cannot marry someone who has a decent job or you can lose your caregiving benefits," he says. "That is a travesty, a complete injustice that makes people with disabilities second-class citizens who can't save for their future or pass any inheritance down to their children. That is insanity and it needs to change."

He's been working to provide employment mentoring around the country for people who are looking for support in getting back to work, and guiding them on how to transition off of Social Security and disability, or how to manage those benefits so that they aren't lost. More Than Walking is working with SPINALpedia, one of the web's premier SCI hubs, to tackle mentoring and other critical issues. "Jon is a pro and he takes it to the next levels," says SPINALpedia founder Josh Basile. Sigworth is also involved in local advocacy in Connecticut, trying to improve the timeliness of wheelchair repairs and wheelchair deliveries.

A MISSION OF SOCIAL INVOLVEMENT

Sigworth is a busy man with a clear mission, and knows the value and power of socialization. In his view, socialization is not only about learning independent living skills and meeting people: The heart of his work is actually encouraging and empowering people with SCI to become leaders and helpers in a larger movement.

"No one wants to join this club," he says. "For many people it has always started as a tragedy. So, to come from there and

to see our mission as making the world more open, more inclusive — while challenging our own assumptions and prejudices as a result of our disabilities — it can be so healing for us and for the world around us.

"To see ourselves as part of that global movement, and to see our role as helping make the world more open and inclusive in all its forms — I think that's our larger mission." **MM**

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1. Hollister data on file, ref-00614, July 2018.
2. Dean, N (in press). Microbial Transfer by Intermittent Catheters: Evaluation of Effectiveness of Protective Features. *Journal of Wound, Ostomy and Continence Nursing*. Testing performed on *Candida albicans*, *Enterococcus faecium*, *Escherichia coli* bacteria.
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Potentially PANAMA

A woman wearing a cap and sunglasses is seated in a red and black wheelchair on a grassy field. Behind her are large, ancient stone ruins with brick window openings. The sky is blue with some clouds. The title 'Potentially PANAMA' is overlaid at the top in white text.

A wheelchair user considers the benefits and drawbacks of moving abroad

BY LILLY LONGSHORE

I KNOW I NEED A PLAN FOR MY FUTURE CARE. I want it to be good and lead to peace and comfort in my twilight years. Over my 21 years of living with quadriplegia, I have independently cared for my personal needs with minor help from my husband. I know this will not last forever. We are both aging, and I continue to lose vision due to an inherited retina disease. I will need more help in the future. And I will have to pay for it myself.

In thinking about my options, one tantalizing idea from the July 2021 issue of *New Mobility* stood out. The article, “Expats: Building an Accessible Life Abroad,” featured three wheelchair users who had left the U.S. and Canada to live abroad in Japan, Cambodia and Panama. They shared windows into their lives and how they handled their care needs and costs. I was riveted. I lived in South America way back when. Why not go abroad again?

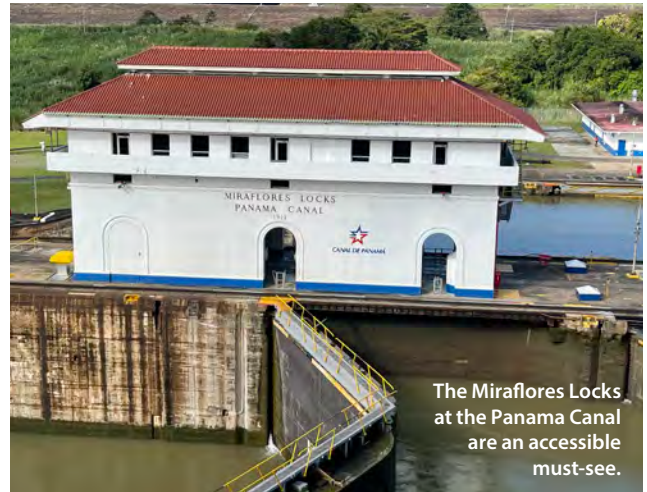
Of the countries mentioned in the article, I focused on Panama. I love warm tropical breezes, sandy beaches, palm trees and vibrant parrots. I like the friendly, family-oriented Latin culture. My Spanish is decent. And Panama is closer than Cambodia and Japan. I wondered, should my future home be in Panama?

MY RESEARCH

I kicked into research mode, looking for the answers anyone considering moving abroad would want — and those most important to a wheelchair user. I was happy to find out Panama has more sidewalks and ramps than most Central American nations. It is one of the wealthiest Central American countries because of the famous canal. It has some of the best water treatment in Latin America due to significant infrastructure put in place by the U.S. military during its 95 years of Canal Zone control. As a result, it is perfectly safe to drink the tap water there. The electricity in homes is the same voltage and amperage as in the U.S., and Panama uses the U.S. dollar for currency. These are all very handy attributes. What’s more, medical facilities are good. There is a Johns Hopkins Hospital affiliate in the capital, Panama City. And the Panamanian government makes it reasonably simple for U.S. citizens to become legal residents and own land. All of this makes Panama an attractive option for an aging quad, but I needed to know more.

MY VISIT

My husband and I flew into Panama City’s Tocumen International Airport, planning to take a taxi to a few selected towns after checking out the capital. I whittled down which towns to visit based on my own needs and criteria. I wasn’t looking for fancy, just accessible. Like much of the U.S., the newer neighborhoods tend to be more accessible but also more costly. As a wheelchair user, naturally I focused on areas with sidewalks that I could independently navigate. I cannot drive a car because of my vision, so sidewalks and the availability of taxis are critical. I ultimately decided to



The Miraflores Locks at the Panama Canal are an accessible must-see.

explore a few neighborhoods within the capital, including Costa del Este and Casco Viejo, then visit the expat town of Playa Coronado, the mountain town of El Valle de Anton, and Penonome, the home of Tony Boatright, the expat from the July 2021 NM article.

PANAMA CITY

Modern and impressive, Panama City boasts numerous high-rises that merge to produce a remarkable skyline. Expansive, world-class malls, like Albrook and Multiplaza Panama, and scores of quality restaurants and shops make this a very convenient, comfortable city.

Big cities anywhere are pricier than their nearby small towns. This is true of Panama, but food and taxis in Panama City still cost less than in the U.S. I got a breakfast sandwich, fruit and cafe con leche at a nice sidewalk cafe for \$6; a chicken Caesar salad or a sandwich with side cost \$8-\$10 each. Groceries I bought were 20%–30% less than at home. I loved the excellent mountain-grown Panamanian coffee for \$5–\$8 per pound. On Amazon, the same thing is \$24.

Since buses are not wheelchair accessible in Panama, I relied on taxis. Taxi service was \$4–\$7 per ride around the city. And the 48-mile trip from the capital to Playa Coronado was \$75 — much less than an Uber at home.

Absurdly, in my 21 years of wheelchair use, I never realized how essential sidewalks are to my independence. Where I live, they are simply there. In Panama, although there are laws encouraging construction of sidewalks, it became a treasure hunt. I successfully found pockets of accessibility in Panama City primarily based on existence and quality of sidewalks. Most public malls, grocery stores and museums are accessible from the parking lot. Some great tourist sites, like Miraflores Locks and Canal Visitor Center, Panama Viejo, and the Amador Causeway are wheelchair-friendly. To live here, though, I would need housing with at least a few blocks of adjacent, usable sidewalks.

My visit to Costa del Este revealed a very wheelchair-accessible neighborhood. I wheeled along wide, well-maintained sidewalks in the 90-degree heat, among magnificent



Panama City's Amador Causeway offers miles of prime rolling with the skyline as a scenic backdrop.

palms. Never far from the ocean, I heard seagulls calling on the gentle breeze. Most buildings are high-rise apartments, which means elevators. I successfully found apartment buildings with multiple elevators and backup generators in case of power outages, making the high-rise scenario plausible.

Closer to the center of the city, Avenida Balboa also has potential for accessible living, with a scenic sidewalk running continuously along the avenue, all the way down to the fish market by the sea. Unfortunately, the neighborhoods were expensive.

Finding a small apartment affordable for a manual chair user might be doable, but I was looking for a place with enough space for my power chair, eventual live-in help and visitors. I used encuentra24.com to compare rental costs for furnished three-bedroom accommodations across Panama. With desirable locations, low crime and newer buildings, listings in Costa del Este and Avenida Balboa started around \$3,000 per month. I found a number of areas with similar rentals running around \$600 per month, but in less-desirable neighborhoods with less, if any, access.

I was disappointed when I took a taxi to see the historic neighborhood of Casco Viejo. The architecture is beautiful. San Jose Church, which houses the historic gold altar that privateer Capt. Henry Morgan tried to steal, is magnificent. But the sidewalks are too narrow to accommodate a wheelchair.

OUTSIDE THE CAPITAL

The drive to Playa Coronado, 54 miles southwest of Panama City, gave me an opportunity to practice Spanish with Oscar, my driver. Oscar dropped me off at Hotel Coronado Inn. The hotel has an accessible lobby, a room with toilet grab bars, and an awesome open cafe, but the town of Coronado is not for wheelchair users. There are no sidewalks anywhere and the streets are in poor condition. I viewed everything from

the window of a cab. The gorgeous beaches are inaccessible, unless one has a beach wheelchair. I would get one if I lived here. Wheelchair users are at least on the radar, though, as both the local grocery and shopping center have ramps. I spent one night in Playa Coronado, feasting on excellent panfried red snapper fillet with veggies and rice for only \$6, then took off to see Boatright in Penonome.

I met Boatright at the local hospital. It was a convenient rendezvous spot and provided an opportunity to check out the small, clean medical facility. In terms of size and quality, it reminded me of a community hospital in the U.S. If I lived in Panama, I would opt for the Johns Hopkins affiliate in Panama City for major surgery.

We stayed with Boatright for two nights in his secluded, rambling home. I knew that Penonome would not work for me because of the absence of sidewalks and my inability to drive. So, instead of exploring the town, we relaxed and chatted on his fantastic deck overlooking Rio Zarati — why leave such a great place with an awesome view? Boatright gets around by driving to destinations with entry ramps. He is elated with his relaxed, tropical life, his open-air-style home and his warm, adopted Panamanian family.

We wrapped up our trip visiting the beautiful mountain town of El Valle de Anton. Higher in elevation, nestled in a valley surrounded by verdant mountains, this small town is cooler, often in the 70s. A good sidewalk/paved bike path runs the length of the town. Many but not all of the stores and restaurants are wheelchair accessible. I loved this place, even when I got caught in a tropical downpour and was soaked to the bone in seconds by warm rain. I escaped into an inviting cafe for a hot cup of excellent mountain-grown coffee. El Valle would be a great choice for me, except that there are essentially no long-term rentals listed — only Vrbo, Airbnb, and homes for sale at \$375,000 and up.

IN A NUTSHELL

Of the Panamanian towns and neighborhoods I visited, I really like Costa del Este and Avenida Balboa in Panama City, and El Valle de Anton. The capital would be easiest for finding helpers since that's where most people live. A brief search for domestic helpers showed workers available for \$35 per day. It is common to have live-in help in Panama — it's part of the culture. Ease in finding affordable help is a huge plus in my book. Transportation, medical care, and access to goods and services are easiest in Panama City. But the quiet mountain town of El Valle de Anton calls to me. So, it remains on my list.

So far, Panama has potential and meets part of my needs — I would just have to find the right neighborhood. Wherever I live, I want a home where I can roll out my door to a useful or interesting place. My next step is investigating more neighborhoods in Panama City, especially former U.S. military bases that have reverted to Panamanian control.

Whether I end up moving abroad or staying in the States, going through this process has helped me better understand what I am looking for and how to find it.

MI

ADAPTIVE PANTS

Three New Styles Reviewed

Finding a pair of jeans that checks all the boxes for a wheelchair user can be difficult. Pants that fit well and hold up to extra wear and pulling, while allowing you to cath or tend to other needs — AND that look good and don't break the bank — are few and far between.

Adaptive clothing company No Limbits has designed a line of pants that aims to address all of these issues and retails for a reasonable \$75. Erica Cole, an amputee and the founder of No Limbits, says the company is committed to improving its products and growing its selection of offerings. She was kind enough to send us three pairs of their new pants to review, two for men and one for women.

To round out the review party, we got our hands on a pair of JCPenney's new a.n.a Adaptive Womens High Rise Straight Leg Jean. They feature a number of options designed for active wheelchair users, including a high-rise fit that provides better coverage while sitting, Velcro replacements for zippers and buttons, and more. Along with their adaptive features, the jeans include classic styling and detailing, making them look like any other pair of jeans. Starting under \$30, they're also the rare accessible design that's affordable too.

Here's what our reviewers found.



NO LIMBITS WOMEN'S LIGHT WASH WHEELCHAIR PANT

The first thing I noted when I unpackaged the Women's Light Wash Wheelchair Pant is that they are sturdy, good-quality denim made of 97.5% cotton and 2.5% spandex — definitely not a lightweight, stretchy denim wannabe. The legs are cut wide, and the seven belt loops are large and sturdy enough to assist in pulling up the pants. In addition, each side of the jeans has a 13-inch zipper embedded in the seam, including a zipper pull with a thumb loop. These jeans have four pockets: two at the waist and one on each thigh. There are no back pockets to cause skin breakdown. The front waist pockets sat nicely and didn't bunch up. The pockets on each leg close with a zipper but don't have a thumb hook, so that I, as a C6-7 quad, could not open them and they lay flat on the legs.

I'm around 5 feet 9 inches tall, so I ordered a long length with a 34-inch inseam. Still, the jeans were barely long enough once I transferred to my chair. They aren't tightly fitted through the hips. The waist is higher in front than I'm accustomed to in adaptive jeans, while riding a little low in back for seated pants.

The pant legs are wider than I'm used to after years of jeggings and bootcut jeans. I was afraid they'd look messy with my atrophied legs, but my 20-year-old personal care assistant assured me this was in style and they looked cute.



My first attempt to try on the jeans was unsuccessful. In my bed, with the jeans unzipped at the sides, I fed my legs through the stiff denim, then slowly worked the pants up to my hips. But the back of the pants folded under as I pulled them up. I rolled back and forth multiple times but couldn't get the "flap" of material into place. So, I waited until I had a PCA at my house the following week.

Even with my PCA's help, the jeans were not easy to get on. The back flap folded under again. But with a few rolls and an extra set of hands to pull the pants up, we got them in place. I tried closing the zippers myself, but it took time and effort. The metal pulling loops are small and the material is stiff. Over time, as the material breaks in, this may become easier.

By early afternoon, I found myself in a bind. With the higher waist and inflexible material, I needed to unzip the pants to access my Mitrofanoff stoma that sits below the waistline so I could cath. I tried unzipping the side zipper, and with some work, managed to get the zipper down several inches. For women who cath through the urethra, these pants could be a great option for easy-access cathing without the need to pull pants down completely. But once the zipper was down, I couldn't pull it back up. I needed a fully functioning hand to hold the top of the waist together and another to pull up the zipper. So, I remained unzipped for the rest of the day. Thankfully, I was working from home, although even if I had been out, my shirt would have covered the small gap.

I recommend these if you like high-waisted jeans with wide legs made from sturdy denim. They could be a great fit for women with curvier hips and thighs for whom other adaptive jeans like Target's Universal Thread bootcut jeans may not work.

Jenny Smith says the No Limbits jeans passed the fashion test, but she found the zippers difficult to manage with limited grip strength.



I look for both fashion and function in my clothing. The No Limbits wheelchair pants passed the fashion test but failed in function for a C6-7 quad. At \$75, they cost more than the average pair of jeans at Old Navy or Target, and more than twice as much as JCPenney's newest adaptive jeans. But that price is on par with higher-end clothing lines. The quality and attention to detail are impressive. If the pants fit and work with your function, it's money well spent.

— JENNY SMITH, C6-7

NO LIMBITS ADAPTIVE MEN'S WHEELCHAIR PANT

Both pairs of No Limbits Adaptive Men's Wheelchair Pants that I tried — the light wash and khaki — fit exactly as I hoped. I usually buy a 34-inch or 36-inch waist depending on the brand, so I got the 34-inch and they fit perfectly. I'm 6 feet 3 inches tall and usually get a 34-inch inseam, so I was a little concerned when I saw that the No Limbits pants' longest inseam for a 34-inch waist was 32 inches, but the length was perfect. Both pairs of pants are made of high-quality material and fit better than any of the "regular" pants that I own.

No Limbits pants are designed with several features to address the needs of wheelchair users. My opinion on these features is mixed, so I will start with the good. The pants are made without back pockets to eliminate potential irritation points, which is nice because I usually have a caregiver remove the pockets from pants that I buy. The belt loops are bigger and seem to be reinforced for easier adjustment

and to hold up after repeated use. I appreciate this, as my caregivers and I have ripped several belt loops trying to adjust my pants over the years. Like some other adaptive pants that I have tried, the back is higher to provide better coverage when seated.

But the most notable adaptive features of No Limbits pants are also the ones that I had the most problems with. The pants are designed with zippers that go from the waist to about the mid-thigh, and open for easier dressing and access for cathing. When unzipped, the No Limbits pants provide a large opening that made it much easier for my caregiver to cath me. However, the zippers may be more of a hinderance for other quads who cath independently, as they were very difficult for me to unzip. For one, the ring on the zipper was barely large enough to fit my finger in. Secondly, to pull up the zipper, you must be able to pull the fabric tight while pulling the zipper closed. Without hand function, this was difficult to do. Another problem I had with the zippers is that the backrest of my wheelchair is contoured and wraps around right above my hips and waist, which is exactly where the zipper ends. This made it impossible to pull the zippers up while seated.

The No Limbits pants also have thigh pockets with zipper closures. The pockets themselves are nice to have and large enough for my iPhone and wallet, but the pull tab on the zippers did not have a ring, which made it impossible for me to open or close. Adding a ring here would be a simple solution to the problem.

Altogether, I think the No Limbits Adaptive Men's Wheelchair Pant would be a great option for many. They look good, are well made and offer features that many wheelchair users would like. Unfortunately, because of my lack of hand function and the way my wheelchair is designed, they don't work very well for me.

— MICHAEL FRANZ, C6

Michael Franz liked some adaptive features of the No Limbits pants, but he struggled with the zippers.



JCPENNEY A.N.A ADAPTIVE WOMEN'S HIGH RISE JEANS

After writing an article announcing the launch of JCPenney's new adaptive jeans, I saw they were on sale for \$22 a pair and decided to try a pair for myself. I ordered a size 4 of the light stellar blue a.n.a Adaptive Women's High Rise Jeans. Although I typically wear a size 4, these jeans run big. I would recommend sizing down. Loose-fitting baggy jeans are in style, so I didn't mind how they fit around my thighs and calves; however, the waist was way too big for me and there was an excess amount of fabric.

Instead of using a typical zipper and button, the pants have Velcro on both sides. As a C6 quad with limited hand use, I found the Velcro to be really strong. I had my sister open and close both sides several times to loosen them up. I would've preferred the Velcro in the front of the jeans, replacing the zipper, instead of on the side where it was awkward to line up.

The jeans are ripped and the bottom of the pants are frayed, which made them difficult to get on as my feet kept getting snagged in the holes. Don't get me wrong, I love the look of ripped jeans — but for an adaptive pair it doesn't make the most sense. JCPenney has other styles without rips that I would be more inclined to try if I ordered again.

There are belt loops on the front and sides of the jeans. I would've preferred to also have a loop in the back, where the elastic is, to make it easier to pull the jeans up. Lastly, the pockets in front are fake, which I will never understand. Even though they didn't work perfectly for me, I'm glad I tried these jeans and commend JCPenney for adding an inclusive line.

— SHANNON KELLY, C6



JCPenney's new adaptive jeans weren't perfect for our reviewer, but at \$22, they were too affordable to pass up.



DISABILITY MATTERS

By Greg Moomjy

ADULTING WITH CP

“What the hell did you just do?” I could hear the little voice in my head screaming before I could make sense of the words coming out of my mouth. “Yes, I will do shots of Funfetti vodka with you guys.” We were at Bill’s Bar and Burger, and it was my birthday. I knew the vodka would be gross, but looking around the table at the small gathering of friends smiling warmly at me, something told me that this would be the best birthday ever. It only took 28 years.

The flavored vodka wasn’t the only unusual aspect of that party. It was also the first time I dined with someone in a wheelchair. In fact, everyone at the party was disabled. We had just attended a meeting of the Adult Cerebral Palsy Support Group, a monthly gathering organized by The Weinberg Family Cerebral Palsy Center at NewYork-Presbyterian Hospital. I had only been attending for a few months, but the mothership had clearly arrived to take me to my wheelchair-accessible home planet.

Being born with a congenital disability means I have used a power wheelchair for my whole life. Also, like many others, I am the only one in my family who lives with cerebral palsy. Consequently, my life since my late teen years has been a search for people who “get it.” That night, something clicked, and I knew I was among people who did get it.

Life with a physical disability is complex and always evolving. As your needs and wants change, you must constantly reinvent ways of working with your dis-

ability to achieve your goals. This is why it is extremely important to connect with other disabled people and find community. Thanks to these awesome humans, I have begun uncovering my own internalized ableism; now, I view my disability as a joyously complicated experience that is a crucial part of me.

Until I graduated from high school, I thought that my CP only affected me physically. I became painfully aware that disability has complex emotional, psychological and social components. I still don’t feel comfortable sharing this with my caregivers. I keep thinking: Why make them feel bad for something that is out of their control? And would they understand? Through the support group, I realized these are manifestations of internalized ableism.

When I was 13, my parents did try to connect me to the wider disability community. They sent me to Camp Jawonio, a summer camp for people with disabilities. I still cringe at my excitement. I could not wait to discover how many surgeries we all had, who our doctor was, what hospital they worked at and just how often we saw them. Honestly, I thought that was what disabled people did.

I arrived to find everyone in music class. They were singing about the Rainbow Express, a train that takes you to the end of the rainbow to find the leprechaun’s pot of gold. Later, I reluctantly introduced myself to my fellow campers via “the name game.” Most of the campers had intellectual disabilities

“Life with a disability never stops being difficult. But once you find the right people, you have a whole community behind you.”

and I struggled to connect.

I went home that night mortified, thinking, “Why would my parents have me join a camp that didn’t fit my needs?” My mother maintains that Jawonio’s administration told her that they had a group that would suit me. As angry as I was, it was not my parents’ fault. Rather, the people who run the camp failed to recognize that disability is not a monolith. You can’t group people without paying attention to their needs.

When I joined the New York support group around 2017, I finally found people who were witty, passionate, outspoken and supportive. It quickly became more than just a safe space for me. Not only could we talk about anything ranging from sex to inspiration porn, but I learned by example how to live with my disability and advocate for my needs as an adult man with CP. Some members even live

independently. It is unbelievable what merely seeing disabled people taking charge of their lives can do. I still have a long way to go, but without them I would not be where I am today.

Thanks to the support group, I finally realized that I could have a voice in my own medical care. I receive regular Botox injections to manage spasticity. Normally, to enhance the treatment's effects, the shots are accompanied with a painful electrical stimulation. When I mentioned the pain to my doctor, they were surprised. No one ever told them how painful this was. I brought it up to the group, and not only did I find several people with the same experience, but they asked me, "Do you still want them? Because you can always say no."

This was a shocking revelation. My parents had always been in charge of my medical care, and I didn't realize that I could decline treatment. I thought my parents obviously must know what's best. Why would I ever contradict them? So I took the bold step of talking to my doctor. Now they use ultrasound instead of electrical stimulation. A few months later, I participated in a panel discussing sex and CP. As I stressed that patients have a right to ask their doctors questions in private, I could hear everyone from the group cheer me on in my head and how proud of me they would be.

Returning to my birthday party: We had the Funfetti vodka, along with questionable burgers and milkshakes. However, all the cheap booze and dive bar food in the world could not erase why I look back on that birthday as the beginning of my disabled adulthood. Life with a disability never stops being difficult. But once you find the right people, you have a whole community behind you, and if CP has taught me anything, it's that finding your tribe is the best thing ever.



"I found United Spinal shortly after I was diagnosed with syringomyelia. I finally had all this information that I didn't have before, and I realized there were other people like me out there."

- Madison Russell, United Spinal member



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IN THE MEDIA

By Teal Sherer

WHEELCHAIR USERS' VOICES BOOMING IN HOLLYWOOD

When Danielle Perez learned she was cast to play Sun-Spider, Marvel's wheelchair-using spider hero in *Spider-Man: Across the Spider-Verse*, she couldn't believe it. "It wasn't until I was driving onto the Sony lot to record the voice-over, that I was like, oh my God, this is really happening," says Perez, a bilateral below-the-knee amputee and wheelchair user. "The security guard knew who I was, and everyone was excited to have me there to create and play and to make movie magic."

Voice-over is a highly competitive industry that is hard to break into, but lately more and more wheelchair users like Perez are booking jobs. Animated series and movies are including more characters with disabilities in their storylines, and their creators are hiring disabled actors to voice them. Additionally, some wheelchair users, like Santina Muha, are getting hired to voice nondisability-specific roles. Muha played the Evil Realtor, a nondisabled character in Netflix's adult animated comedy *Inside Job*. "Why not?" says Muha. "I don't think a lot of people know this, but Mel Blanc, who voiced Bugs Bunny, was not actually a rabbit. With voice-over you can literally be anything. That's the cool thing."

Katie McGrath, director of the Diversity Department at Kazarian/Measures/Ruskin & Associates talent agency, has multiple clients with disabilities who are series regulars on animated series for Disney, Nickelodeon, Apple and DreamWorks. She says that, for the most part, casting directors are open to auditioning KMR's disabled clients for all roles, though they have seen the most bookings when the character has a disability. "We've made strides in regard to authentic and inclusive casting, but it does seem like it's happening a little quicker in animation right now," says McGrath.

Ali Stroker, a KMR client, began auditioning for voice-over jobs in 2009 but didn't start booking work until after she won the Tony Award for her role as Ado Annie in *Oklahoma!* in 2019. Stroker credits her years of acting experience for helping hone her voice-over skills. "Voice-over actors are seasoned. They only have their voices to tell the story, so they need to be dropped in. They need to be able to do a bunch of skill sets. That comes from experience," says Stroker.



Danielle Perez enjoys the spotlight at the world premiere of *Spider-Man: Across the Spider-Verse*.

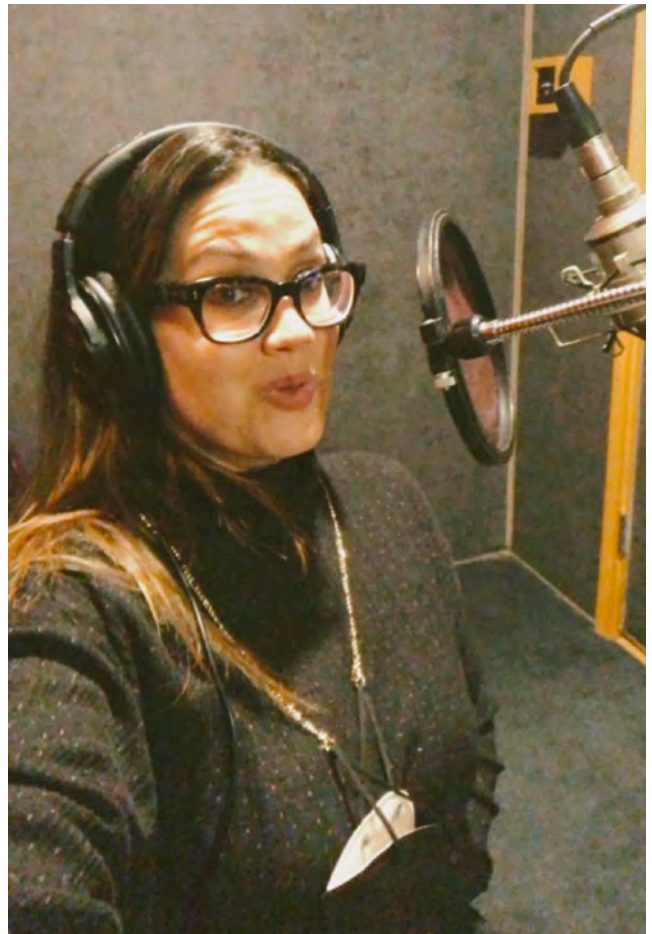
Stroker narrates audio books, most notably Judy Heumann's memoir, *Being Heumann*. She also voices characters, including for two Disney animated series, *Alice's Wonderland Bakery* and *Firebuds*. In Nickelodeon's Emmy-nominated *Big Nate*, Stroker plays Amy, one of the title character's misfit friends, who sports a black power wheelchair with pink accents. Stroker praises the disability representation in *Big Nate* because Amy's storylines do not revolve around her disability. "I think it's great that cartoon characters can exist, being disabled, and they don't have to be explained. That's always been my goal, especially with children's content and middle-grade content, because then it models that if you are disabled yourself or have a friend who is, you don't have to explain yourself," says Stroker, who has written books for children and middle-graders.

A More Accessible Experience

One great aspect of voice-over work is that you can record it virtually anywhere with the right setup, making it more



Ali Stroker records an audio book from home.



Santina Muha hams it up in the recording booth.

accessible for people with disabilities. Stroker used to drive to a studio in New York City to record Amy’s dialogue, but when Stroker got pregnant with her son, she built a recording booth in the corner of her home office. “It is covered in soundproof material, and I have big, heavy curtains,” says Stroker. “Once I set up the mic where I want it, I pull the curtains closed.” Stroker conferences by video with the director and sound engineer, and uses Source-Connect, a remote audio recording app. “It’s amazing what technology has allowed us to do,” says Stroker. “And for me, accessibility-wise and with having the baby, I just have to go into my office.”

Accessibility is one of the reasons Muha loves doing voice-over work. “Usually, most of the studios where you do voice-over are accessible, and once you get to your spot you are good to go,” says Muha. “There is no changing in and out of costumes and going to different locations.”

One of Muha’s favorite voice-over jobs is playing Dr.

Melton’s receptionist in *Wine Country*, a 2019 film directed by Amy Poehler. “Amy said that sometimes she thinks doctor’s office receptionists have sort of like a sweet, caring voice with, like, a little bit of a bitchy undertone. And she felt like I would be perfect for it. I felt so seen, like she really gets me,” says Muha, who met Poehler through doing improv at the Upright Citizens Brigade comedy group.


Perez stays busy as a stand-up comedian and an actor for TV series like *Russian Doll*, *Special*, and *With Love*, but she hopes her role in *Spider-Man: Across the Spider-Verse* leads to more voice-over work. “I had so much fun recording Sun-Spider.

I had the scripts and my lines, but I was also encouraged to ad-lib and make jokes,” says Perez. “You can do anything with animation. And to be disabled in an animated universe is just so exciting because we get to show the power we have.”



Stroker plays Amy in *Big Nate*.

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