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NEW MOBILITY

THE MEMBERSHIP PUBLICATION OF UNITED SPINAL ASSOCIATION

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COVER STORY

CELEBRATING 35 YEARS OF PRINT

In our last bimonthly print issue, we reflect on NM's long legacy as we transition to our new digital future. We tell the origin story, dig into the archives, reunite with some longtime contributors and familiar faces, and share some of your favorite memories.

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BULLY PULPIT

By Ian Ruder



NEW MOBILITY IS THE BIMONTHLY MAGAZINE OF UNITED SPINAL ASSOCIATION

PRESIDENT & CEO: VINCENZO PISCOPO
VP OF PUBLICATIONS: JEAN DOBBS

EDITORIAL

PUBLISHER: JEAN DOBBS
EDITOR-IN-CHIEF: IAN RUDER
DIRECTOR OF DIGITAL CONTENT STRATEGY: SETH MCBRIDE
SOCIAL MEDIA MANAGER: TEAL SHERER
EDITOR EMERITUS: TIM GILMER
SENIOR CORRESPONDENT: BOB VOGEL

CUSTOMER SERVICE

Toll-free 800/404-2898, ext. 7203

ADVERTISING SALES

ADVERTISING ACCOUNT EXECUTIVE: GREG DENNIS, 856/430-9898, gdennis@unitedspinal.org
AD MATERIALS: JEAN DOBBS, jdobbs@unitedspinal.org

CIRCULATION

CIRCULATION MANAGER: BEVERLY SMITH

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BE HERE NOW

There's a good chance that more people read or watched *NEW MOBILITY* content in October than in any other month in its 35-year history. In addition to our regular print and web readers, Seth McBride's YouTube review of the new \$1,000 Not A Wheelchair racked up over 50,000 views in its first week online, and thousands of viewers clicked through to read the accompanying article on our website, with many of them sticking around even longer to peruse more of our content.

With all of this in mind, I've had a hard time wrapping my head around the fact that this will be the last regular print issue of *NEW MOBILITY*.

Since its inception as *Spinal Network Extra* in 1989, and through all of the various iterations in the four decades since then, *NEW MOBILITY's* primary goal has been to amplify the voices of active wheelchair users and collect and share their stories and insights to help and entertain our fellow wheelers. For a long time, print was the only option. The internet provided a new venue, but for a while print retained the status, reach and visibility we needed. For good or bad, that is no longer the case.

The print lover in me would love to argue that we can translate the increased October engagement to more print subscribers and advertisers, more revenue and a more sustainable future. I could do so until I'm blue in the face but there's no denying digital distribution is the best way to reach the most people and have the greatest impact.

But if living with a spinal cord injury has taught me anything, it is to avoid getting lost in the *what ifs* and *what could have beens*, and appreciate what you have and where you are. *NEW MOBILITY* editor Barry Corbet came to this same realization (much more eloquently) in one of his Bully Pulpits years ago (see page 44), and it seems fitting wisdom to guide us as we start our next era.

Thanks to the hard work of all of our team, I truly believe we are better positioned than ever to build on October's record engagement. I don't expect us to match the October numbers every month, but steadily growing our reach as we hone our content and refine our methods seems eminently attainable. McBride's viral hits and Teal Sherer's vibrant management of our social content are just two of many examples of our ability to not only adapt to the digital world, but thrive in it.

As much as I'm dreading the feeling that will come with seeing the empty spot on my table where the latest *NEW MOBILITY* used to live, I've grown to love refreshing my

"If living with a spinal cord injury has taught me anything, it is to avoid getting lost in the what ifs and what could have beens."

browser to see how many people are viewing our stories. Seeing friends of friends discussing our articles in lengthy forum discussions, or watching the thumbnail of McBride's video pop up in my social feeds reassures me we are on the right path to ensuring *NEW MOBILITY's* legacy.

All that said, I still worry about losing contact with longtime print subscribers and readers who don't have easy access to the internet. I still think about a newly-injured person who might now miss out on a story or connection from a print copy they received after a criminally short rehab stay. Like all of our team, I'm committed to figuring out how to address these issues and hope you, our readers and friends, will continue to help us do so.



BEHIND THE STORIES

With Ian Ruder



There's no way I can encapsulate what **Tim Gilmer** has brought to **NEW MOBILITY** in a 250-word blurb, but if I had to try, I can't think of a better way to start than highlighting his approach with the two stories he contributed to this issue. His personal essay shines for its candid discussion of issues we all struggle with. The other is a deeply reported, well-written breakdown of a complex healthcare situation. They couldn't be more different in approach and theme, but they both reveal Gilmer's ability to find the humanity at the core of the stories and present it in an accessible, helpful way. His talent for doing this — as the editor for nearly 18 years, and as editor emeritus and regular contributor for the last six — has been at the heart of **NEW MOBILITY**'s mission since he arrived. "I try to write directly with the reader in mind, knowing we are part of the same community," says Gilmer.



As we close out the era of regular print issues, who better to feature than the woman who graced what was arguably the most famous print cover of **NEW MOBILITY**. **Ellen Stohl**'s iconic 1994 cover would be enough to merit her inclusion here on its own, but she has been so much more than a cover model. She has written and contributed numerous articles throughout the years and always served as a trusted confidant. "NEW MOBILITY has always been a touchstone for me to connect with the SCL community," she says. "It taught me to laugh about some of the things we have to endure, and to find the humanity in the experience." In keeping with the reinvention theme of her article in this issue, Stohl,

a longtime college professor in California, has applied to be a Fulbright Scholar in Greece, where she hopes to educate a European audience about disability justice and more.

Jean Dobbs' history of **NEW MOBILITY** (page 37) introduces you to the key players who made it the iconic publication it is, but she has downplayed what I would argue has been the most important factor in **NM**'s longevity and success: her vision and leadership. Anyone who knows her is probably saying, "Yup, that sounds like Jean." Humble and averse to the spotlight almost to a fault, Jean is the rare leader who is effectively able to get the most out of her team from the shadows while she works her damndest to make sure the spotlight shines brightly on whatever we are working on. Publisher, her official title, doesn't begin to describe all the roles she fills for **NEW MOBILITY**. She is responsible for the print layout, managing the budget, interfacing with United Spinal leadership and managing our small, ragtag staff. Whatever she does, she sets a high bar — and inspires those of us around her to reach it. As staff members, as readers, and simply as disabled people, we have been lucky to have her on **NEW MOBILITY**'s team for 33 years.



COLUMNISTS

MAT BARTON • MIKE FRANZ
SHANNON KELLY • REGAN LINTON
GREG MOOMJY • TEAL SHERER
HANNAH SOYER • REBEKAH TAUSSIG
KARY WRIGHT

CONTRIBUTORS

KIM ANDERSON • JOSH BASILE
LAWRENCE CARTER-LONG
RORY COOPER • DEBORAH DAVIS
JENNIFER FRENCH • ALEX GHENIS
GARY KARP • PAULA LARSON
CORY LEE • LILLY LONGSHORE
KATE MATELAN • BEN MATTLIN
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SHARE

“It feels like a fantastically innovative model that is desperately needed!”

SEPTEMBER-OCTOBER 2024

The \$1,000 Wheelchair

As an everyday wheelchair user, I have gone through some wheelchairs in my day. I would love to tour the facility and speak to someone about what, I believe, could be done better with wheelchairs themselves. I will be doing everything I can to buy myself one of these. Can't wait to see how long they last for someone who is relatively hard on my chairs. Great idea and makes me excited for the future of wheelchair users.

Kailah Mustain

Newmobility.com

So excited about this! For years I've dreamed of a "Build a Chair" workshop (like Build-a-Bear), where you could roll in and pick what you want, without insurance limitations, unnecessary costs, or long waits, especially for those of us who have used chairs for a long time and have a good sense of what we need. Not a Wheelchair seems like the start of something really groundbreaking. Perhaps in the future there could be networks of independent PTs, bike shops, etc., that could help users a la carte if they need some small help with specs or adjustments. It all feels like a fantastically innovative model that is desperately needed!

Regan Linton

Newmobility.com

This chair only costs a quarter of what my custom one did AFTER insurance — and my custom chair also came with obligatory fights with Numotion, and an eight-month waiting period. This is incredible work.

e30999

Newmobility.com

From an OT whose mission in life is to make stroke recovery more accessible, this is absolutely incredible! You typically have to jump through a thousand hoops to get insurance to cover a wheelchair (if you're lucky), and if you pay out of pocket, you're looking at spending several thousands of dollars. This is a game-changer. Thank you!

poststrokeorg

Instagram

Video Review: Is This \$1,000 Wheelchair Any Good?

youtube.com/@NewMobilityMedia

Something needs to be done about prices in the U.S. medical sector being artificially driven up by the private health insurance industry. Thank you for helping to make these necessary devices more affordable, Zach.

@DanielCrist

YouTube

VERY detailed review — I have a good friend who has been looking for one. Inexpensive and light, maybe not perfect, but I'm gonna send her this video.

@doctorbeanis

YouTube

I had to fight with insurance just to get a basic wheelchair that didn't fit, then save up to get a custom chair, only to have that stolen — and now my insurance is dragging its feet on replacing it. I can easily save up and get one of these and be mobile again. In America, it totally sucks for wheelchair users to find good quality and affordable chairs to make life a little easier. I am getting one of these chairs.

@bdctrans70

YouTube



Finding a Way Out of Bladder Hell

I read and reread your bladder story, which is really a version of a sick health-care ecosystem.

At the age of 78 and with 17 years of SCI life, I broke my hip, of course on the side with partial paralysis, of course on vacation. I was taken by ambulance to the community hospital in Ashland, Wisconsin, where I found myself continually teaching about SCI care. Great people and a good facility. From the ER to the end, it was exhausting talking about SCI.

Needing and expecting rehab, I transferred to a high-end fancy suburban address of a LTC Transitional Care Unit owned by the largest extended care provider in St. Paul. The care was lousy, and it was exhausting explaining bladder and bowel cares. The rehab was spotty, inconsistent and ignorant of SCI, but I am sure they were paid well by the Medicare ecosystem.

What your bladder encountered is an ecosystem which is heavily tilted to paternalism, is enabling and creates dependency rather than independence, self-care or interdependence.

My career was on the inside of this system, and I have seen my share of the outside of the system. Sad to say, like your bladder, it looks the same from either side. Maybe your bladder taught it something.

Dan Nicholson

Via email

Just went through the same bacteria. My husband is lucky enough to have a urologist that specializes in neurogenic bladder. She had us irrigate the bladder with a betadine solution. It took months, but it worked. He is colonized so we called it when the soldiers were ready to come out of the valleys and attack.

Lori Miller

Newmobility.com

I can feel your frustration. Renacidin, recommended by literature from the PVA, worked for me. However, after a few years use, I became concerned about the long-term effects on my bladder.

My solution for now is to change my catheter every three weeks, breaking up sediment as soon as it starts by rolling the tubing sometimes helps. I don't run fevers, so it's challenging to guess when it might need treatment. Incontinence is a key identifier. Bactrim worked for me until I developed an allergy to it (hives).

I moved to a different state in December and am in the process of finding care providers. Systems are exceedingly challenging to navigate and very different here. I thought I was moving to a state with infinite resources. Seems right now that I was very wrong!

Carla Steinbuchel

Newmobility.com

The Miracle on Flight 3313

It was with a mix of bemusement and anger that I read your recent column. As a frequent Southwest passenger, I can tell you that people faking disability to preboard is a huge problem with that airline in particular. I can tell you the reason in two words: "open seating."

Open seating provides a huge incentive for people to fake it because it gives them choice [of] the prime seats up front and empty overhead bins for their oversized carry-ons. I have personally experienced being at the front of a line of 10 to 15 people sitting in airport wheelchairs trying to beat each other out of the best seats. Thankfully almost every Southwest gate agent is on to their antics

and makes sure that those who truly need the preboard are first down the jetway and on the plane.

Then the rest of them go down the jetway in their airport wheelchairs, while those passengers with A-group boarding passes wait and try to pick through the crumbs of whatever good seats are left.

Then when we get to the destination, not one of those "disabled" people are getting off after everyone else goes off — they jump right up and are one of the first off the plane — because they are sitting in front of course.

I was mentioning this phenomenon to a flight attendant, and she said they have a term for it — they say the passengers found "jetway Jesus." I hope with Southwest moving away from open seating that it will remove this incentive to fake disability.

Paul Choquette

Via email

Last year I flew Southwest and was shocked at the number of wheelchair users preboarding on each leg of my flight. I hadn't flown since 2019 and had never seen so many people in the preboarding line. I have medical disabilities, but don't use a chair. I was physically having a difficult time, especially during my return flight. My mom had been a quad before she died. Both meant I wasn't in a great mood for the people who seemed to be "fronting the line" just like kids did in elementary school. But that was the fun of it all, adults talking about how like being in first grade the whole process seemed with people trying to jump in line in order to get the best seats.

Deborah

Newmobility.com

I am an ambulatory wheelchair user with an invisible disability. This article challenged my prior assumption that I only have to worry about the misconceptions and negative judgment of [nondisabled] people when using a wheelchair to get by at the airport.

Dismayed

Newmobility.com

Dealing with Spasticity

My 33-year-old daughter has diplegic athetoid cerebral palsy and had taken oral baclofen since early childhood. Her doctor was concerned about potential liver damage due to her taking it three times daily. Our independent pharmacist suggested having it compounded into a topical cream. She's used that for several years with much success. Topical baclofen may not work for everyone, but it's another potential aid in our repertoire of resources. It's not covered by insurance or Medicaid, unfortunately.

Sharlene Simon

Via email

Phoenix i is the First Wheelchair with Integrated Power Assist

I truly wish this kind of new technology was affordable in North Carolina. After being paralyzed for 32 years, I have learned that if you weren't rich before the accident, and the accident was your fault, then all the cool new stuff will never be available. I have had three rotator cuff surgeries, and now my wrist and forearms are starting to go ... and I have been in a powered wheelchair for six years. I would rather have something like the Phoenix. Maybe in my next life.

David Anderson

Newmobility.com

Bowhead Releases a High-Performance Everyday Wheelchair Wheel

I love that attention is being paid to the need for high-performance wheelchairs. Now what can we do to get attention paid to the need for high-performance power wheelchairs? I love to go out dancing in mine. I have to sit out for nearly half the songs every night because the motors overheat. The only response I get from the mobility provider or manufacturer is that they were not designed for this. There's no focus on improving the product so we do not have to limit our lives to stay within the product's intended functions.

Doug Sample

Via Email

Readers Weigh in on the End of an Era

Comments from Our Recent Reader Survey

Life is Too Digital Already: I am not in favor of seeing NEW MOBILITY move to a digital platform. I am already on a computer 12 hours a day when I'm working in an office. The last thing I want to do after being on Teams calls, Outlook, instant messaging and networks all day is get online. I also travel frequently, so it's nice to be able to throw the magazine in my backpack and bring it along without having to stare at a device on the airplane.

Ben Rathke

Keep the Vibrancy: I think the magazine has always had great photo quality, and I hope that the online imagery can be as vibrant. I loved in the introductory letter how you talked about considering things like podcasts, which I think is a great pivot.

Nickole Cheron

Liked Everything in One Place: I've appreciated getting so much varied information in one place while looking through the magazine (print and on my tablet) to find what's pertinent to me. The first time I discovered a copy of NM was like a miracle because in 60 years I'd never encountered anything written specifically for my disabled self. I'm going to be very sad to have to look through the variety of new ways you'll be delivering NM information and stories to find what's important and interesting to me.

No name provided

A Lifesaver: It is a shame to see the print version go. When I am finished reading my issue, I leave them in waiting rooms wherever I go. That is how I discovered it years ago. It was like newsprint, not glossy and fancy. This was in 1989. It was a lifesaver for me.

Bonnie Richardson

Keep the POV: What should you preserve? The sense of celebrating the whole person with a disability via using full body pictures. Also, it is so important the voice with which you speak about people with disabilities. No one is held up as special

because of their daily life existing. It's unique in the world of reporting. Most publications glorify simple accomplishments by people with disabilities because they see us as less to start with or as figureheads for inspiration.

Allaina Humphreys

Remember Rural Readers: Just keep in mind some people who live in rural areas do not have access to this kind of info unless it comes through the mail. I enjoy reading articles on Facebook and from the magazine in the mail. While I am a very informed disability advocate because I have been disabled all of my life, I have had staff and friends who would see the magazine on my table and ask to take it because they learned about something that they thought would help someone else in their life. Living in a small area, it really was the only way they had info like this.

Brittany Stovall

A Ripple Effect: This magazine was everything to me when I discovered it at the hospital in 2008, as I was becoming a wheelchair user — it also has helped educate so many people I know and their parents when they encounter it at the wheelchair van place, for example. I've read more issues than I can count while waiting for wheelchair van repair work!

Leah Hagedorn

Coffee Table Power: The reason I like the magazine is it's great to have on a coffee table at a place of business like a rehab center where family members can read stories and get the latest and greatest NEW MOBILITY information when they may not be looking online. I think it's good for people to still have a print copy where they may not have access to internet or a phone or computer.

Natalie Barnhard – Castrogiovanni

Here for Every Issue: Sad to see it go since I subscribed to issue #1 when it was a newsletter. This will make it impossible to donate my copy to the lobby

of the rehab center where I worked.

Kathleen Leslie Dunn

Instant Community: I leave the magazine around the house for my disabled child to pick up and peruse. He is a wheelchair user. When we don't have screen time, it's nice to have print materials around the house — especially things that can connect him to the community and people like him, which he doesn't see much of out in the world.

Roni Waitovich

Tangible Peer Support: I'd rather have print — a hard copy is always good. I have most of my magazines still in a spot put up in my house in case I ever run into somebody newly paralyzed. I bust out some magazines to show them to help them out.

Johnathon Escalona

Confidence Booster: I have found articles, interviews and reviews interesting and useful. I have certain confidences from learning about the experiences of others, as well as a better understanding my needs and the ability to convey them to doctors/vendors. I saved every issue and, pre-Covid, often lent a copy to someone who was describing a problem NM addressed. I also lent copies to neuro-PT/OT therapists, who found NM a wonderful resource, as I did.

MeLissa Gabriels

My Own Personal Archive: Honestly, I am sad about this transition away from print. I save all my old copies and go back and look at them for different topics — that is way harder for me to do/find digitally. Can you have an increased history of articles and a better search feature for online issues?

Addie Killam

EDITOR: Thanks for the nudge, Addie. In 2025, we do plan to digitize and archive more of our previously-published content on newmobility.com. Please visit us there.

Fable: Earn Money From Home as an Accessibility Tester

A Q&A WITH NEW MOBILITY EDITORS

What kind of services does Fable provide?

Fable is a platform that provides companies with on-demand access to people with disabilities for research and testing. Researchers run user research and prototype reviews with members of the disability community, empowering companies to build awareness and empathy across their organizations, leading to impactful change. People with disabilities can join Fable's Community and be paid a competitive rate to test digital products and provide feedback or to respond to surveys.

What kind of companies does Fable work with?

The best digital teams work with Fable to make products more accessible for over 1 billion people who live with disabilities. Some of our amazing clients include Walmart, Slack, Shopify and more. Fable ranked #3 on the 2022 LinkedIn Top Startups Canada list and *Fast Company's* 2023 Most Innovative Companies in Design list.

What is the process to join Fable's Community?

There are two ways that people with disabilities can join the Fable Community and contribute to making the digital world a more accessible place:

AS AN ACCESSIBILITY TESTER

Test digital products and provide feedback, earning a competitive hourly wage. You can also complete online surveys.

To qualify, you must be a native user of at least one of the following assistive technology categories, living in Canada or the United States:

- Alternative navigation (switch systems, headmouse, Dragon NaturallySpeaking for navigation, etc.)

- Screen magnification (ZoomText, OS Zoom, iOS Zoom, Android Zoom, etc.)
- Screen readers (JAWS, NVDA, Voiceover, etc.)

AS A SURVEY RESPONDENT

Participate in online surveys and get paid for the ones you complete. Past surveys have explored the accessibility of media, voting and elections, travel, and more. To qualify, you must identify as a person living with a disability in Canada or the United States.

How to join Fable's Community

- Step 1: Create an account

Create an account at app.makeitfable.com/community-sign-up/form and verify it by email. You must verify your email for your application to be processed.

- Step 2: Tell us about yourself

Share a bit about yourself, like what type of work you're looking for and what assistive technology you use (if any).

- Step 3: Let's connect!

A Fable team member will email you to discuss accessibility testing and survey respondent opportunities and determine the best fit.

How much work is available and how much does Fable pay?

Fable Community members have the flexibility to set their own hours and select the research requests they'd like to complete. Our gig-economy model makes it easy for

Community members to work as much or as little as they'd like. A Tester's hourly rate is determined by their assistive technology and previous experience, with Tester average earnings on par or above average hourly earnings for the technology industry.



VISIT FABLE.
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Folding a More Affordable Wheelchair

You've probably heard of origami, the Japanese art of folding paper, but have you heard of kirigami? It's a lesser-known variation of origami that adds cutting to expand the range of possible designs, and research engineers at the Human Engineering Research Laboratories at the University of Pittsburgh are hoping it could revolutionize affordable design for custom wheelchairs.

Led by wheelchair user and award-winning engineer Rory Cooper, HERL's team has built a slick-looking, customizable wheelchair that can be cut and built from a single sheet of aluminum. "The driving motivation for the kirigami chair is to make something that's cheaper by being easier to manufacture," says research engineer Jessica Steinberg. "The goal is that whatever prototype turns into a product would be covered by insurance, and



This idea could revolutionize affordable design for custom wheelchairs.

we would have a higher quality wheelchair customized to the person and their individual dimensions — bringing a higher quality of life to the person who otherwise would be stuck in a chair that gives them shoulder pain or is heavy and difficult to move around."

Steinberg says her team can already cut and assemble a wheelchair in around four hours, and she envisions reducing that time as they refine their processes. See the kirigami chair for yourself at bit.ly/48wJakk.



Jennifer French is the Winner of the Neilsen Foundation's 2024 \$1 Million Visionary Prize.

This September, the Craig H. Neilsen Foundation announced that neurotechnology pioneer Jennifer French is the 2024 recipient of its Visionary Prize, an unrestricted \$1 million award given annually to community leaders who improve the lives of people with spinal cord injuries.

French is a longtime advocate for making sure that people with disabilities are guiding the direction of SCI research. She is founder and executive director of Neurotech Network, a nonprofit that advances access to and education about neurotechnology to improve the secondary complications of SCI and other neurological disabilities. "It is humbling and a huge honor to be recognized by my peers," says French. "It's my passion to help advancement for people with SCI."

French is a United Spinal Association member and has contributed to NEW MOBILITY, helping explain complicated health topics like SCI research and bowel and bladder function.

Past winners of the Visionary Prize include a long list of trailblazing wheelchair users, including accessibility advocate Victor Calise, inclusive marketing professional Carmen Daniels Jones, attorney Josh Basile, medical professional Dr. Feranmi Okanlami and others. Four NEW MOBILITY People of the Year have also won the award: Vincent Pierce, Yannick Benjamin, Reveca Torres and Andrea Dalzell. Read more at bit.ly/4f15mW9.

Wicked-ly Good Representation

Wicked is one of the most beloved musicals of our time, but disabled actors have long been bothered by the fact that they have been left out of the casting for a wheelchair-using character. While Nessarose uses a wheelchair in the Tony Award-winning musical, eventually she can walk when her sister Elphaba casts a spell on her shoes. In a decision that hopefully reverses the trend, Marissa Bode became the first wheelchair user to play Nessarose in *Wicked*, the first installment of the major motion picture adaptation, which hit screens Nov. 22. While Bode can't reveal how the plot point will be depicted in *Wicked Part 2* (to be released in November 2025), she told *Variety* that it is handled with care. "Casting authentically and showing an authentic disabled person is very important, but it's also very important how we're shown," she says. "I am very happy with the changes that have been made, for sure."



JPerry-JCPenney Launches Adaptive Clothing Line

JCPenney has released a new line of attractive and functional apparel designed specifically for women who use wheelchairs. The limited-time collaboration with disabled writer and athlete Jamey Perry features 18 stylish and functional pieces, including blazers, dress slacks, blouses, cocktail outfits and more. Available in women's sizes XS-XXL, the collection ranges from \$44-\$99. Find out more details and see what our reviewer thought about the new options at newmobility.com.



Shannon Kelly models one of the cropped jackets.

DARUMA Now Streaming

Billed as "the first film in U.S. cinematic history to star two authentically-cast disabled leads in a narrative not about overcoming disability," *DARUMA* is now available for streaming after a limited theatrical run. Executive-produced by Oscar winner Peter Farrelly and starring Tobias Forrest, a quad, and John W. Lawson, a double-hand amputee, the indie film tells a story that everyone can relate to, about friendship, fatherhood and found family.

Forrest, a United Spinal member, says he enjoyed tackling scenes and dialogue that weren't all disability-driven. "Hopefully, *DARUMA* will inspire conversations about fatherhood and

friendship as well as highlight the importance of authentic casting and inclusive storytelling," he says. "Every entertainment company would benefit instantly from an increase in the employment of people with disabilities at every level of production."



Tobias Forrest, left, and John W. Lawson star in the first U.S. film to cast two authentically disabled leads in a narrative not explicitly about disability.

LISTEN



WITH SHORT, WELL-EDITED EPISODES INCORPORATING INTERVIEWS AND REPORTING, *I'M STILL ROLLING* GIVES MIKE SUGERMAN AND JANICE WRIGHT, TWO LIFELONG BROADCAST REPORTERS FOR CBS, AN IDEAL VENUE TO SHOW OFF THEIR SKILLS AND TACKLE THE MANY NEW ISSUES THEY ARE FACING SINCE MIKE WAS PARALYZED IN 2022. THERE IS SOMETHING FOR EVERYONE — WITH EPISODES RANGING FROM EMPLOYMENT, TO CELEBRITY, TO EXOSKELETONS AND MORE — AND MIKE AND JANICE ARE ENJOYABLE HOSTS. FIND *I'M STILL ROLLING* ON ALL THE MAIN PODCAST SOURCES AND AT REDCIRCLE.COM/SHOWS/IM-STILL-ROLLING.

By Shannon Kelly

Hurricane Relief

Hurricane Helene devastated communities, leaving many without essential resources. For wheelchair users the situation was even more severe: power outages, flooding and inaccessible shelters created life-threatening challenges.

United Spinal is offering personal grants and working with disaster-response agencies to support wheelchair users impacted by Hurricane Helene. This assistance can include replacing lost or damaged equipment, housing, securing accessible transportation, and covering other urgent needs.

The organization has connected with chapters in the affected areas to identify those who need support. If you have been impacted by the storm and need assistance, contact the Resource Center at unitedspinal.org/ask-us or 800/962-9629.



Accessible Yellow Cab Victory

United Spinal Association and fellow plaintiffs scored a long-overdue victory in the battle for accessible transportation in the Southern District of New York. Judge George Daniels ruled the city must honor its 2013 settlement to make 50% of its Yellow Cab fleet accessible.

“It’s been a long time coming, given that the settlement was over 10 years ago,” says United Spinal Association General Counsel James Weisman. Weisman was instrumental in writing the transportation section of the Americans with Disabilities Act, which underpins the settlement. “Finally, New York City is well on its way to complete access.”

New York City flouted a 2023 deadline — already an extension due to the COVID-19 pandemic — to fulfill the commitments imposed by the settlement. This year, the city asked the court to entirely release it from the settlement terms. In response, Judge George Daniels ruled that all new Yellow Cabs in New York City must be accessible until the original settlement terms are met. Currently, only 35% of the city’s cabs are accessible.



Meet Member Vanessa Crabtree

T12 SCI, Age 40 from Rio Phoenix, Arizona
Occupation: Systems Librarian

Why did you join United Spinal Association?

I received some copies of *NEW MOBILITY* magazine, and that's how I discovered United Spinal. Being connected to United Spinal seemed like an obvious choice being new to life with a spinal cord injury.

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

I could live without this, but using a bowel irrigation system means I have less worry, spend less time, and have better results with bowel care. I use the Navina Smart system, and learned about it and realized it could benefit me from a post on Instagram by Jesi Stracham.

What would you change in the world?

Affordable, effective and relatively independent transportation means access not only to medical care, but to friends, family, support, recreation and entertainment. These connections promote a healthy lifestyle with far-reaching impact.

Rolling Through Life

United Spinal's newest peer support group, Rolling Through Life, offers members an opportunity to connect on complex issues the disability community faces as they age. "I'm hoping the group will be a place where we can encourage each other to live a healthy lifestyle as we age in the midst of all the challenges," says Marka Danielle Rodgers, the group's facilitator. "I hope people will feel comfortable to ask questions, share ideas and generally lift each other up!"

Rodgers, a member of the organization's South Carolina chapter, endured two cervical spinal cord injuries in 1994 and 2012 and uses her passion for dance and movement to help people of all ages and levels to stay fit.

"We know age-related functional decline among people with disabilities is a chronic problem that can be difficult to manage. However, we also know that the influence of lifestyle, resilience, adaptation, autonomy, social connections and physical health can play a very impactful role in our lives as we age," says Lindsey Elliott, United Spinal's senior director of community and peer support.

The group will meet every fourth Wednesday of the month at 7 p.m. Eastern time. Register at unitedspinal.org/events/aging-with-a-disability.



SWTCon 2024 Focuses on Quality of Life

Wheelchair users, healthcare experts, corporate partners and allies joined United Spinal at this fall's StrongWheeled Together Conference. Connected by this year's theme of Wellness, the virtual events series provided discussions about the transformative power of care, mindfulness, travel and technology in bettering the lives of wheelchair users.

Trauma-Informed Care: This presentation identified the impact of patient and provider experiences of traumatic events and how they affect rehabilitation.

From Surviving to Thriving: This session looked at the healing process that comes with a life-changing trauma.

Mindful Movement: Instructor Liz Ann Kudrna, a T5 paraplegic, developed several classes directed toward those with mobility challenges, based on exploring her own experience and those of her clients with mobility challenges. She shared her expertise in this class.

Innovations and Insights for Booking Accessible Travel: Attendees learned about the obstacles faced by wheelchair users when traveling, from booking on a website to securing accommodations. Experts in the travel industry shared their efforts to make the travel experience more accessible.

Tech Access: Exclusive Product Updates for Wheelchair Users: Tech Access Initiative partners reviewed exciting accessibility features such as eye gaze, voice and movement commands, and more.

United Spinal also held an in-person reception at the Abilities Expo in Fort Lauderdale, Florida, on Oct. 19. The organization recognized three StrongWheeled Together Award winners chosen for the impact they make in our community.

Award categories included Community Visionary (technology, science and entrepreneurship), Community Builder (advocacy, activism and community development) and Community Voice (the arts). With support from sponsors, prizes included a Permobil wheelchair and two Restorative Therapies RT300s.

Meet the winners:

Community Visionary: Jennifer French is the past president and founding member of the North American Spinal Cord Injury Consortium, founder of Neurotech Network, colead on the SCI Powered Network Survey, and co-organizer of the iBCI Collaborative Community. She is a Paralympic medalist and an accomplished parasailer.

Community Builder: Mack Marsh has advocated for over two decades for people with disabilities in employment, emergency preparedness and community access. He is a founder of and heads daily operations for the Parking Mobility program to end accessible-parking abuse.

Community Voice: Regan Linton is an award-winning actor, director, filmmaker, writer, educator and internationally recognized leader in inclusive practices in the arts. She is a featured columnist for *NEW MOBILITY* magazine and codirector of the award-winning documentary *imperfect*.



L-R: French, Marsh and Linton

DAY IN
THE LIFE



MUHAMMAD HUSSAIN SHAH

Muhammad Hussain Shah grew up in rural northern Pakistan as one of 10 siblings, with five brothers and four sisters. His father was a laborer and Shah and his siblings used to help on his job sites. In 2016, two years after getting married and one year after having his first child, Shah got caught under a collapsing roof and sustained a spinal cord injury.

Shah quickly exhausted his family's savings paying for hospital care, and had to spend his share of his father's land for treatment and borrow money from friends. He continued rehab until 2019 when the doctors declared him permanently disabled.

To support his family, Shah learned to sew and started making clothes as a professional tailor. Having seen the need of other Pakistanis with disabilities, he started an organization to support

them called the Special Welfare Organization. He repairs broken wheelchairs and designs and builds custom wooden wheelchairs, well suited for the hilly, unpaved terrain he calls home. "So far, we have helped disabled people, orphans and poor families. God willing, we will continue like this," he says.

Shah works around regular power outages, a lack of running water and mountainous terrain, and prides himself on staying active and connected to his community. He says, "I don't consider my disability to be a limitation. I regularly take special time for my friends and relatives and keep in touch with them. Many people with disabilities tend to stay at home and cut off relationships with family and friends, but I believe this should not happen. Health and wellness are beyond our control; they are all part of my Creator's will."

4 a.m. I wake up for morning prayers. Since we use wood to heat water and my parents sleep in the kitchen during the winter months, I perform tayammum — an Islamic cleansing ritual where you rub a small amount of sand, dust or dry earth in place of water. It takes me around 15-30 minutes to complete my morning prayers, and then I go back to sleep.

8 a.m. I wake up again and start my day with stretching exercises. For my upper body, I stretch and do some push-ups. For my legs, I perform some circular movements with my toes, as well as some hip and knee movements while lying in bed. This routine lasts about 30 minutes. Afterward, I head out to the front yard, where I sit and have a cup of tea. I usually don't have breakfast. By this time, most of my family members have left for their daily work or school. My wife and I discuss what to cook for lunch.

10 a.m. I meet up with friends. My younger brother and I hang out with people from the local village. If they're busy I still enjoy being in nature among the trees, spending time on my own. Later, I continue exploring the area in my wooden wheelchair.

11:30 p.m. Lunchtime. Our meals typically consist of vegetables or lentils since chicken or meat is not always available or affordable for us. We usually eat chicken or any kind of meat just once a week, rarely twice, so most of our lunches consist of lentils or various vegetables accompanied by traditional Pakistani roti (a flat bread), which my wife prepares. The scarcity of firewood means we usually only cook once

a day, so we try to make things with leftovers. After lunch, I offer noon prayers.

1 p.m. I start work on sewing clothes or designing different types of wheelchairs. I used to work full time as a tailor, but now my primary focus is on helping other people with disabilities by designing and building various types of wheelchairs.

Electricity isn't consistently available. Typically, we get electricity from 1 p.m. to 3 p.m., so during these two hours, I work on cutting different types of wood and use drills and other equipment to build wheelchairs. If I have clothes to sew, I also work on cutting and stitching them during this time.

3 p.m. When the electricity goes out, there isn't much I can do, so I try to find something else productive. I often go out with my brother to find someone we can help.

5 p.m. The return of electricity for a couple of hours makes for a busy evening. My brother and I get back to working on either wheelchair projects or sewing machine. Before I begin working, I always perform my late afternoon prayers. Once the evening prayer time arrives, I have usually completed most of my work for the day.

7 p.m. I enjoy spending time with my family.

9 p.m. I use Facebook Messenger and WhatsApp on my mobile phone to keep in touch with my relatives and friends.

12 a.m. Time to sleep.

The website for the Special Welfare Organization is specialwelfareorganization.org. Follow Muhammad on Instagram: [@wheelchairandfurniture](https://www.instagram.com/wheelchairandfurniture) and [@mhshah34](https://www.instagram.com/mhshah34).

UNITED SPINAL CONNECTION

SHAH WORKS FROM HIS HOME WORKSHOP USING POWER TOOLS AND WHEELCHAIR PARTS SENT TO HIM BY UNITED SPINAL MEMBER ERIK KONDO AS PART OF HIS INITIATIVE TO PROMOTE A DIY WHEELCHAIR MOVEMENT. "MUHAMMAD IS AN AMAZINGLY SKILLED CARPENTER AND TAILOR. HIS WHEELCHAIRS ARE SOLID AND HIGHLY FUNCTIONAL. HE IS MAKING THEM OUTSIDE WITH JUST BASIC TOOLS. I AM VERY IMPRESSED WITH WHAT HE HAS ACCOMPLISHED," SAYS KONDO.



See more of Erik Kondo's projects at erikkondo.com.

GROUNDING

BY THE T.S.A.



WHEN CAN I GET MY WHEELCHAIR BACK?

IT'LL BE WAITING FOR YOU IN JAIL IF WE DON'T GET THE ANSWERS WE NEED.



ACCORDING TO T.S.A., YOU'VE BEEN HOSTILE, NON-COMPLIANT, EXPOSED YOURSELF ON MULTIPLE OCCASSIONS, AND YOU THREATENED THE SAFETY OF THE ENTIRE PLANE.

I CAN EXPLAIN.



WELL, THIS WHOLE THING STARTED WITH THE T.S.A.

I NEED BACKUP. WE'VE GOT A HOSTILE REFUSING TO STAND UP FOR A PAT DOWN.

I CAN'T STAND UP.



ANIMALS ARE TREATED BETTER THAN I WAS.

OK, HOW DO YOU EXPLAIN THE CHARGE OF INDECENT EXPOSURE?



I WAS TRANSFERRED TO THE AISLE CHAIR IN FRONT OF ALL THE PASSENGERS.

ARE MY PANTS DOWN?



SO YOU LIKE THE AISLE SEAT? I'M A WINDOW MAN MYSELF, I LIKE TO KNOW WHAT I'M FLYING OVER.



NO, AN AISLE CHAIR IS THIS HUMILIATING DEVICE I'M SITTING IN NOW. IT WAS INVENTED BY THE AIRLINES SO THEY WOULDN'T HAVE TO MAKE THE AISLES BIG ENOUGH FOR WHEELCHAIRS.



HOW DO YOU EXPLAIN THE PUBLIC URINATION? OR IS YOUR PENIS EXEMPT FROM MY A.D.A. - ACT DECENT AMERICA!



AFTER THE UNTRAINED GOONS TRANSFERRED ME TO MY SEAT AND BRUISED MY LEG, WE WAITED ON THE TARMAC FOR OVER TWO HOURS.



I REALLY HAD TO PEE AND IF I DIDN'T IT COULD HAVE CAUSED A STROKE OR EVEN DEATH.

THAT SOUNDS MADE UP.



IT'S NOT. IT'S CALLED AUTONOMIC DYSREFLEXIA. LOOK IT UP.

JENKINS, LOOK IT UP, LOOK IT UP,



IN ANY CASE, I WAS USING A BLANKET AS COVER AND THE FLIGHT ATTENDANT PULLED IT AWAY, HUMILIATING ME AGAIN.



AND YOU WERE SO UPSET YOU THREATENED TO TAKE DOWN THE PLANE.

THAT'S NOT WHAT HAPPENED, I SAID...



I'M GONNA BURN THIS AIRLINE TO THE GROUND!



ALTHOUGH THAT MIGHT NOT BE THE BEST WORD CHOICE, IT DOES SEEM LIKE YOU ENDURED A LOT OF INDIGNITIES TODAY.



I'D LIKE TO APOLOGIZE AND PROMISE TO DO BETTER.

JENKINS, GET THIS MAN HIS WHEELCHAIR.



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Taking Action Against a Hospital

How one United Spinal member sued her local medical center to secure ADA compliance

BY TIM GILMER

When Barb Zabloutney looks back on the series of events that led her to file a discrimination lawsuit against her local Pennsylvania hospital in 2022, there isn't just one moment or one specific incident that pushed her to the decision. Zabloutney, 34, a T8-10 para from Windber, Pennsylvania, had never filed a lawsuit or even been in a courtroom before and wasn't eager to embark on the long, potentially invasive process of filing suit. Yet when she reflected on the treatment she received and the conditions she witnessed at Windber Hospital over four visits in the winter of 2020-21, she couldn't shake the feeling that she had been repeatedly wronged, and that if she didn't take action, other people might suffer even more.

'WHY AM I NOT BEING LISTENED TO?'

That feeling had its beginnings in a visit to the emergency room in late 2020. Zabloutney had tested positive for COVID-19 and was battling low oxygen levels. She knew she was very sick, and after watching her father and brother struggle with the virus, she feared for her life. When she fell while transferring, she packed up her positive test and had her brother take her in.

Unfortunately, things did not improve at the hospital. Dizzy and lightheaded, with her oxygen levels hovering in the 80s, Zabloutney was made to wait ... and wait ... and wait. After listening to an F-word-filled tirade from a male nurse who mistakenly assumed her doctor had referred her there and was inexplicably angered by this, she reluctantly agreed to a second COVID-19 test, then waited for the results alone in her room

for almost an hour, all the while listening to the same nurse joking around with colleagues in the hallway. "They were talking about what they're doing for Christmas and the Steelers game and shooting animals and goofing around," she says.

When her nurse reentered the room with no test results, she asked what's going on, why the delays? He kept saying he was busy, providing no other explanation. After what seemed an interminable wait, she pushed back. "I've been waiting forever, this is ridiculous," she said. "You know what, I'd rather just go home." She started slowly rolling toward the door. He said she first had to sign a form saying she was denying treatment. She refused, saying there had been no treatment. Then he accused her of being noncompliant.

She told him, "Well, no, you're not believing me or doing anything. You're letting me sit in a room completely alone with absolutely no monitoring, nothing. I don't understand why you need a second COVID test. Even if it's negative, are you going to send me home? I'm still telling you I have symptoms, and you can still tell my pulse-oxygen was low. I'm still dizzy. Why am I not being listened to? This is unacceptable. This form does not define what happened or why I'm leaving. I'm going to write down what actually did happen and why I'm leaving." He told her to go ahead and do whatever. After adding her comments to the form, they both signed the form, she left and went home.

Concerned about her lingering breathing problems and COVID-19 complications, Zabloutney's family doctor ordered follow-up exams, testing and evaluations. So she returned to



Barb Zabolney kept thinking, *What if I don't fight this discrimination, and another wheelchair user goes to the hospital and dies?*

the same hospital — the only choice in her hometown — for three outpatient visits in February 2021. On her first follow-up, staff explicitly ignored her family doctor’s instructions indicating the best site to establish an IV, which had always been a serious problem. It became increasingly clear that the insensitive care she experienced on her first visit to the emergency department was only the tip of the iceberg.

Staff didn’t provide accessible transfer equipment for her CT scan (no transfer board). The hospital didn’t have an operable Hoyer lift, accessible wheelchair scale, or patient rooms with accessible bathrooms. Additionally, it was clear the staff lacked training on working with a wheelchair user. On top of that, external and internal ramps were too steep, layered parking lots were either difficult or impossible to navigate for a wheelchair user, and there was inadequate signage.

In March 2021, Zabloutney was still having breathing problems and could not stop going over in her mind all the issues she’d witnessed. As a longtime disability advocate and United Spinal Association member who has submitted her master’s thesis in disability studies, something didn’t sit right with her. “After the headache I went through getting all the testing done, I realized this has to be illegal,” she says.

Unsure who to call, she remembered that a friend and fellow disability advocate, Josie Badger, had recommended Nye, Stirling, Hale, Miller & Sweet, LLP, a law firm in Pittsburgh. “I trust her,” says Zabloutney. “She’s a respectable advocate, not some firebrand. I called the law firm and discussed the whole situation with a legal assistant.” To document her claims, Zabloutney sent copies of the form she modified and signed, her emails with hospital staff, and her medical records.

In July 2021, the law firm sent Windber Hospital a demand letter on her behalf, the first step in trying to gain cooperation in making needed alterations and accommodations. Then Zabloutney and her lawyers waited for a reply.

A LITANY OF VIOLATIONS

Nye, Stirling, Hale, Miller & Sweet, LLP is a nationally respected firm that represents individuals with mobility disabilities in health care access litigation in federal courts throughout the country — one of the few that do. Benjamin Sweet, managing partner of NSHMS’s Pittsburgh office, says the firm prides itself on working with the other side to find mutually beneficial solutions and avoid trials. He was surprised by Windber Hospital’s response to the demand letter. “They essentially told us that they were not willing to negotiate,” says Sweet. “And then their counsel informed us that he would be willing to accept service of a complaint, effectively inviting us to file a federal action.”

NSHMS took time to gather the pertinent information, and filed a formal complaint in March 2022, amending the complaint in July. “You’re talking about a health care facility that was really woefully deficient in terms of compliance with the

1990 Americans with Disabilities Act and Section 504 of the 1973 Rehabilitation Act,” he says. The complaint also referenced violations of the Obama Administration’s Affordable Care Act, Section 1557. Windber denied all violations.

To survey and document noncompliance, Sweet hired Mark Derry, the president of Eastlake, Derry & Associates, LLC. Derry describes himself as “Mr. Fixit,” and has a long resume working on both the construction and policy sides of accessibility. A below-knee amputee, he served on the U.S. Access Board that drafted guidelines for accessible diagnostic equipment in 2016 and has a decades-long career as an ADA expert in health care accessibility. “Hiring outside investigators in a case like this is somewhat unusual,” says Sweet, “but we think it’s important in the right case to have somebody of his caliber to defend, to support our claim.”

Derry visited the hospital, inspected the facility, prepared a report and sat for a deposition. Sweet says Derry’s report showed “a litany of accessibility violations throughout the hospital.”

INVASIVE AND CONFUSING

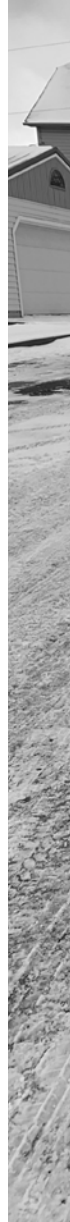
The litigation process was demanding, and for Zabloutney, invasive. After the demand letter was rebuffed, then came mediation, discovery, lengthy and exhausting depositions, and a courtroom attempt at settlement. At each stage she had to decide whether to go on. Her father, a pharmacist, owned his own business in town. Her brother, the town chiropractor, also owned his business. And her sister was a psychologist in town. “I didn’t want to attack the hospital that allegedly is helping the people of my town and giving them employment, and I didn’t want the lawsuit to create enemies for myself and my family. That’s what I struggled with the most, because it is a small close-knit community.”

But she also thought about others in town who could be affected, especially two young kids she knew of who used wheelchairs. “They’re very shy and introverted compared to me. God forbid they go to this hospital one day, and something happens and I hear that they died or something. I’m going to always think, could I have done something more? I was hoping that we’d get the typical result, and they would just fix it with the complaint.”

But they didn’t.

The next step was mediation. Mediation took place via Zoom, with each side in its own Zoom Room. The process went back and forth, with the mediator focusing on getting both sides to agree on a plan for remediation. Following more than four hours of nonproductive sparring, Windber and its lawyers walked out. With that, the discovery process began.

Windber’s lawyers requested access to all of Zabloutney’s social media, phone, email and text history. “They want it all, and that feels very invasive, very invasive, like I did something wrong, like I’m a criminal,” she says. “Here are these strangers





Zablotney felt uncomfortable going against the grain in her small, rural town, but she persevered until the lawsuit was settled — almost three years after the distressing emergency department encounter.

that caused me harm. And here's their attorney, asking for these personal things of mine. And what are they going to take out of context? What if they think it means something and it doesn't mean that? I really struggled mentally with that. ... On their original ask, I was like, 'Oh, hell no. This is nuts.' That was something that I guess I didn't anticipate."

Her legal team fought back, successfully restricting information to relevance and a limited time period. Then came a seven-hour deposition marathon, also on Zoom, with more invasive and redundant questions. "The defense attorney made multiple personal attacks on me," says Zablotney. "They pulled up security footage of my whole time at the hospital from when I drove onto the property until I left, asking questions the whole time, making me feel like I did something wrong by having surveillance footage of me."

They also showed videos she had posted, and questioned the

"I didn't want to attack the hospital that allegedly is helping the people of my town and giving them employment, and I didn't want the lawsuit to create enemies for myself and my family. That's what I struggled with the most, because it is a small close-knit community."

abilities she showed in them. In one of them she talked about the Supreme Court decision in *Cummings v. Premier Rehab Keller*, and they claimed she wasn't a legal nor an ADA expert — to which she replied, "not yet." "They really focused hard on the narrative of me being on Medicaid services, trying to paint me like a welfare queen or something. Most people would probably be intimidated, but I felt safe that Ben was there to say, 'OK, she needs a break.'"

Windber's attorney shifted focus to Zablotney's medical records, combing through about a decade's worth, asking about every single time she had gone to the hospital over the 13 years she had been a paraplegic. "Most people can't remember certain things from a decade ago when they went for what reason and why and what happened. It seemed like they just kept trying to get me to say something, so they could then say, 'Oh, well, you got service then, so you're fine.'"

SECURING REFORM

The tide turned when Sweet's law partner Jonathan Miller took the deposition of the opposing side's accessibility expert, an architect with degrees from multiple Ivy League institutions. Testifying for Windber, the accessibility expert tried to portray Derry as not up to the task by comparing his education and business status to Derry's grassroots history, but it backfired. After initially denying that there were ADA violations, Miller got Windber's expert to concede that Derry's report was an accurate portrayal of the litany of accessibility violations at Windber. The judge, according to Zablotney, did not seem happy with the defense attorney's bad faith tactics at times. Other defense witnesses' (hospital employees) depositions were also discredited.

"This happens with hospitals a lot," says Derry. "They will bring in an architect with lots of letters behind his name, who's good at talking over people and has no respect for people with disabilities. He places himself above you because he's educated and tries to dismiss you from a position of authority. I read his report and tore it apart during the deposition and stood my

ground on the fact of having all these years of doing all of this accessibility advice and training.”

The settlement process began in court, with the judge eventually ordering Zablotney’s counsel to draft a proposed settlement agreement. The final settlement was publicly filed on October 13, 2023, as an exhibit to Sweet’s motion to recover his attorney’s fees and costs from Windber Hospital. The settlement order covered a wide range of the physical and training issues Zablotney and Derry had documented, including:

- Providing Hoyer lifts, a wheelchair scale, accessible exam tables and other diagnostic equipment — and training on how to operate all equipment.
- Removing a “Sleep Lab” from public use because the entry ramp far exceeded acceptable slope (Derry described it to me as a “toboggan run”).
- Remediating inadequate space in waiting areas and adding signage to guide wheelchair users to accessible restrooms and diagnostic and other treatment areas.
- Adding signage and fixing agreed-upon slope and parking space violations in six different parking areas.
- Hiring an ADA coordinator and having ADA-specific training for all patient-facing staff for at least three years.
- Giving the plaintiff and the plaintiff’s counsel the right to inspect and monitor the premises for a period of three years for compliance with the ADA, the Rehabilitation Act and the ACA.

- Ensuring that at least one hospital patient room is fully accessible, including bathroom, within two years.

While the settlement ordered some physical improvements with limits on dollar amounts, no personal compensation or damages were awarded. Pennsylvania, like most states, does not have laws supporting damages for emotional or personal damages.

A MORE ACCESSIBLE FUTURE

Zablotney was very pleased. Sweet says every settlement is a compromise, but the most important thing is how the plaintiff feels about it. Zablotney is especially happy with all the training that will have to take place, because, she says, a well-trained staff that knows how to interact with patients with disabilities can usually solve most problems. Still, having to go through the process is not fun. “It’s tough. It’s a lot of mental labor,” she says.

That said, Zablotney doesn’t regret her decision. “I learned so much and got to see all the blood, sweat and tears that go into the enforcement of civil rights legislation on the plaintiff’s side,” she says. “It made me see a clearer picture in the built world of why we have accessibility.”

Zablotney also came away with a deeper appreciation of the gaps in the ADA and why lawsuits like hers are sometimes needed. “It made me understand why the ADA is not easily enforceable and how most disabled people don’t have the privilege of the



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“I learned so much and got to see all the blood, sweat and tears that go into the enforcement of civil rights legislation on the plaintiff’s side. It made me see a clearer picture in the built world of why we have accessibility.”

“Healthcare is nonnegotiable for me — being from a rural setting with the next nearest hospital being a 20-minute drive — while other disabled people may not even have the privilege of transportation to access medical facilities that are a further distance. If any public facility should be accessible and should have employees trained on disability law, etiquette and safety, it should be a hospital.”

Now, with all the hassle and work behind her, as Windber works on complying with the settlement, Zablotney is proud of what she helped accomplish. “I know that I did everything I possibly could to make Windber Hospital more wheelchair user-friendly so if — God forbid — I hear of something happening in the future to these children who use wheelchairs in my community, I won’t question ‘what if I could have done more?’” **MM**

emotional bandwidth needed to figure out how to enforce their rights,” she says. Her experience motivated her to work toward becoming a certified ADA coordinator and keep fighting to update the law to fit disability health care needs.

Despite learning about herself and the legal process, Zablotney says she wouldn’t go through the ordeal again for an out-of-compliance retail business or restaurant but wouldn’t hesitate to enlist Sweet and NSHMS again to fight for equal rights at another medical institution.

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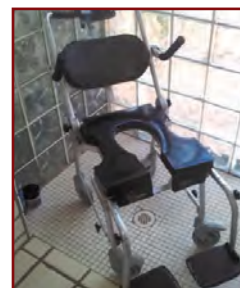
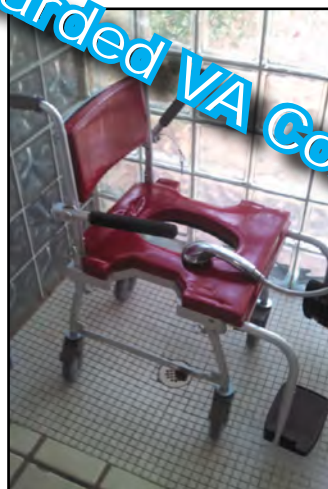
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In Greater Fort Lauderdale, we're excited about welcoming everyone under the sun and providing access for all, from beach wheelchairs and accessible pathways to the Hidden Disabilities Sunflower Program at FLL airport. Learn more about local resources and plan your trip at [VisitLauderdale.com/Accessibility](https://www.visitlauderdale.com/Accessibility).





Rediscovering Myself IN GREECE

BY ELLEN STOHL

“Life is not what it’s supposed to be. It’s what it is.
The way you cope with it is what makes the difference.”
— Virginia Satir

On the precipice of 60, I was unceremoniously dumped by my husband of 25 years, who, without any discussion, revealed that he had been planning his departure with an “old friend” for several months. As I watched my daughter seamlessly embrace the responsibilities of adulthood, I realized that the last year had delivered a life-altering trifecta. These upheavals left me reeling but presented an unexpected opportunity to redefine myself. While my professional identity as a dedicated professor and passionate advocate remained intact, my role within my family was profoundly altered. I couldn’t help but wonder: What would this new iteration of my golden years look like?

In that moment of introspection, I knew I needed a bold move to usher in my next decade. For years, my individuality had been obscured by caring for and identifying with others. And though it felt cliché, like so many middle-aged cinematic heroines, I needed to rediscover myself, reshape my home life, and gain a fresh perspective. I had always dreamed of traveling to Greece and easily persuaded my daughter Zoë, her partner Chaise, and my best friend Kristen to join me. I was eager to embrace the unknown and savor life’s simple yet profound beauty. I just hoped it would be accessible.

PHOTOS BY C. WANSTREET

ATHENS

With five days to explore Athens, I planned an ambitious itinerary that allowed us to see a number of the most famous archaeological sites, along with some of the modern marvels, all while sampling the rich cuisine and local street life.

TEMPLE OF POSEIDON

I was delighted with the newly constructed pathways that made access at the Temple of Poseidon easier. However, the sidewalk ended well before reaching the temple. Desiring a closer view of the 2500-year-old structure and the Aegean Sea, my companions aided me over a rocky incline beside the stone stairs. At the summit, I could navigate independently. The experience was awe-inspiring.



TEMPLE OF POSEIDON

TEMPLE OF ZEUS

The Temple of Olympian Zeus was one of the highlights of a city tour that included watching the iconic changing of the guards at Syntagma Square and strolling through the Panathenaic Stadium.



TEMPLE OF ZEUS

POWER ASSIST

My Yamaha Navi One power assist made navigating Athens' mostly accessible curb cuts manageable but figuring out public transportation in Athens on the fly proved tricky. I discovered that many taxis in Athens are station wagons capable of holding a manual wheelchair without disassembly, and the drivers we met were friendly and helpful. Later, I found out that the entire public transport network is also wheelchair accessible and less spendy.



POWER ASSIST OVER COBBLESTONES



PUSH TO THE TEMPLE OF POSEIDON



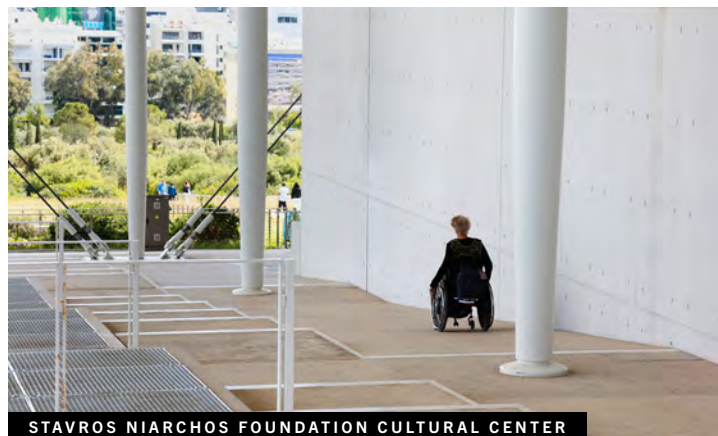
STAVROS NIARCHOS FOUNDATION CULTURAL CENTER



ELEVATOR TO THE ACROPOLIS



VIEW FROM OUR HOTEL



STAVROS NIARCHOS FOUNDATION CULTURAL CENTER



TATTOO TIME

GETTING A TATTOO

Since the trip celebrated milestone birthdays for my daughter and me, we booked a session with a local tattoo artist to commemorate the occasion. We both got forearm tattoos—mine a dragonfly with Zoë’s name in Greek, and hers inscribed with “endless wonder.”

THE ACROPOLIS

The Acropolis is magical, and more accessible than ever. Thanks to recent upgrades, including a modern slope elevator, new accessible paths around Acropolis Hill, and special vehicles, this iconic site is now fully accessible. As the elevator made its 90-degree ascent, one companion joined me while the others took the stairs. At the summit, we marveled at the Parthenon and the breathtaking cityscape.

ATHENS—NYX HOTEL

Our luxurious five-star hotel located in the heart of Athens, served as the perfect launchpad to explore the vibrant city. Each morning, we enjoyed a sumptuous breakfast buffet with an unobstructed view of the Acropolis. Though on the more expensive end, the room was well-equipped for accessibility, featuring a roll-in shower, a raised toilet with bars, and ample space.

CULTURAL CENTER

The views from the “Lighthouse” at Stavros Niarchos Foundation Cultural Center were stunning, and the roll down the sloping side ramp made me feel like I was floating on air.

PLANNING & GETTING AROUND

I planned when to travel based on two overarching goals: saving money and minimizing hassle. After discovering that ticket prices to Athens soared after early May, I opted for an April departure. As a wheelchair user due to an SCI, I wanted to avoid multiple plane changes and minimize layovers. There were many options, but United Airlines offered the most convenient schedule.

Crafting an itinerary was my next challenge. I turned to Visit Greece, the official website of the Greek National Tourism Organization (GNTO), and its Traveling Beyond Barriers page for accessible travel tips. The This is Athens site also provides tailored itineraries for travelers with mobility impairments. Despite the wealth of online resources, the complexity of planning an accessible vacation, in my state of mind, was overwhelming. Overcome by information overload, I reached out to my contacts at the GNTO, who helped streamline a fully accessible itinerary.

Upon arriving at Athens International Airport after a challenging 24-hour journey, complete with a misplaced wheelchair and a crying toddler, I was thankful I arranged for an accessible van despite the additional cost. The convenience and peace of mind it provided were invaluable. Later, I discovered that Athens has many affordable transportation alternatives.

CRETE

After a short flight from Athens to Crete, we landed in Heraklion, the largest city on the island. Time in Crete flowed differently; we spent our days exploring the island, visiting historical sites, and basking in the luxury of resort life. The Incredible Crete website became our go-to guide, enriching our journey with insights into Crete's hidden gems and local culture.

ACCESSIBLE RESORT

For our time in Crete, we stayed at Grecotel Creta Palace on the north-facing beach in Rethymno. The resort's integrated ramps and amenities ensured a barrier-free stay. My room was thoughtfully arranged with Greek pastries, champagne, and a birthday cake to honor my milestone. Lounging under beach cabanas, we sipped cocktails and let the sand slip through our fingers. We meandered through the hotel's lush gardens, explored the shops, and enjoyed various amenities. The hotel, already notable for its inclusive features like accessible beach pathways and navigable grounds, is set to enhance its facilities further with upcoming winter renovations, promising even greater accessibility.

BIRTHDAY LUNCH

I celebrated my 60th birthday in downtown Heraklion at Petousis Taverna by raising a glass of champagne to new beginnings and the decade ahead at precisely 4:24 PM on my birthday, April 24, 2024.



BOARDWALK TO THE BEACH



ACCESSIBLE CABANAS



AN INCLUSIVE RESORT



HAPPY 60TH



IMPERFECT ACCESS AT AN ANCIENT MONASTERY

ARKADI MONASTERY

A makeshift wheelchair ramp at Arkadi Monastery is a modern symbol of independence, echoing the site's historic resilience during Greece's fight for freedom.

AGRECO DINNER

Our final day in Crete ended in a memorable dinner at Agreco Farms with the director of GRECOTEL. Watching the sunset over the Aegean Sea, our engaging conversation deepened our appreciation of Cretan culture and hospitality.

RECHARGED AND READY

The trip ended too soon, but I returned home, ready to embrace the changes that had upended my life. The last year reminded me that life is unpredictable and doesn't always turn out how it's supposed to. It's what one does that makes the difference. Unfettered by home-life obligations now, I plan to apply to be a Fulbright Scholar so I can teach Disability Studies at the University of Crete in Spring 2026.

RESOURCES: SEE NEWMOBILITY.COM



DINNER OVERLOOKING THE AEGEAN



DREAMING OF A LONGER STAY IN CRETE

From 'Roughing It' to Glamping:

**ADAPTIVE CAMPING
FOR WHEELCHAIR USERS**

BOB VOGEL



Bob Vogel found that bringing extra gear helped make camping more comfortable and accessible for his aging body.

Kristi Grotting Hruzewicz camping on a multi-day cross-country ski trip in the Sierra Nevada mountains.



As the first rays of dawn illuminate the inside of my tent, the chirping of birds complements the wind whispering through the forest. The air smells of the ocean and redwood trees. I've only been here since yesterday afternoon, but I already feel mentally refreshed, unplugged from the daily grind. This moment reminds me why I love camping.

The cool thing about camping is that there is no “right” way to do it. It’s adaptable to your budget, level of function, time constraints, and how adventurous you’re feeling. Here’s how four wheelchair users camp at various levels of comfort, from basic “roughing it” to car camping and glamping.

ROUGHING IT

One of the main attractions of basic camping, also known as roughing it or minimalist camping, is that it can be done on a whim because it involves a minimal amount of gear and packing. With more prep, it can also provide a base for adventure trips like handcycling, rafting, kayaking or cross-country skiing.

“Basic camping is my favorite — it’s a great way to recharge my batteries and retune with nature,” says Topher Downham, 55, a C6-7 quad and accessibility outreach manager for the city of Boulder, Colorado. Some of his most memorable short trips involve driving out into the Canyonlands desert in Utah. “I sleep outside without a tent and there are millions of stars overhead, and [in the morning] I can watch the sunrise from my cozy sleeping bag,” he says.

Of course, roughing it is on the low end of the comfort spectrum. “A camping trip usually involves a little bit of misery that is not fun at the time, but in hindsight makes the trip more memorable,” says Downham. “[On] several different occasions, I have gotten wet and cold during the night, which is really rough because as a quad it is impossible to warm up, but in time it will be the story I remember.”

This brings up an important gear tip: Invest in a warm sleeping bag. Paralysis tends to make it more difficult to stay warm. Everyone I spoke with for this article has a sleeping bag rated to minus 20° Fahrenheit. “I bought one because I get cold so easily and being cold is miserable,” says Kristi Grotting Hruzewicz, 49, a T9 para who employs minimalist camping skills for multiday sea kayaking

and cross-country ski trips. “I went cross-country sit-skiing with a friend in the Sierra Nevada mountains and followed a packed snowmobile trail. I pulled a sled with my gear, which included a tent, sleeping bag and pad,” she says. “It was a fun adventure, but it was really cold and we skied back the next day.”

When it comes to sleeping bags, treat the rated temperatures — which seem to be geared toward survivability rather than comfort — with a grain of salt. When Grotting Hruzewicz camps in warmer weather, she still brings her minus 20° bag. “I just unzip it and put a sheet over me,” she says.

Like Grotting Hruzewicz, everyone I talked with for this article enjoys combining basic camping with other outdoor activities. Matt Howard, 33, a T10 para and outdoor recreation coordinator for Oregon Spinal Cord Injury Connection — a United Spinal Association chapter — has roughed it on adaptive mountain bike trips. He shoves all his gear in a dry bag and puts it on the back of his bike, leaving his chair behind for an overnight trip. He sits on the ground while setting up his tent and hanging out around camp, and uses a yoga mat and low-profile ROHO cushion to keep his skin safe.

When I’m out of my wheelchair at camp, I use a Vicair AllRounder O2, a cushion that straps to my butt like a climbing harness. Downham prefers just a Purple Simply Seat Cushion.

Downham has completed several monthlong handcycle touring trips, including one with a nondisabled buddy



Glamping can combine adventure with some of the comforts of home. Matt Howard wakes up to the sounds of the river from his camp cot.

through Holland. They camped wherever they wound up at the end of the day, be it in backyards or open fields. He towed his wheelchair behind him as an improvised trailer, strapping his gear in the seat. He did another monthlong handcycle trip in France, staying at campgrounds along the Loire River.

Whether you're camping for a month or a single night, everyone agrees that a good sleeping pad is another crucial piece of basic camping gear. "I'm extremely careful about

"After a day of camping, I get a great feeling of healthy tiredness where I just zonk out and sleep really deep."

— Matt Howard

skin care because I've had a pressure ulcer and skin-flap surgery," says Howard. "My pad of choice is a Big Agnes Divide sleeping pad. It's 3.5 inches thick, and wider than most sleeping pads. When I'm lying on my side, I don't have to worry about my hip going through the pad and creating a pressure sore."

Grotting Hruzewicz prefers self-inflating pads with a combination of foam and air. If the pad loses air, you still have foam to protect your skin. Her sleeping pad of choice is the LuxuryMap self-inflating sleeping pad by Therm-a-Rest.

For protection from the weather, Howard's tent of choice is a Marmot Tungsten one-person tent. Grotting Hruzewicz also likes the Marmot brand. However, she chooses the Limelight two-person model. Downham currently uses a Mountainsmith Morrison tent. "I like

it but I can't set it up myself, so I have my eye on a Hilleberg one-person tent. Although they are pricey, they are designed for [Mount] Everest climbers to be able to set up with gloves on, which makes them ideal for quad hands," he says.

CAR CAMPING

In my younger days when ground-to-chair transfers were a snap, basic camping was my preference. But with aging shoulders, chair-to-ground transfers have become difficult, and sleeping on ground pads is less than comfortable. I thought my camping days were over until a couple of years ago, when I attended an adaptive camping event and realized how some additional equipment could make camping a whole lot more accessible again for my aging body. Though extra gear takes more time to pack, it enables the back-to-nature rejuvenation I crave.

My wife and I recently joined friends for a three-night campout at Russian Gulch State Park on California's Mendocino coast. Our campsite was nestled among the redwoods, and we enjoyed falling asleep and awakening to the steady babble of a stream beside our tent. We filled our days kayaking with sea lions and mountain biking through fern-lined trails in the forests. In the evenings, we shared meals and stories around the campfire.

For sleeping, I've found that car camping is more accessible and enjoyable with a generously sized tent. I prefer the Big House 4 by Big Agnes. For those who need a more budget-friendly option, the New York Times' product review site, Wirecutter, picks the Coleman Sundome 6-Person Dome Tent for the best budget-friendly family-size tent. You can find it for \$100 or less. Be aware that when it comes to tents, more money often does buy you better protection and stability in bad weather.

A major benefit of a large tent is that it has room for a camp cot. My favorite is the Coleman ComfortSmart Deluxe Cot. It's 15 inches high, which makes chair-to-cot transfers easy, and at 30 inches wide, it's easy to change sleep positions and to dress on. When I need to cath in the middle of the night, I don't want to leave the warmth of my sleeping bag and endure a frigid push to the bathroom.

So I use a Coloplast SpeediCath Flex Set, which is a closed system where you cath into a bag and screw on a catheter seal when you're done. To avoid spillage, you can also make a closed system with your intermittent catheter of preference, some extension tubing and a standard leg bag.

Although rustic, our campsite was an easy 40-yard roll to an accessible bathroom with a roll-in shower and foldout shower bench. Pushing around camp and on trails, I use a FreeWheel Wheelchair Attachment, which makes it easier to navigate uneven terrain. Safer too, as it avoids caster-catching forward tumbles. To protect my skin on the hard shower bench, I brought a ROHO ADAPTOR Pad.

Under the Americans with Disabilities Act, campgrounds are to have at least one or two accessible campsites, and some state parks are adding bare-bones cabins. In Howard's experience, accessibility can be hit-and-miss, and it pays to do some checking in advance. "We went to a campground that was supposed to be all ADA yurts, but the ramps going up to the yurts were way steeper than ADA standards," he says. "Other times I've stayed at an accessible campground and the bathrooms were really accessible, but the path between the campground and the bathrooms was gravel that was tough to roll on, which is something else to ask about."

Howard suggests calling ahead and asking a ranger if they will text you a photo of what the site currently looks like, in case seasonal flooding or other hazards have changed the site. Or if you are going out camping and not sure about accommodations, call a local office of the U.S. Forest Service and ask for recommendations. Tell them what kind of vehicle you have and what kind of wheelchair you use, and ask what places would be good for accessible camping.

Most of Howard's car camping revolves around hunting or fishing. He and his girlfriend prefer a six-person dome tent so there is room to wheel around. That, or his girlfriend's Toyota Tacoma with a shell attachment on the back. "If we are just going to be out for a night, we will sleep in the back," he says. Howard also enjoys camping in groups because when everyone detaches from electronics for a few days, they really get to connect with each other. "After a hard day of camping, I get a great feeling of being tired, but not stressed," he says, "a healthy tiredness where I just zonk out and sleep really deep."

GLAMPING

Glamping is the fun of being in nature without having to plan and pack a carload of camping gear, and often not having to cook, clean or worry about bathroom access. Going with an adaptive program or one that has already worked with adaptive camping is a great way to start, because they have the experience and equipment and usually include a packing list of what to bring.

Grotting Hruzewicz's favorite glamping trips have been with Environmental Traveling Companions, an outfit that offers guided adventures for people with disabilities.

Grotting Hruzewicz has joined them three times for fully supported sea-kayaking trips to Isla Espiritu Santo, a remote, uninhabited island off the coast of Baja California, Mexico. ETC ferries you by powerboat to the island, where everything — tents, cots, kayaks and all — is already set up.

"It's an awesome five-night trip. We were camping on the beach, but they [laid] out carpets from the tents to the kitchen area and the porta-potties," she says. "They have cooks [who] make all the meals, and staff to carry you if you want to go over the soft sand into the ocean to swim. So all you have to do is take care of your personal needs. I could focus all of my attention on enjoying the beauty of the place, paddling and swimming in the warm ocean and enjoying the starry nights." Her favorite part of the trip was swimming with baby sea lions. "It was absolute magic," she says. "It was a little like swimming with puppy dogs."

In a similar vein, though closer to home, I was fortunate to experience Yosemite National Park through Rock 'n Roll Yosemite, a three-day, two-night experience put on by the City of Sacramento Access Leisure. We stayed at Yosemite Housekeeping Camp, which has permanent tent-type units with accessible-height beds, a table, mirror, electric lights and outlets. Meals were catered, so all I needed to bring was my sleeping bag and personal supplies. Be aware, though, that campground beds tend to



When Matt Howard camps on off-road handcycle trips, he prefers to leave his wheelchair behind and use padded mats to sit on at camp.

run on the firm side. It's a good idea to put an extra pad — either an eggcrate or camping pad — on top of the bed for extra skin protection.

It was the joy and awe of camping in Yosemite that I remember — minus the days of planning, packing and unpacking. Better still, every day we got to go on handcycle trips around the valley, guided by adaptive big-wall climber and United Spinal member Mark Wellman. Yosemite's sights, sounds and smells were amazing, and made even better through sharing them with other wheelchair users, some of whom I'd known a long time and others I'd just met. We spent evenings around the campfire, retelling stories of the day, cracking jokes and sharing life hacks. It was the kind of experience that friendships are built on.

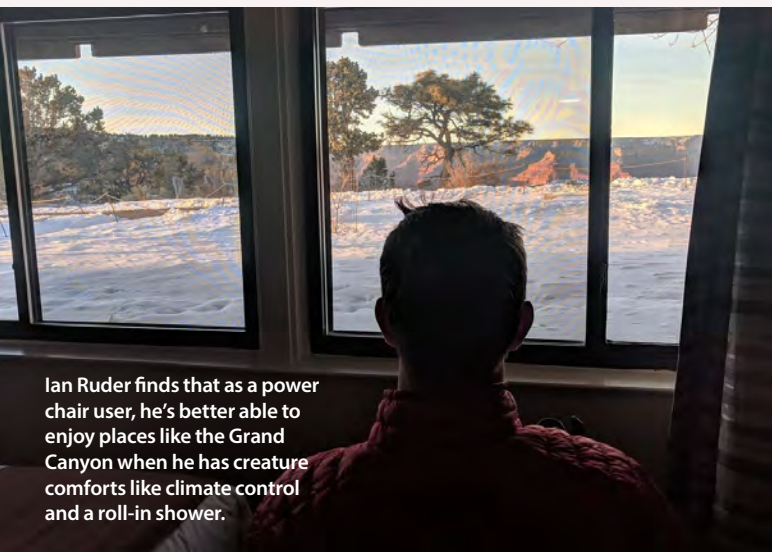
If you aren't looking for socialization, or if you simply want your glamping to include more rest and less activity, there are countless options around the country for self-serve glamping stays. These include everything from yurts to tree houses, vintage trailers, tiny homes, cabins, canvas tents and more. The more luxurious options are set up like a fancy extended-stay hotel room — complete with en suite bathroom and kitchenette — plonked in the forest, desert or whatever landscape you choose. Glamping exists in a regulatory gray area, so accessibility is highly variable, from great to nonexistent.

New Mobility Editor-in-Chief Ian Ruder says glamping offers a blend of nature and convenience that appeals to him as a C5 quad. "When you rely on an attendant, any type of travel requires another level of planning and expense," he says. "If I'm going somewhere beautiful or exotic, I want to minimize possible access issues and maximize comfort."

Ruder enjoys seeing the creative hacks others use to get off the paved paths and closer to nature, but he says he is fine as long as he has his spacious roll-in shower in paradise. "If I can't enjoy a lengthy shower in the privacy of my own accommodations," he says, "count me out."

Adaptive camping allows you to unplug from your daily life while getting a recharge from nature. Whether you want that experience to include the cabin of your dreams or a sleeping pad on the ground and nothing between you and the stars, it's up to you.

NM



Ian Ruder finds that as a power chair user, he's better able to enjoy places like the Grand Canyon when he has creature comforts like climate control and a roll-in shower.

ADDITIONAL ADAPTIVE CAMPING TIPS

1. Bring a headlamp, to light your way in the dark while leaving your hands free to push.
2. A selfie stick combined with a cellphone enables skin-checks without having to carry a mirror.
3. For bowel programs, use a cloth camp chair with a whole cut in the middle and put it over a bucket lined with a plastic trash bag.
4. For those with limited hand function, put lanyards on everything — phone, zippers, you name it.
5. An anorak — a pullover jacket without a zipper — makes staying warm easier if you have limited hand function.
6. Bring antibiotics for urinary tract infections, and a fully stocked first aid kit.
7. Bring a backup supply of catheters in case your primary supply gets misplaced or damaged.
8. Try maps on Gaia GPS or onX to check out campsites — and where campsite bathrooms are — in advance of a trip.
9. Bring heavy wool socks and/or down booties for keeping feet warm and protected in camp.

Topher Downham and a group supported by Telluride Adaptive Sports enjoyed a multi-day camping trip while riding the 100-mile White Rim mountain bike trail in Utah.



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THE IMPROBABLE AND MOSTLY TRUE ORIGIN STORY OF NEW MOBILITY

BY JEAN DOBBS

I was nervous when I knocked on the door of *Spinal Network* in August of 1991. My internship coordinator had told me that it was the best magazine published in Boulder, Colorado, so it was my first choice for learning on the job as I earned my master's in journalism.

A tall, toothy guy who reminded me of both David Letterman and Alfred E. Neuman answered the door. "I want to be your intern," I said without much prelude. "Come on in," he said, cracking that crooked smile. A sea of blue magazine proofs littered the floor, and I got the feeling he could use a hand. Maybe I was the person for the job.

But what exactly was the job? Here, review this book, copy edit this news item, oh and can you go interview a guy named Mike Auberger about how ADAPT is fighting the nursing home industry and trying to redirect 25% of Medicaid dollars toward community-based attendant services?

Why yes, I could do that. I actually understood the issue, and that sounded like a pretty grown-up assignment for a 25-year-old on her first day at J-school. Put me in, coach.

Thus began my 33-year career at *NEW MOBILITY*, originally titled *Spinal Network Extra* because it was a spinoff of the giant resource book *Spinal Network*. I have worked on

350 of 357 issues of the magazine, rising from intern to publisher, and inhabiting several editorial and design positions in between. As I wrap up this last print edition, I need to set the record straight: Yes, my paycheck bounced at least once. Yes, I almost got fired for that outrageous “Sex, Wheels and Relationships” issue in 1997. Yes, I have worked for four wildly different owners of the magazine and somehow made it to the end of the print road without getting killed or caught. Now it’s time to file my last story: the story of *NEW MOBILITY*.

LESSON ONE: WRITE LIKE YOU'RE POPPING GUM

Sam Maddox, that guy with that *Mad* magazine smile, started the business he called “the Spine” because he identified an unserved niche when he met some paralyzed guys and found out nobody was reporting authentically about the life-altering realities of spinal cord injury. By the time I came on the scene, he was a few years into the endeavor and had long since shed any insecurity about

walking in a world of wheelers. His street cred tacked to the wall in the form of a glowing *New York Times* review of *Spinal Network: The Total Resource for the Wheelchair Community*, he doled out insider advice like an old pro. “Write like you’re popping gum,” he urged his tiny team.

So we tried. Some of us were students attempting to learn the craft methodically, others came to it from discarded professions. I remember Marie McCarren, who must have been a nurse in a previous incarnation, feet up on a desk, interviewing guys about injection erections like she’d been reporting from a locker room her whole life. She seemed mature to me, but that probably meant she was like 28. I devoured her incredible articles like so many other readers hungry for truth. I wanted to be her when I grew up.

MEETING BARRY

One day early in my NM life, I was sitting at a shared desk in the Boulder office, earnestly trying to become a Disability Journalist. Bob, our ad sales guy,



Many names from the Spine days have been lost to the sands of time, but Barry is second from left, Sam is holding the youngest baby, and Jean looks like a baby in the very back.

was out of his chair and scooting around on the floor, and Kathryn Zeeb, a writer and OT student, was pounding out copy when Barry Corbet rolled in. Nobody bothered to introduce him as the greatest living writer with a spinal cord injury, so what did I know?

What I didn’t know could — and did — fill volumes of *NEW MOBILITY*. I didn’t know about his chronic pain or his “short, mostly happy life as a metha-

REFLECTIONS

SAM MADDOX | FOUNDER

As for *NEW MOBILITY* ending print, it’s the end of an era, I suppose. It was a good, long run — fun, useful and significant. But ink, so analog, and this economy, ugh, not friendly to specialized service publications. I get it, boss, no margin no mitzvah.

This doesn’t mean the readership has outgrown the need for trustworthy resources, uncompromising reporting and robust lifestyle curation. Or that the community no longer has any character or personality. Or that they don’t buy cars and catheters and chairs anymore. Let’s call it a delivery issue.

I started *Spinal Network* to improve the unmet resource needs of a couple of paralyzed Colorado guys, and a business popped out of it. It didn’t take long to see a wide-open frontier of unmet journalism: PCAs stealing from quads and leaving them to die; paraplegics injecting drugs into their penises to get hard; dude climbing El Cap with just his arms;

rebel gimps chaining themselves to city buses to protest lack of access. Let’s start a magazine!

There was no shortage of personality: Barry Corbet, the wonderful writer and later NM editor, signed on immediately; Ellen Stohl, the first wheelchair model in *Playboy*;

John Callahan, the first and only quad cartoonist to be published in *Playboy*; Marilyn Hamilton, who broke open the wheelchair business with lightweights; Judy Heumann, who broke down the dam that released a flood of disability civil rights; Charles Carson, the cure militant who labeled me “a hyena preying on the bones of misery!” Exactly! What a

time to come into a town that had no newspaper.

To the heirs of this nearly 40-year-old enterprise: Honor the community by mirroring its stories and characters. There’s too much legacy to defend, too much left to explore. Carry forward the message of possibility and opportunity. Pass it on better than you found it.

“It didn’t take long to see a wide-open frontier of unmet journalism: PCAs stealing from quads, paraplegics injecting drugs into their penises to get hard, dude climbing El Cap with just his arms, rebel gimps chaining themselves to city buses to protest lack of access. Let’s start a magazine!”

REFLECTIONS

BOB VOGEL | NM'S LONGEST CORRESPONDENT

It's hard to believe that this will be the last time I will get an issue of *NEW MOBILITY* in my mailbox. It seems like yesterday that I stumbled upon the first issue of *Spinal Network Extra* — the magazine's original name — in my days as a recently minted T10 para. Although I was living a full and active life, it was the magazine that introduced me to disability culture, and the writing captured the cool, edgy world of wheelchair life, naked and raw, but with a wry wit. Little did I know it would also lead to a gig as a freelance journalist, a job light on income but rich with experiences, adventures, interviewing amazing people and forging treasured friendships. I recall the anticipation of checking the mailbox for the month's issue, more so when it contained an article or column I wrote; when it arrived, I would devour the words, cover to cover.

Recently, while leafing through old issues of NM, it struck me how changes on the business side of the mobility product world have affected the magazine, just like things have changed in other forms of print media. It seems like the '90s were the crest of a wave for small, medium and large mobility-related businesses, including wheelchair companies, durable medical stores and a myriad of related products, many of which were advertising and competing for wheelchair users'



Bob on the first cover of *NEW MOBILITY*, left, and one in 2005.

business. This provided diverse revenue streams to keep the lights on, and enough different companies that the magazine had latitude for edgy content. Although we have more amazing mobility products to choose from today, a lion's share is now owned by a few major corporations. This makes the magazine more dependent on fewer advertisers, which makes it tough to keep the lights on and tougher to write edgy print without alienating your income sources.

Although there is a certain sadness with this being the end of an era, I do love the immediacy and unlimited readership that digital publishing provides. A fond farewell to a great print run of *NEW MOBILITY*. I've already switched my habit of checking my mailbox to clicking the link for the latest news from *NEW MOBILITY*.

done junkie." I didn't know about his mountaineering adventures on Everest and other world peaks before the helicopter crash. I didn't know about his family, his kids, his filmmaking — any of it. And I didn't know any of it when he left that day, either. He never said a word about himself, and his extraordinary qualities dawned on me only as I read more back issues and more of the magazines that we worked on together.

This, from *Spinal Network Extra*, Winter 1991:

There's a catch, of course. Methadone seems to allow some alcohol use without evident penalty, but excess is punished abruptly and harshly with runaway depression. As usual, I moderated and wussed around, but I know I am an unrepentant drinker, and grave mistakes seemed possible. I kept writing myself notes to give up methadone or give up alcohol; I gave up writing notes.

Obviously, Barry gave up methadone too, but he never abandoned his honest writing about every aspect of his life. He became editor of *Spinal Network Extra* with the following issue, Spring 1991. "It

wasn't my ambition to become a magazine editor, but now that the reality is upon me, it seems like what I've always wanted," he said. "I've unaccountably found myself with a job I've trained for all my life."

REINVENTING THE SPINE

In 1992, we renamed the magazine *NEW MOBILITY*. It was overdue, as we all knew that *Spinal Network Extra* sounded too medical, and we were about as far from the medical model as you could get. Sam did a trademark search for *Push*, but it was taken by a photography magazine. Barry didn't like it anyway — he said it had the connotation of *being pushed*. I don't remember the other contenders. *NEW MOBILITY* stuck.

Sailing was slated for the first cover, and as chance would have it, Sam and Barry met a young sailor by the name of Bob Vogel at that year's Abilities Expo. "Bob unleashed some of his extremely contagious enthusiasm for the sport, and the next thing we knew he was in the article and the next-er thing we

knew, he was on the cover," wrote Barry in that issue. Perched on his sailboat and sporting his signature red Chuck Taylors, wheelchair to the side, Bob embodies the NM philosophy in so many ways. And that never changed — 32 years later, he has shared his passions in NM longer than any correspondent (see his tribute, this page, and his adaptive camping article, page 30).

THE FIRST CRISIS

Life at the Spine went on like this until it didn't. It seems that Sam had been shielding us from the harsh financial realities of indie print publishing. "We had in effect, been supporting the magazine with Ponzi delusion," he explained, "funneling ad and sales revenue for the book back into the periodical, and as these schemes usually go, the jig was about up." The year was 1993, and the signs were there. We fudged the quarterly print dates because "Winter" could be the end of one year or the beginning of the next, right? We were making frequent trips to the bank to deposit a

handful of subscription payments. My \$137 paycheck bounced.

Sam started shopping the magazine around and even hit up Jann Wenner of *Rolling Stone* via Hunter S. Thompson's son, Juan, who worked as our graphic designer. He didn't bite.

"We made a list of all the angels we knew, and it was a very short list," says Sam. "So, I sent a postcard out to our mailing list — if anyone has any suggestions how we can save this thing, please be in touch."

One of those cards landed in the hands of Tim and Denise Novoselski, who owned several trade magazines in Los Angeles, including two disability-related titles, *TeamRehab* and *HomeCare*. They liked the idea of adding a consumer magazine to round out their portfolio, and they had their people contact our people.

Mother Nature had other plans. The Novoselskis lost their home in a terrible forest fire, putting a possible meeting on hold. Then in early 1994 the Northridge earthquake again stalled Sam's travel to meet the Novos. Finally the key parties met in February and began putting to-

gether a deal. I had graduated in December, and I was eager to work full time at the magazine if it was indeed going to survive. I flew myself out to L.A. and somehow convinced the Novos that they needed me to run the day-to-day operations while Sam served as publisher. I fit into their culture of young women willing to work hard for less money than it cost to live in L.A., so things looked pretty good. On March 29, my mother died suddenly, and Sam took over negotiating the terms of my employment, for which I am forever grateful.

UP FROM THE ASHES

NEW MOBILITY probably saved my life that year. Every day, I tried and failed to conceal my grief behind the ridiculous half-walls of my cubicle at Miramar Publishing. Mortifying, yes, but the work itself brought so much joy. We were making magazines again, and now I had a bigger role: managing editor. The second-chance adrenaline ran high as I reported stories, edited news items,



The late, great Christopher Voelker shot 36 NM covers.

collected art, collaborated with Barry via fax and phone, and ushered the issues through layout. I met Christopher Voelker, the quad who photographed Ellen Stohl for our comeback issue. He was kind of a big deal — he had photographed a Fleetwood Mac album cover, for chrissakes. Maybe this L.A. thing was going to be cool.

That first office was in a lackluster part of Los Angeles, but in another unlikely turn of events, we all moved to Malibu a few months later. The Novos bought a fabulous building near Pacific

REFLECTIONS

ELLEN STOHL | WRITER, COVER MODEL

NEW MOBILITY has been a vital part of my journey, not only by giving me a platform to share my story but also by empowering me to help others share theirs. The magazine has documented my journey from post-*Playboy* to marriage, sex, the birth of my daughter, friendship, travels and even divorce (see page 25). Every milestone is immortalized between the print copy's glossy pages. Being featured in NM has not only validated my experiences but also created opportunities for reflection and growth.

The magazine has also been essential to my development as a writer. Under the tutelage of Tim Gilmer and Ian Ruder, I've had the opportunity to address the challenges of living with a spinal cord injury. Being able to research and write about people, places and topics that open a dialogue about the complexities of disability identity has deepened my understanding of the disability community and helped me find my voice as an advocate. It has given me the chance to explore critical issues like accessibility, representation and independence while also fostering connections with others who share similar experiences.



Photos by Christopher Voelker

Ellen on the 1994 comeback issue, left, and a 2004 issue, right.

The magazine's focus on real-life stories and innovations has profoundly impacted me, not just by helping me grow as a writer but also by empowering me to contribute to meaningful conversations about disability and advocacy. It has created a space for me and others to share our stories, challenge societal perceptions, and inspire change within the disability community and beyond. NEW MOBILITY whether print or digital, will always be an integral part of my life.

Coast Highway, and we landed in much better cubicles, some with windows. The place buzzed with young talent, including Doug Davis, who has illustrated close to a hundred stories for NM, and Alan Alpanian, who would go on to design NM's iconic logo in 1997.

At Sam's insistence, the Novos hired Barry Corbet full-time, and he worked from home in Golden, Colorado, long before technology made that easy. We became a team, talking on a land line multiple times a day, madly faxing, somehow making printer deadlines with a mostly analog workflow of film and hard proofs. Ad sales were strong, and in our new home we had a circulation director, a production director and other professionals running the show. Surely it was time for NEW MOBILITY to make a profit.

"I never made any money from NEW MOBILITY, and neither did the Novos," Sam noted in 2013. "But they pumped life into it, pouring good money after bad into a full color redesign. They upped the frequency to monthly. They allowed me to hire Barry Corbet to set it on course toward its stature today as a cultural touchstone in the global disability community. If you're fond of the magazine, now you know who gets the save."

Another bellwether hire for NM was Martin Bibow. In 1996, he art-directed an ad campaign that took the community by surprise. "People of Colours" featured wheelchair users with progressive imagery such as a paraplegic woman spilling out of her overturned chair under the title "Sensuality" and a pregnant quadriplegic woman, naked from the belly down, under the title "Birth."

There were five or six such ads that were made into posters and displayed at Abilities Expos, where they met with considerable pushback from a conservative mobility industry. To us, they were 100% aligned with NEW MOBILITY, so we wasted no time in hiring Bibow as associate publisher. He brought his vision to several NM photo shoots before he acknowledged that corporate life was not for him and opted for the less soul-sucking job of "creative consultant." Bibow was an incredible visual collaborator.

THE HEART OF NEW MOBILITY

BY TIM GILMER

NEW MOBILITY has a beating heart. I'm not talking metaphorically. The heart is real, and it belongs to Jean Dobbs, a woman who has dedicated her life to nurturing the magazine from its earliest years. Now that NM is moving on from print, I decided to ask her about something that had been lingering in my mind.

TG: *What drew you in the first place to a magazine about wheelchair users with spinal cord injuries?*

JD: *In 1985 or '86, before NEW MOBILITY even existed, I was in college at the University of North Carolina in Chapel Hill and was the co-chair of the Hunger Action Committee, working on local and global hunger issues. The committee received a letter from a man named Bernie Jorn, a C4-5 quad and graduate student, who asked for volunteers to help him eat lunch. As a committee we felt it was a disability issue, not a hunger issue, but two of us decided to help him anyway.*

TG: *How long were you involved with him?*

JD: *What started as volunteer shifts evolved into a friendship. He was a few years older than me, studying rehabilitation counseling but ironically facing discrimination and a lack of accommodation from the school, like when he was penalized during a period of skin breakdown. He was laid up in his room a lot while he tried to heal, and we spent hours listening to Pat Metheny and talking. He taught me about the concept of independent living and let me see how he did it — with attendants, a mouthstick, an old ice cream truck that he had converted to a wheelchair van. I ended up doing a photo essay on him for a photojournalism class. Eventually he rejected the UNC program and enrolled in seminary in South Carolina. He went on to become a hospital chaplain, get married and raise three daughters.*

TG: *A "meant-to-be" story?*

JD: *That's not all. The next semester I took a class on the psychology of aging, which had a practicum at a local nursing home. Our assignment was to get to know someone there, visit them regularly, then interview them for a final class paper. As I wandered the depressing halls, a voice called out from a resident's room: "Hey, can you turn this cassette tape over for me?" I said sure, and he invited me to sit down. His name was Thurman George, and he was a quad with no hand or arm function who had been living from a bed for close to a decade. He was there because his wife couldn't handle his care anymore, and this was the only way that Medicaid would pay for his basic needs. To me, he seemed full of stories and life, but he was resigned to living out his days in an institution. He felt trapped, treated badly at times and saw no way out. I learned from both these guys about the most important aspect of the disability movement — the difference between independent living and being stuck in a nursing home.*

The "tale of two quads" set the stage, so that when the opportunity at NEW MOBILITY arose, Jean was ready for it, not afraid. Since her first day in 1991, from behind the scenes, she has brought her journalism training to every issue — whether about independent living, body image, sexuality, healthcare equality, employment, accessible travel, disability art, civil rights, discrimination, relationships, parenting, recreation — the list goes on. Jean Dobbs' leadership has been the most important ingredient in the NM mix for decades. We — the entire community — owe her a well-deserved thank you for her decades-long sense of purpose, determination and heartfelt dedication.

rator, and we carried forward his ethos whenever we could afford to.

As Sam said, the Novos invested heavily in NEW MOBILITY, and they deserve much credit for saving the magazine, but in 1998 they reached the limits of their beneficence. NEW MOBILITY was once again on the chopping block.

OWNER NUMBER THREE

Of all the unlikely champions of NEW MOBILITY, Jeff Leonard may be the most improbable. Small and squirrely, with a shock of black, curly hair, he's the kind of man who has been underestimated his whole life. But make no mistake, he is sharp. When our paths crossed, he was running an ad rep business in Horsham, Pennsylvania, and several magazines outsourced their ad sales to him — including NEW MOBILITY by the spring of 1998.

Jeff also had his own product, a direct mail packet of Disability Product Postcards, which he mailed to the largest database of disabled consumers in the country. Acquiring NEW MOBILITY seemed like a no-brainer to him — so what if he'd never published a magazine before? He already owned the most important financial pieces: an ad sales team and a relevant database.

Jeff agreed to take over publishing NM — but only if I came with it. I didn't want to quit, but I admit I took some convincing: Southern California had grown on me, and I didn't fancy a move to suburban Philadelphia. "You can work from home in Santa Monica," he offered, and that cinched it.

Once I dropped my skepticism, I saw that he was that rare and generous boss who was going to give me free rein. Not only that, he was going to let me hire more people. Barry and I had been editing the magazine by ourselves for some time, and it was wearing us out.

I knew that I should be the last non-disabled person on the editorial masthead, and I made it part of my mission to find qualified people with disabilities. In 1998 I hired Douglas Lathrop as associate editor. He had had a journalism degree, lived with osteogenesis imperfecta and had five years of clips from

another disability magazine. Score.

In 2000 I hired Josie Byzek. She brought a fearless advocacy voice from years of writing for *Mouth* and *Ragged Edge*, had lived experience with MS, and helped us expand our point of view. In retrospect, I think hiring Josie gave Barry permission to retire; he needed to for his health, but he didn't want to leave me in the lurch.

"No one has cancelled a subscription and sent us a shredded copy of the offending magazine in years. Is that a good thing or a bad thing? Hard to say."

Barry and I worked together to find his replacement. To be honest, there were only two viable candidates for the top editor job: a quad and rehab educator in Colorado, and a para and former English teacher in Oregon. We put them through the paces with writing and editing tests, and Tim Gilmer excelled. Tim, Jeff and I flew to Colorado to meet with Barry so we could all see if Tim was really the guy. We sat out on Barry's deck overlooking the Continental Divide, exchanging ideas for a gentle while, and Barry voted yes. We all did — and it was once again the end of an era.

FAST-FORWARD TO THE FUTURE

I have written elsewhere about the early years with Tim Gilmer, about our struggles over religious content and other points of disagreement. Our shared commitment to NEW MOBILITY sustained us through those awkward times, and now they are a distant memory, replaced by a 17-year run of imperfect badassery, NM-style. Of particular note: In 2006 *Utne Reader* named NEW MOBILITY one of its Top 15 Magazines of the Year; our work was recognized and honored beyond the disability echo chamber, and it was a wonderful bonding moment for us.

As NEW MOBILITY continued to

evolve into the publication you know today, we faced another threat to our survival when a decade of booming print ad sales started to decline. Jeff saw the writing on the wall and started shopping the magazine around to publishers with deeper pockets. We caught wind that one of the disability nonprofits had ambitious plans for a grassroots reboot — could that be the answer to our worries? Turns out it was, and in 2010 Jeff sold NM to United Spinal Association.

There was plenty of drama in the early days at United Spinal, but perhaps I'll save those stories for my memoir. Time has a way of smoothing out the wrinkles, and I can honestly say that each United Spinal CEO has been a champion of NEW MOBILITY, in one significant way or another. Most importantly, the organization has offered NEW MOBILITY financial stability, and with that the invaluable chance to develop a younger staff that will propel the NM brand forward on new platforms for decades to come. I am truly grateful — and let's hope it's the last time a new owner has to save NEW MOBILITY.

I suppose stability has come with a few tradeoffs. In some ways, NM print has inched ever closer to the establishment we railed against in the early days. No longer scrappy and independent, we doubled down on polish and professionalism. No one has cancelled a subscription and sent us a shredded copy of the offending magazine in years. Is that a good thing or a bad thing? Hard to say. But the improbable history of NEW MOBILITY print ends here, so it's up to the next generation of editors to shake things up in their own way.

There are certainly plenty of 21st century fails in need of a disability media spotlight: mobility-industry monopolies, airline discrimination, and a deeply inaccessible and unresponsive health-care system, to name a few. Fighting this good fight is the current NM staff — Ian Ruder, Seth McBride and Teal Sherer — and they will carry you forward into a digital future. I know they need no introduction to today's readers, but I will say, for the record, that the stars have aligned again for NEW MOBILITY.



REVECA TORRES | 2015 PERSON OF THE YEAR, WRITER

When I was younger, I loved looking through magazines: the fashion kind, *National Geographic*, *Highlights*, and even the boring ones at doctors' offices. Magazines were a way for me to learn new things, dream and imagine worlds different than my own. When I was old enough to afford it, I got subscriptions to fashion magazines like *Harper's Bazaar*, *W* and *Vogue*. I'd cut out fashion trends and use them as inspiration while pursuing a degree in fashion design. I love holding a fresh new magazine — the smell and the glossy pages! I still cut them up to make art.

There is one magazine subscription that has never been close to shears or X-ACTO blades — *NEW MOBILITY*. The first time I held it in my hands and read it, I was beyond excited to find this unique connection to the words and stories on the pages. I was seen! This magazine reflects who I am as a whole person with a disability. I find this feeling in the content, page after page. I have been disabled long enough to have witnessed the evolution of the magazine as it changed names and editors or staff. One thing that hasn't changed is that I am always excited to open the cover and read it from beginning to end. *NEW MOBILITY* magazines can be found on my kitchen table, in the bathrooms, in my office and in the car. After I read an issue, I leave it out so the "nondisableds" read it too and hopefully see the world differently.

I've had the opportunity to contribute story ideas, write the "Re-framed" column for a few years, create art that was featured on the front cover ... and even be on the cover as Person of the Year! That has been one of the coolest recognitions I could receive — my very own rock star moment — like I was on the cover of *Rolling Stone* magazine!

It is bittersweet that I get to write one last reflection to be published in the last print edition of *NEW MOBILITY*. Thank you for changing my life and that of so many wheelchair users globally.

ANDREA DALZELL | 2021 PERSON OF THE YEAR

I remember the first time I saw Cody Unser on the first issue of *NEW MOBILITY* sent to my home. I saw a kickass woman with my disability on the cover and vowed to meet her one day and to grace the cover like her ... I just didn't know how it would happen.

Two years later at transverse myelitis camp, we met! We instantly bonded, and she encouraged me to go to college and explore the world.

Fast forward to 2020: I had become a nurse and faced every obstacle head-on — and my words came to life when I was named *NEW MOBILITY*'s Person of the Year. I created change, and *NEW MOBILITY* spread the word to the community to change how we see our health care team.

NEW MOBILITY is the full circle of disability opportunity explored in the least-expected areas.

KENNY SALVINI | WRITER

The news that the powers-that-be had decided to phase out its print division hit me like a gut shot. I remember first seeing copies of *NM* strewn conspicuously about coffee tables and magazine racks during the endless string of hospital visits after a 2004 snow skiing accident left me a high quad. In retrospect, the glossy cover photos of wheelers doing life in all its raw and unapologetic glory represented a window into a world I wasn't ready to peer into for quite some time.

But as the years wore on and the shroud of my denial gradually lifted, my appreciation grew for the magazine's unfiltered peek behind the curtain of the issues we all face. Every issue seemed packed with useful tips and poignant insight from everyday folks, and the irreverent humor of the comics always made me smile.

A brief chapter profile in 2015 gave me the first chance to see my words in print and led to a semiregular gig as a contributor. Getting copies of my articles became a personal highlight, and it's hard to articulate the rush I felt when I first saw Doug Davis's illustrations accompanying my articles on air travel.

But far beyond any benefits I've received as a reader and writer, I have seen the publication's truest value as a crucial addition to the care packs we deliver in my work as cofounder of The Here and Now Project. As the medical-industrial complex continually erodes inpatient rehab stays of the newly injured, the assorted copies we included in each backpack have played an increasingly vital role for those waking up to a new reality.

As much as I will miss seeing copies in my mailbox, I suppose the transition to digital was inevitable. What I do know is that I have faith that the creative folks at the helm will continue to churn out content that is meaningful to our community far into the foreseeable future.



Editors shape a magazine in many ways, none more obvious than *voice*. Barry Corbet, Tim Gilmer and Ian Ruder wrote hundreds of pieces for *NEW MOBILITY*, often saving their most personal stories for the editor's column, *Bully Pulpit*. Here are three to remember.

3 EDITORS, BULLY PULPITS



BARRY CORBET, EDITOR 1991-2000
TIM GILMER, EDITOR 2000-2018
IAN RUDER, EDITOR 2018-PRESENT



YELLOW DOG DAYS

BY BARRY CORBET
AUGUST 1997

In the room, the yellow dog comes and goes and not a word about Michelangelo. He's fidgety because I'm spending a few weeks flat on my back to heal some skin, and he's not getting his customary sport. Nor am I, although he deals with it better. Inside, outside, it's all jake with him. Me? I'm suspended between two worlds.

The one to my right, seen through the wide-screen window next to my bed, is pure spectacle. By just turning my head, I can see the Continental Divide rising 6,700 feet above and Clear Creek Canyon falling 2,300 feet below. By craning my neck a little, I can see the edge of a prairie ocean that stretches to Nebraska and beyond.

This place has muscular architecture and matching moods — winter winds that roar like colliding trains, summer lightning that bites the tops off the ponderosas. The sunsets are splashy, chrome yellow and indigo fading to night, to moonset, to silence of snowfall. I hear coyotes, owls, the cheerful panting of my yellow dog. In this bare-bones bedroom, I live my bare-bones life. I watched Hale-Bopp from this window, and the damn dog snores.

That's one world. The other is to my left where I see a crude roll-in shower, a raised toilet seat, a transfer lift — all the relics of disability, all idled like me.

Disability and its trappings don't disappear just because you're stuck in one place, but that's my point. Neither does

the rest of the world. The yellow dog — with his goofy grin and his stuffed-bear tongue — teaches me that life is just as intense and juicy and thick with gratification as it ever was. Until the fat lady sings, life keeps happening. All of it. Not everyone believes me, but it's perfectly clear to me and the dog.

My family and friends have long since moved past society's standard assumptions about my quality of life. Haven't we all lived it together? Yet I think they're saddened by my exile-at-home. They drop by to fill in the gaps they perceive. That's enriching for me, but there are no gaps. Life doesn't go away. Where could it go?

Between my two worlds — which are, of course, only one world — is my work. Squawk of conjoining modem meets squeal of coupling hummingbird. Deadlines approach, thunderstorms recede. Data flows, grass grows. The connective tissue of my life.

I think of how many of us are stuck in one place, with known limitations and unknown prospects. Then I remember how frequently non-disabled people feel beached and restrained and uncertain. My yellow dog says that's the essence of being human. He says that's our highest goal, to be fully and truly what we are. Like him, actually. Life isn't all about fire hydrants, he says, but about being in the right place, in this place. It's about what we can see from here.

Easy for him to say, as he comes and goes with his goofy grin. But yellow dogs surely know.



CRIPLESSNESS

BY TIM GILMER
SEPTEMBER 2015

Many of us like to say things like, *my disability does not define me*, and *I don't think of myself as disabled*, but really, just how far can we go with that mindset? I remember it was a big deal when I turned 40 and realized that since I was paralyzed at 20, my life could be divided neatly in half — 50 percent able-bodied, 50 percent disabled. Now that I am 70, I have to lay hands on a calculator to figure the percentage. Let's see, 50 divided by 70 = 72.429 percent of my life I have lived with a disability.

Mathematically, for those of us with acquired disabilities, the percentage grows each day but will never quite reach 100 percent, even if we live to be 3,482 years old. In my case, on my 3,482nd birthday, I will have lived 99.426 percent of my life with a disability. And what of those of us who were born with a disability? If you have been disabled for 100 percent of your life, how can you not think of yourself as disabled?

I will let you in on a little secret. At the age of 70 I enrolled in an online class at a major university. It doesn't matter what the subject is. The class is run like an intimate workshop. We started with eight in the class, and now we are down to seven. We meet once weekly for three hours by Skyping. We look at each other's faces and listen to ourselves interact with the instructor and each other, and I would

estimate that I am the oldest student by at least 30 years. I'm older than the instructor by about 20 years.

I'm also quite sure that I am the only paralyzed, below-the-knee amputee wheelchair user in this class. What makes it interesting, at least for me, is no one in the class knows that I am sitting in a wheelchair. They only see me from my chest up. I have the perfect setup to exercise the mindset of *I don't think of myself as disabled* because as far as anyone knows, I am not.

Usually, in public or when meeting people in person for the first time, my disability is the most obvious thing about me. But now that I have a foolproof opportunity to reverse that perception, I have no need for it. In fact, the opposite is true. I am dying to tell my classmates that I am paralyzed, crippled, with one leg missing below the knee, and that I have been wheeling around for 50 years. My crippled identity is just bursting at the seams to express itself! *Calm down, Gimpster ... calm down.*

But since the class has nothing to do with disability, I can't find a logical way to divulge my true identity, unless I decide to spontaneously blurt it all out and spin circles and do wheelies in a wanton display of — dare I say it? — *disability pride*.

Truth is, I feel damn good about my disability. Without it, I am not me.



I AM NOT YOUR INSPIRATION

BY IAN RUDER
AUGUST 2019

Whenever anyone tells me how inspirational I am, I think back to Nike's famous 1993 commercial featuring NBA legend Charles Barkley.

With the camera zoomed in on his right eye and nothing but the sound of the basketball bouncing in the background, Barkley told the audience, "I am not a role model. I am not paid to be a role model. I'm paid to wreak havoc on the basketball court. Parents should be role models. Just because I dunk a basketball doesn't mean I should raise your kids."

Over the years, and the many instances of people patting me on the shoulder or giving me the thumbs up as they told me how inspiring I was, I came up with my own play on Barkley's words.

In my dream version of the commercial, the sound of my power chair cuts out as I tell the audience, "I am not your inspiration. I am not paid to be your inspiration. Just because I use a wheelchair doesn't mean I should motivate you to live your life."

I've never actually said this to anyone, but just thinking about saying it, and picturing the look on the face of the person I said it to always gives me a brief moment of satisfaction.

If you use any sort of mobility device or live with any kind of noticeable disability, chances are someone has told you how inspiring you are. Actually, chances are pretty good lots of someones have told you that. And chances are you know how frustrating it can be.

It's not that there is anything wrong with being in-

spirational — people need inspiration, and there are countless stories of people doing amazing and heroic things that are ripe for the picking — but when that inspiration is grounded in ignorance, its benefits are suboptimal.

Until our society can get past the notion that life in a wheelchair is a burden and that all of us "wheelchair-bound" people are doing yeoman's work just by existing, we will be exploited for the inspiration of others.

You may ask, is inspiring someone else really harmful?

I'd say yes. When the bar is set so low — simply existing with a disability — it reinforces uneducated stereotypes and misperceptions about living with a disability. As Emily Ladau points out in her excellent essay on inspiration porn, the mischaracterization and labeling can lead to identity crises for people with disabilities.

When others see your day-to-day existence as a Herculean achievement, how are you supposed to feel when you accomplish a long sought-after goal you really had to fight for?

For a long time, when people told me I was inspirational, I'd look in the mirror. Where they saw inspiration, I just saw a guy trying to get through the day and live my life.

Today, I'm more likely to smile and start a discussion to see exactly what they find so inspiring. If the results are predictably disappointing, I take solace in knowing I've got the perfect thing to say. "I am not your inspiration ..."

NM ADS OVER THE

Nothing documents a culture quite like advertising. For the disability community, the '90s and early oughts delivered a heyday of cringe and cutting-edge.

Dancing in the Shadows.

Our customers tell us our Rigid Chair is the quickest, fastest, most danceable chair they have ever owned!

Originally designed for tennis and basketball, the sleek, functional design and tight turning radius of the Shadow Rigid work equally well on the dance floor, at lunch, or in competition.

Available in four seat angles and in custom colors limited only by the rainbow and your imagination! Shipment within five weeks of order.

SHADOW

BY IMAGINATION (800) 342-1579
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20604 84th Avenue South, Kent, WA 98032
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Call now for team discounts and more information. Insurance assistance available.

1990: The '80s called, and they want their everything back.

WARNING: Lightning Handcycles Exceed All Posted Speed Limits!*
*Radar Detector Sold Separately

"Lightning is the first handcycle worthy of being called a racing cycle. Light, stiff, responsive and extremely comfortable. It is also fast and stable, retaining maneuverability. Helmets off to Lightning. Will satisfy both the serious competitor and the serious tourist."
- Dr. David Cornelison, AXA World Ride '95 World Champion

Call and ask about a full-size poster of our lovely model, Rhonda.

Custom fitted to your body • Patent pending, all mechanisms • Call about financing
Test rides at all Abilities Expos • Deliverable in 14 days, 25 1/2 lbs. ship wt.
10 1/2 lbs frame weight: like no other manufacturer

LIGHTNING HANDCYCLES
360 Sepulveda Blvd., Suite 1030 El Segundo, CA 90245
Phone 310-821-0259 Fax 310-335-1543
Toll Free 888-426-3292 (HANDCYC)

DEALER INQUIRIES WELCOME

NOW VA Listed VA Approved

1997: No words ... we did not order the full-size poster of Rhonda but have no doubt that it existed.

Higher Consciousness

NEW MOBILITY REPRESENTS

AN OPENMINDEDNESS THAT HELPS ME TO BECOME AWARE OF MYSELF WITHOUT FEAR.

AS A READER, IT PUTS ME IN TOUCH WITH AN ENTIRE CULTURE.

AS A WRITER, I CAN'T THINK OF A BETTER FORUM TO SHARE MY THOUGHTS ON LIFE AND LIVING.

BHAVNA MEHTA
NEW MOBILITY WRITER

800 / 543 - 4116

New Mobility

1996: We always did think highly of ourselves.

go where you want to go.

With the Chairman2K Stander, you can bring yourself upright from virtually any position. Its rugged, versatile C2K power base is combined with a fully integrated, powered seat system. And unlike other standing chairs, the C2K Stander includes 175-degree recline and 16-degree tilt functions. You can work, play, cook, shop, interact with others...and take care of other important duties as well. It's the next step in powered mobility—and it's available only from Permobility.

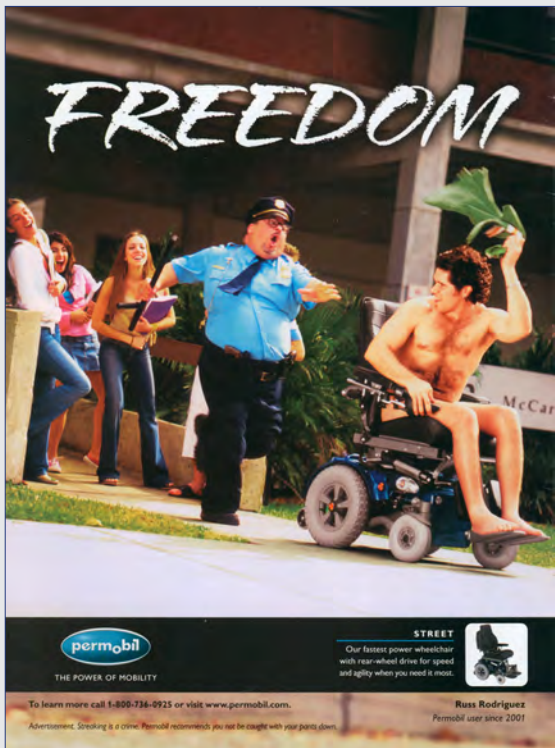
permobil
THE ART OF MOBILITY
WWW.PERMIBIL.COM

2003: If this ad doesn't make you want a standing wheelchair, nothing will.

YEARS



1996: Colours caught hell for its progressive ad campaign. We loved it so much, we hired its art director, Martin Bibow.



2005: Finally, some male nudity — let the gender parity begin.



Goldstein's commode/shower chair packs up for easy travel.

'WHEN YOU'VE GOTTA GO ...'

Go! Mobility Systems is one of NM's most loyal advertisers, having placed more than 200 print ads since 2007. A wheelchair user since 1978, owner Rick Goldstein had a few parting words about our long partnership.

What do GO! Mobility Systems and NM have in common?

What sets GMS and NM apart is our shared commitment to creating solutions by wheelchair users, for wheelchair users. The GMS product line was designed and developed by individuals who understand the unique challenges and needs of our community. As a C5-6 quad, I was inspired to invent a portable commode/shower chair that addresses the limitations I faced while traveling. This innovation has become a basic necessity for many, offering a safe, lightweight, portable and affordable solution that also enables bathtub use where roll-in showers are not available.

Together, GMS and NM have made a profound impact, providing invaluable products, services, and information that have opened doors and expanded horizons for those who may have felt confined. Our partnership has empowered individuals with mobility impairments, offering the tools and resources necessary to travel, explore, and experience the world with confidence.

How have your products affected your own travel experiences?

Without my GO-Anywhere Chair, I certainly would not have dared venturing to some destinations. No longer do I lie awake at night worrying that I won't get the roll-in shower the hotel promised me when I get where I'm going. Europe, Asia, South America — I've taken some long trips. Obsessing while sitting on a 12-hour flight is pure torture. Roll-in or no roll-in, with my GO-Anywhere Chair, I can use a roll-in shower or I can slide across a bathtub wall, but I WILL be taking a long, hot shower when I get there.

With each passing year my yearning for adventure wanes and my appreciation of cruising grows. I've fallen in love with the idea of traveling to one place and letting the destinations come to me. The accessible cabins are always set up differently, but I've yet to come across one that didn't work better with my trusty GO-Anywhere Chair. Next up: Alaska on Celebrity Cruises. And with that, I'll remind you of GO! Mobility's motto: *When You've Gotta GO, We GO With Ya!*

See Rick's ad on page 23. Learn more at goesanywhere.com.

THEN AND NOW



MARK JOHNSON THEN: 1989, 2001

Any readers who made it to the back of our inaugural issue in 1989 got a sneak peek of the coming disability rights movement, thanks to Mark Johnson. In “Disability Rights: A New Breeze is Blowing,” Johnson, one of the founders of ADAPT, wrote about the “new consciousness” emerging that would culminate in the following year’s signing of the Americans with Disabilities Act.

A decade later, we selected Johnson, a C5-6 quad, as our Person of the Year for his efforts organizing a two-month, 24-city torch relay to celebrate and shore up support for the 10th anniversary of the ADA, which was under attack in Congress and the Supreme Court. Even after successfully pulling off the relay, Johnson was adamant that the disability community’s work was far from over. “All along this thing was supposed to be a campaign, not just a relay,” he said. “The flow is continuing — the Rolling Freedom Express, the March for Justice, it keeps going.”

NOW

Like the many campaigns for disability rights he has helped launch, Mark Johnson, now 73, just keeps going. Two-and-a-half decades after gracing *NEW MOBILITY*’s cover as the 2000 Person of the Year, Johnson remains a passionate organizer

and vibrant voice for our community. And while the years have taken a slight toll on his luscious curly hair, his charming Southern accent hasn’t changed a bit and remains perfectly suited to recounting the rich history of the disability rights movement.

In addition to helping found ADAPT and spearheading the 2000 Spirit of the ADA relay, Johnson created and oversaw Shepherd Center’s advocacy program, chaired the ADA Legacy Project around the Act’s 25th anniversary, and fought relentlessly to improve opportunities for people with disabilities. His efforts have been recognized by numerous organizations and he has won many awards, including a 2015 Viscardi Achievement Award.

“Semiretired” since 2019, Johnson and his wife of 43 years enjoy occasional travel and spending time with their grandson. He can still be found volunteering and collaborating with anyone working to bolster the disability community. He’s currently working with the National Park Service and other disability leaders on an event to celebrate the 35th anniversary of the ADA in 2025.

Asked what message he would give to the newest generation of disability advocates and activists, Johnson said he would encourage them to create an environment where it’s all right to be pissed off. “Channel your energy to create change for yourself and others,” he says. “I’m convinced the sooner you identify as one of us, the sooner you get on with your life.”

Bring It On

BY JOSIE BYZEK



On Feb. 16, 1999, Minna Hong, 34, and her husband, Tony, were driving home from North Carolina, where they had recently purchased property for their restaurant business. They had decided to turn the trip into a vacation, maybe even teach their two kids, Megan and Christopher, to ski. On the return trip to Atlanta, Minna, who hates long-distance driving, offered to take over for Tony, who was tired. "I thought I wanted to be a good wife," she says. "So I said, 'You know what, honey, let me drive the rest of the way home.'"

Driving in the fast lane, Minna noticed a tractor-trailer rig suddenly inching toward her from the right. She had to do something fast or the truck would crush her Land Rover. "I must have been in his blind spot," she says. She veered left into the median, and the Land Rover rolled—she passed out somewhere between the second and third roll. "My kids were in the back seat and when I gained consciousness everybody was gone. I was the only one there with a man behind me saying, 'Ma'am what ever you do, please do not move.'"

"Am I the worst, am I the worst?" she asked him. "Yes, yes, you're the worst," he told her. "Oh thank God," she thought. Then she heard a policeman say, "One man deceased, two kids on the lawn, and the best consciousness again."

Days later she regained her husband of nearly 12 years from a hospital gurney. Tony had flown through the Land Rover's air roof, dying on impact. Her 9-year-old daughter, Megan, had broken her leg, and her 6-year-old son, Christopher, had only a scratch. Minna's spinal cord was injured at T12-L1. The truck driver didn't even stop.

Weeks later in rehab, when her roommate's family members came to visit, she looked hopefully up at the door for Tony—and then remembered that he wasn't coming to see her, ever again. "And you dream, and you think, please come in my dream and comfort me," she says. "And that's how my life as a para started."



Minna Hong, with son Christopher: "My mother is the best mom in the world because she does twice as much as other people."

"Wife and Mother Equals Minna"

"Asian people in general are very... introspective," says Hong. "Asian people in general do not write love letters or anything like that. So my husband did not write love letters and he wrote how grateful he was that I was his wife and how much encouragement I gave him. But he gave me a Valentine's card and he wrote how grateful he was that I was his wife and how much encouragement I gave him. But he gave me a Valentine's card and he wrote how grateful he was that I was his wife and how much encouragement I gave him. But he gave me a Valentine's card and he wrote how grateful he was that I was his wife and how much encouragement I gave him."



Ask Minna Hong who has her back now and she says, "Me... I've come this far and I think I've been through the hardship, so bring it on, baby. Bring it on!"

into the marriage; after two kids, and all our dreams were unfolding, finally. So yeah, it was rough."

She adds the house she loved and bought a new wheelchair-modified home and for a whole year after her accident she clung to her homemaker identity. In front of her children she pretended she was fine. "I'd get up in the morning and make breakfast, send them to school. But I couldn't wait until they left so I could lie down in my bed and just look up at the ceiling."

The reality slowly settled in that Tony was not coming home—she had to find her own way through life. "I was lost for a long time," she says. "It was just an empty hole I had and I didn't know how to fill it."

It was the scariest thing I've ever been through. But with gratitude came a serious amount of clarity. "When you know that no one has your back and you're that you kids' lives depend on the choices you make, it becomes very scary," she says. "I know I couldn't do it alone so I sought out a shrink, and that really helped."

Get a Job

Tragically or not, she still had to get out of bed each morning, and the bills still had to be paid. "God, who's going to need to pay for your ride?" she began asking herself. "Period," says Hong, borrowing a term from such famous television cop shows as *Starline* and *Hitch*. "I've never had to work for anything. I never had to struggle for anything. So I think, boy, when this accident happened, the shit really hit the fan. I grew up." Of the shit really hit the fan, she says, she wishes she could take the accident back. "But I can't and I'm not going to sit and cry about something that's not going to happen. I have to move forward."

The Hong had just reached the place in marriage where they finally knew they'd make it—they'd be the couple celebrating their 20th anniversary. "We got to a point where we know that, 'OK, he's got my back.' Period," says Hong, borrowing a term from such famous television cop shows as *Starline* and *Hitch*. "I've never had to work for anything. I never had to struggle for anything. So I think, boy, when this accident happened, the shit really hit the fan. I grew up."

OCTOBER 2009 33

MINNA HONG

THEN: 2003

When we first spoke to Minna Hong in 2003, she shared how her life changed after she became paralyzed and lost her husband in a car accident. She had to learn to navigate her new identity as a wheelchair user, cultural stigmas around disability in the Asian community, and being a single parent to her then 9-year-old daughter, Megan, and her 6-year-old son, Christopher. With her "Bring It On" attitude, she found purpose working at Shepherd Center supporting newly injured individuals through their hardest days and connecting them to resources and community. And that was just the beginning of her journey to being a key advocate for the disability community.

NOW

Minna Hong supported hundreds of wheelchair users at the Shepherd Center, but after 18 years it caught up to her emotionally. "We work with people that have gone through something very catastrophic. It's deep. It's not a situation where you can just leave it at work and go home," she says.

Before she left, she was recruited for the Delta Advisory Board on Disability, where she has been able to share her personal travel experiences with one of the nation's largest airlines. "The focus now is on safety and emergency evacuation," Hong says. "We spoke with TSA and people along



the travel ribbon to make sure that they understand what our needs are. It's the concept of 'nothing about us, without us.'"

Hong eventually remarried, and her children, now in their 30s, have followed her footsteps in advocacy. "I'm advocating for people with disabilities, my daughter is advocating for animals and their welfare at the Athens Zoo, and my son is working with an older population with dementia as a music therapist," she says.

She and her husband have eight grandchildren, with another on the way. She says her disability has made them aware of acceptance and inclusion from the get-go. "They don't think about it as, 'oh, my Mimi is different.' They think it's interesting that certain things aren't accessible, because they know what I'm capable of doing, since they see me at home," she says. "It's about changing the narrative of what disability looks like."

Art has been, and continues to be, at the center of many of Hong's efforts. "After my injury, it was a wonderful therapy for me—I started making jewelry a lot," she says. "My finger dexterity has been such a gift in terms of being able to be expressive."

She is working with the Santa Fe Art Institute to start a consortium to provide a thematic residency for people with disabilities and remains committed to removing the stigma on disability through art. One of her projects was making jewelry out of her catheters. "I use eight a day and this is something that keeps me alive. So why do I hide it?"

ADAPTING AND EVOLVING INTO NEW MOBILITY 2.0

OUR LATEST YOUTUBE VIDEO USHERS IN THE FUTURE

BY SETH MCBRIDE

It's the middle of September 2024. I have a brand-new wheelchair, built by a company founded by YouTube stars. On Oct. 1, they will be launching this new chair to the public. Seems like a good idea to do a video review, right? The only problem: I have no idea how to make videos.

I mean, I've filmed a couple of clips before, and recorded a voiceover talking about how I transfer to a bed. But a complex video? The kind we'd need to fully explain what this chair is, where it came from and whether it's any good — no clue. I have two weeks to figure it out.

CRUNCH TIME

I spend most of the first week diving into YouTube. My first lesson: YouTube is a fantastic place to learn new skills. I was looking for information about lighting, editing, camera selection, operating as a one-person film crew and talking to the camera. I found it all, along with innumerable other insights. Second lesson: People build professional-looking YouTube channels all the time serving as a one-person film crew. I've no doubt that as a quad, it'll take

me longer to do everything, but if we want to make videos, it's got to start somewhere.

Week 2, I start writing a script and thinking of shots that can illustrate what I want to say. I shoot B-roll, curse the sun and my brush-chipping neighbor, fumble over my words while talking to the camera, tape my script to the tripod in a windstorm, wear the same outfit three days in a row because I can't get everything done in one day. I rely on tripods for almost all my shots. Half the time I hit the record button with my fat thumb and it tilts the camera angle, so I have to reset and start over. It is exasperating. It's also the most fun I've had producing a story in a long time.

By the time I finish filming, there are three days until the story publishes, and I still must edit the entire video. Coffee is my lifeblood. I fry one GoPro battery, max out the hard drive on my MacBook and get deeply acquainted with the limitations of iMovie.

I send the first draft of the video to our team on Sunday night. It has to be published by Tuesday morning. Jean uses her design skills for title cards and thumbnails, Ian catches places where I cut too much context, and Teal helps with captions and posting. On deadline, we publish the video.

Deep breath.

Twenty-eight days after publishing, the video review has 63,000 views. It's by far our most successful video to date. Its success shows what a need there is for in-depth disability videos.

Looking back, I don't know exactly why I was confident our team could make a quality video in two weeks. Partly sheer optimism. A bigger part confidence in our team. It's the same when Ian spends years corresponding with wheelchair-using prison inmates so readers might have an idea about life behind bars. Or Teal reworks a print feature on ways to prevent shoulder damage, so our Instagram-only followers get the same benefits. If there's an idea for a good story, our team will figure out how to get it polished and over the finish line.

WHAT'S NEXT?

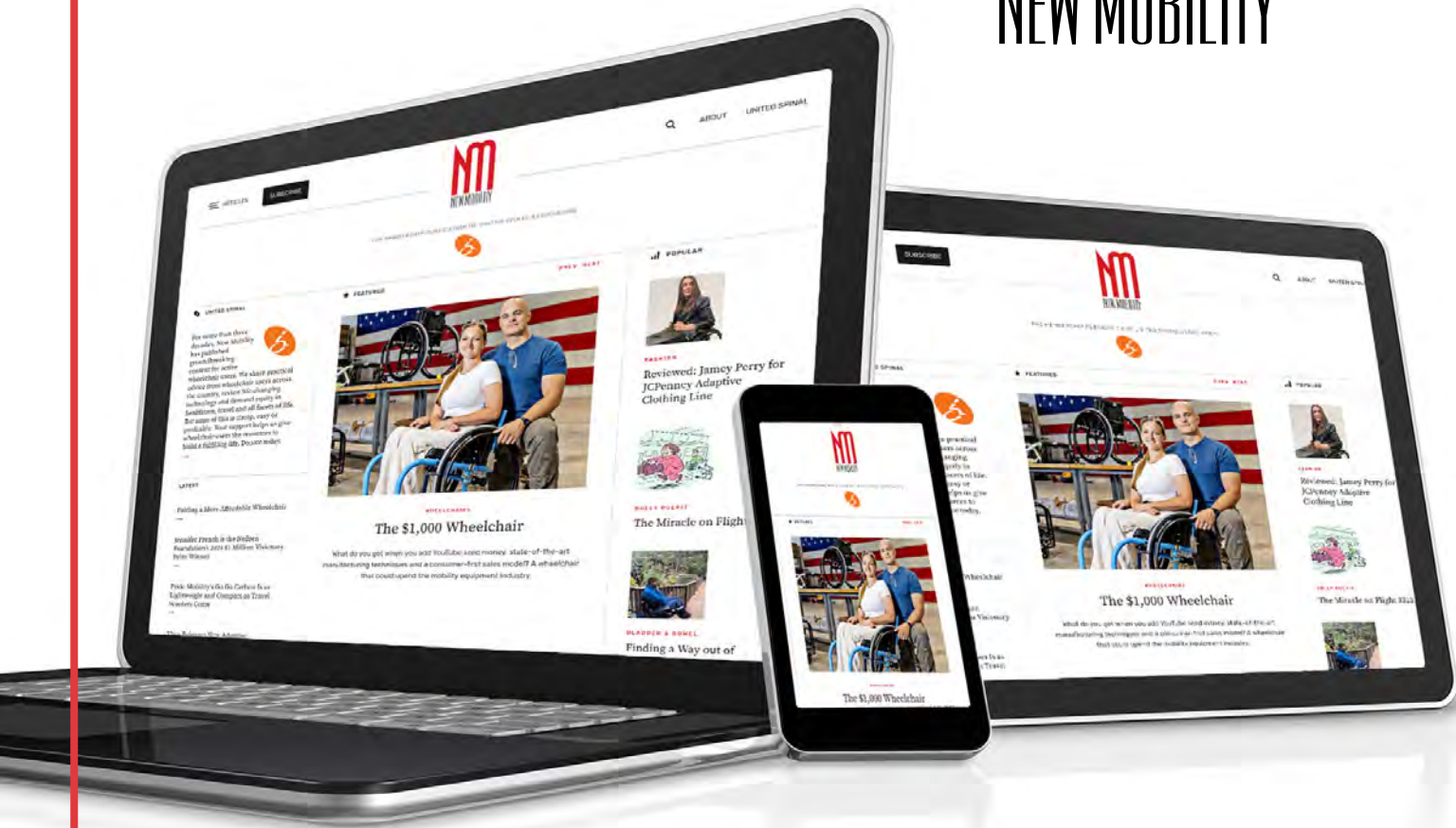
As we transition to a primarily digital media outlet, none of us know what the future looks like. Technology and media habits evolve too fast for that. We have immediate plans: We're leaning into video while also planning other formats like topic-based newsletters and occasional, resource-heavy print issues aimed at newer wheelchair users. Who knows, you may even see a podcast down the road.

Like everyone in the disability community, we'll keep learning and adapting to an ever-changing world. Whatever the delivery mechanism, the mission stays the same: to provide high-quality, authentic stories from and for our community.

We hope you'll continue the journey with us. To stay up to date with our latest content, go to youtube.com/@NewMobilityMedia and subscribe to our YouTube channel, and visit newmobility.com/newsletter to subscribe to our newsletters.

MM





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VIDEO CONTENT
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NEWMOBILITY.COM

NeuRx DIAPHRAGM PACING SYSTEM:

A Breath of Fresh Air for People Living with Spinal Cord Injury

A Q&A WITH NEW MOBILITY EDITORS

Q: What is the NeuRx Diaphragm Pacing System?

A: The NeuRx DPS is a groundbreaking treatment to reduce or eliminate dependence on mechanical ventilation which may significantly improve your quality of life if you have a spinal cord injury. It involves using a small, implanted device to stimulate your diaphragm, the main muscle used for breathing. This can help you breathe more naturally, reducing your reliance on a ventilator, which has an impact on helping restore your sense of smell and taste, your mobility, and overall sense of independence.

Q: What advantages does the NeuRx DPS offer?

A: Respiratory complications are a major concern for people with SCIs. These complications can lead to pneumonia, a serious lung infection that can be life-threatening. The NeuRx DPS may help reduce the risk of pneumonia and other respiratory problems caused by using mechanical ventilation.



Q: Who is a good candidate for the NeuRx DPS?

A: People with high-level spinal cord injuries who require mechanical ventilation may be good candidates for the NeuRx DPS. Your doctor can evaluate your individual situation to determine if this treatment is right for you.

Q: What are the benefits of the NeuRx DPS?

A: The NeuRx may offer several benefits, including:

• **Improved breathing:** You may be able to breathe more naturally and comfortably, reducing your reliance on a ventilator.

• In one study, 96% of SCI users successfully used NeuRx DPS without mechanical ventilation for at least four continuous hours at a time.

• In another study, 58.5% of SCI users successfully eliminated mechanical ventilation with NeuRx DPS, pacing for 24 hours per day.

• In peer-reviewed scientific literature, up to 96% of users completely weaned from mechanical ventilation.

• **Improved quality of life:** NeuRx DPS pacing can significantly improve your overall quality of life, as reported in peer-reviewed literature:

• 64% users reported fewer secretions.

• 100% users described an increase in mobility.

• 95% users reported more freedom and feeling of independence.

• 100% users recommended the NeuRx DPS to other tetraplegics.

• 48% users with a chronically cuffed tracheostomy no longer required a cuffed tracheostomy.

• 15.9% users with a chronically cuffed tracheostomy were completely decannulated.

• **Ease on Caregivers**

• 91% caregivers stated that NeuRx DPS is easier to use than mechanical ventilation.

• 68% caregivers reported less need for suctioning.

• **Peace of mind.** The NeuRx DPS runs on standard C-size alkaline or lithium batteries, which reduces the need for an external power source and concerns about power outages. Synapse also offers 24/7 manufacturer support.

Q: Is the NeuRx DPS safe?

A: The NeuRx DPS is safely placed using standard minimally invasive laparoscopic techniques. The electrodes are implanted directly into the diaphragm muscle and not under the phrenic nerve. To date, there have been no reported cases of nerve injury related to treatment. Many users pace 24/7, and one person has been pacing for over 20 years.

Q: How can I learn more about NeuRx DPS?

A: If you are interested in learning more about diaphragm pacing visit synapsebiomedical.com/united-spinal. Always consult with a physician, as they can help decide if this treatment is right for you.

INTENDED USE:

The NeuRx DPS is fully approved by the FDA and is intended for use in patients with stable, high spinal cord injuries with stimulatory diaphragms but who lack control of their diaphragms. The device is indicated to allow the patients to breathe without the assistance of a mechanical ventilator for at least 4 continuous hours a day. For use only in patients 18 years of age or older.





PARENTING FROM A WHEELCHAIR



In 2018, we published a collection of essays from wheelchair-using parents, all at slightly different stages of their parenting journeys. Now, Parenting from a Wheelchair is back. Six years later, the same cast is adapting to new challenges.





In sports and in life, Lou does Lou.



Don't let the smiles fool you — three out of four members of this family are obnoxiously competitive.

LESSONS FROM MY CHILDREN

ABOUT FRUSTRATION, DISABILITY AND WANTING IT ALL

BY SETH MCBRIDE

I am aware that a large part of the draw for my son wanting to play soccer with me is the opportunity for him to beat an adult. And not just beat. Even if I'm trying my hardest — fueled by a cup of coffee, with fresh taped gloves on my hands, and having done some warm-up pushing — Dad versus Ewan looks like a high school player getting toyed with by Lionel Messi. Or if you're not a soccer fan ... like Rocky chasing a chicken.

It's great fun for Ewan. He plays "outfield" and I play defense on the paved parking pad in front of our house. The goal is a cheap, sun-bleached folding net. I chase him around in my everyday wheelchair, playing chair position to block his path. He's already learned that wheels don't change direction like feet do — he'll lead me hard one direction, before cutting back behind me. As I spin around, he's already tapping the ball into the net. If give him too

much space, he just sprints in front and boots it past my flaccid feet. Ewan 2, Dad 0.

It's fun for me too, if I can get over myself. There was a large period in my wheelchair-using life — beginning immediately after my C7 SCI and continuing for about 15 years, through a Paralympic career that relied heavily on wheelchair speed and agility — when getting trounced by a 7-year-old would have annoyed the shit out of me. I don't know at what age I expected my children to surpass my own sporting abilities, but I'd hoped to hold out longer than this.

Ewan inherited obnoxious levels of competitiveness from both me and my wife. As I try to teach him that not everything has to be a competition and we can't always win, 41-year-old me is still coming to grips with these sentiments as well. I'm getting a good workout, I tell myself. It's satisfying to watch Ewan exult in that unique feeling of improving

at something. It doesn't matter that I can't stop more than one in 10 of his shots, can't make him work harder, can't show him how to improve his footwork ... we're having fun ... who am I kidding?

During a recent session, I got tired of getting beat. I stationed myself in front of the net and told him he had to shoot from a distance. At first, he loved booting the ball at me as hard as he could. Then he realized that my wingspan obscured all but the far edges of the goal. The tables had turned. Somewhere around my ninth block, Ewan's frustration center overloaded. "Baba!" — this is what he's called me since he learned to talk — "This is no fair! You're too big — it's too hard!"

"Ewan. When we were just playing, how many shots did you make without me blocking one?"

He paused. Annoyance settled on his face as he realized where this was going. "A lot."

"And what did I do when I was getting scored on over and over again?"

"Kept trying." The annoyance turned to a pout when he said it. He didn't like the lesson, but he didn't have an argument either. We kept playing.

Ewan wants to be the best at everything, and he wants it now. A huge part of sports is learning how to win without getting too cocky and how to use losing for growth and motivation rather than an excuse to shut down and stop trying. Today he got to work on a little of both. I tried not to be smug.

SAME GENES, DIFFERENT RESULTS

My daughter, Lou, helps balance us out. She's about to turn 3 and if she has the competitiveness gene, it has yet to activate. Whereas Ewan started racing me down the sidewalk shortly after he learned to walk, Lou is unconcerned with who is ahead and who is behind.

Ewan watches pro baseball players on TV, then goes out and tries to emulate their perfect form. I watch a baseball game, then cradle a ball between three quad fingers and shot put it. Lou watches us, then picks up the ball and a stick, twists her torso into a discus-throwing position and does a spinning fling that sends them both in opposite directions. "Baba! Did you see my cool Lou throw?!" In sports and in life, Lou does Lou, and she is often pleased with the results.

Not that Lou-life is without its frustrations. Far from it. Lou wants to do everything herself and she is not afraid to scream — high pitched, like a bald eagle — and throw and stomp when her uncoordinated little limbs won't do what she wants them to. I feel her anger. Just last month I let out a "Gah!" and threw a click strap across the driveway after my 15th failed attempt to zip-tie it to my handcycle frame. I felt dumb after I threw it, but calmer too. My childish explosion had released a little of my bubbling anger. A few attempts later, I got the plastic devil zipped into place.

So, I try to remember that outbursts, whether toddler or adult, have their uses. "You're allowed to be angry. You're not allowed to be mean," my wife tells Lou. And that seems like good advice for dealing with disability too.

NEW PERSPECTIVE

The first time Ewan told me he wished I wasn't in a wheelchair, we were sitting on the pullout of a bike path overlooking the Columbia River Gorge. We were about 600 feet above the river and could see its white-capped waters winding through cliffs and plateaus and rolling hills. We'd just climbed a couple of miles to get there, he on his mountain bike and me on my handcycle. There were high clouds over a blue sky, a cool breeze and we were both rosy from exertion.

"YOU'RE ALLOWED TO BE ANGRY. YOU'RE NOT ALLOWED TO BE MEAN," MY WIFE TELLS LOU. AND THAT SEEMS LIKE GOOD ADVICE FOR DEALING WITH DISABILITY TOO."

I was as content as I get — until he dropped that wish on me. I looked at him for a second as he took a bite of his granola bar and asked him, "How come?"

He finished chewing and said, "You know, so you could do more stuff with me."

That stung. "Well. We're here right now. Riding bikes together. We get to play basketball and soccer and go mountain biking. ..."

"Yeah, that's all fun, but we could still do more. Like go hiking or jump on the trampoline."

"That would be fun," I said. "I guess we've just gotta enjoy the stuff we can do as much as possible."

"Uh huh," he said between bites.

I couldn't be annoyed that he wasn't impressed with my answer. It didn't feel very satisfying to me either.

I thought back to a recent day mountain biking. Lou was riding on my lap, and we chased Ewan on the trails while my wife got a quick break to ride at adult speed. The dogs were running beside me, and Lou was laughing and yelling, "We gotta go fast! Go get him!" as Ewan pedaled furiously down a winding forest path. Everyone was present. Everyone was happy, and I felt like the most capable Dad in the world.

A few days later, after I dropped off Lou at her hippie, outdoorsy preschool, I got stuck in a patch of deep gravel on my way back to the truck. I had to have another parent rescue me from what may as well have been quicksand. So much for capable. I got pouty and petulant, annoyed at myself and annoyed at the world, and it ruined most of my morning.

Before becoming a parent, I thought the feeling of always wanting more was mostly due to various annoyances of living with a disability. But the more I'm around two little people just learning how to process their emotions, the more I realize I'm not that special. I want it all. But I can't always have it. Just like everybody else.

SAFETY, BOUNDARIES AND FUN AS A WHEELCHAIR-USING PARENT

BY STEPHANIE ARRACHE

In 2020, when the world was shut down in the pandemic, my husband and I decided to trade in the palm trees of Palm Springs, California, for the wide-open plains of Wyoming. We could both work remotely, and we'd planned to move that summer anyway, as he'd taken a job at a new museum in the small western town of Dubois. My son, Henry, was 4. He and I had figured out how to navigate the concrete jungle that is Southern California and were thriving. But now we were trading sidewalks for dirt roads; indoor malls for national forests; chlorinated pools for rushing rivers. I knew it would take some time to find new, accessible ways to continue two of my most important jobs as a mom: keeping Henry safe and having fun with him. The learning curve was huge in the beginning. We first moved into a small log cabin. Henry slept in a loft that I couldn't access unless I butt-scooted up the stairs. Before too long, we traded in our lofted log cabin for a log cabin with all the bedrooms on one floor. One worry solved, a million more to go.

I loved our new home, but I especially loved our front yard. It was about an acre, and flat. I could explore with Henry, looking for dinosaur bones — in his world, any bone we found was a dinosaur bone — or playing fetch with our dogs.

While we lived in Dubois, I slowly finished my caseload in California and decided to close my law practice. On a whim in 2019, my husband and I had purchased a shop that is part bookstore, part gift shop in Dubois. I'd loved the store for the years we'd been vacationing in the small town, so when we heard the owner was interested in selling, we took a chance and bought it. We ran it from afar for the first year, so when we moved permanently to Wyoming, I ran it full time. I was living the Hallmark life. Life was peaceful and lovely, with the biggest annoyance being the drama that can happen in a small town where everyone knows everyone else and rumors travel faster than truth. While everything was fine, I started to feel like my son was missing out on some very important things.

My husband, son and I are more organized-sports people than hunting-and-hiking-on-the-weekends people. Sure, we had off-roading vehicles and would take off into the forests sur-



The Arrache family moved to Wyoming for a more relaxed lifestyle, and they love spending time exploring together.

rounding us, but Henry was missing out on things I felt were very important. Swimming lessons were at the top of the list. My little water-baby loves swimming. And there wasn't a single pool for him to use. For a few weeks, the school bussed kids over an hour away for lessons, but that wasn't enough in my opinion. My husband and I could have been fine in the small town, but I knew my son needed different things.

So, for the third time in three years, we moved. This time it was to Casper, Wyoming, which still has the small-town Wyoming feel that we love, but the amenities that we missed from California. Swimming lessons. Organized sports with many teams for fun competitions. Movie theaters. A hospital. A mall.

WATER SAFETY

I often joke with my son that if he were to fall in a pool, I would get up and run to save him before my brain remembered that my legs don't work. I picture the Road Runner with his legs in a blur. But the truth is, even if I was right next to a pool and managed to jump in, I can barely keep myself afloat. And sometimes Henry and I go to a pool without my husband. That is why swimming lessons are so important to me. Not only does Henry love the water, but Wyoming is full of rivers and lakes. My parents live on a beach in California. We love boating. There's a lot of water in his future, and he needs to be able to swim safely.

That's not to say that I don't help him in the water. Henry has progressed to the stage where he's learning new swimming strokes and how to push off the wall. My gym has a heated pool, so we're able to swim year-round. I love swimming because it's a great way to stretch my body and is amazing exercise. When Henry and I go to work on his swimming, I'm able to hold onto the wall with one arm and help position his body or feet with my other. And now that he's 8 years old, he's able to help me too. He loves to operate the pool lift, even when I don't need him to. He giggles when he gets to dunk Mama in the water. But he has also started holding my towel and wheelchair in place when I transfer so they don't move. I suspect his thoughtfulness has developed from growing up with a parent who uses a wheelchair and by watching the little everyday things his daddy does to help me.

SETTING BOUNDARIES

In my last article, when Henry was 2, I mentioned using a leash to keep him close when we crossed streets. As he got older and was able to comprehend more, it became clear that I needed to set strict boundaries and rules with him — the main one being Thou Shalt Not Take Mama's Chariot. He loves to ride around in my wheelchair when I'm sitting on the couch or other chair at home. But the rules about this are clear. He asks first. He always has to bring it back to me. And never is he to move my chair in anger. I was a moody teenager once upon a time, so I know there are slamming doors and other acts of rebellion in our future. Some are already present. I have made it very well understood by him, then, that if he ever moves my wheelchair out of meanness or spite,

“I SUSPECT HIS THOUGHTFULNESS HAS DEVELOPED FROM GROWING UP WITH A PARENT WHO USES A WHEELCHAIR AND BY WATCHING THE LITTLE EVERYDAY THINGS HIS DADDY DOES TO HELP ME.”

there will be dire consequences. If I ever have to drag myself or crawl to him, there will be hell to pay. That may sound extreme, but it's important he knows it's something he's never to do. And so far he never has.

Another rule is that my stairlift is not a toy. Our house has a fully furnished basement, where my library, craft room and punching bag are located. My stairlift is a very expensive piece of machinery that is fascinating to a kid. He has to ask permission if he wants to use it. He is really good about respecting that rule. When his friends come over and want to use it, I've overheard him telling them how important it is to me and that it isn't a toy to play on. And I'll be honest, I also use it as a bribe when I've forgotten something upstairs and don't want to take the time to get it myself: “I'll let you use the stairlift if you go get X, Y or Z.”

HAVE FUN

One of the rules I live by is to have fun with your kid. Sure, there are things that can go wrong. And things that we can't do because of wheelchair limitations. But I'd challenge you to find any good parent who doesn't get anxious over things or who doesn't have limitations in one way or another. I've learned that many things can be adapted or worked around.

A few weeks ago, I was at a park with my husband and son. We met up with friends who have a son the same age as Henry. The first time the boys met, they were instant friends. The park itself has great climbing trees, so the friend and some of the other kids were climbing and sitting on branches. Henry tends to be an overthinker, so he's more cautious — the opposite of “shoot first, ask questions later.” He came over to where the parents were sitting and was a little deflated because he'd never climbed a tree before, didn't know how and feared getting hurt. My husband offered to lift him, but to Henry that was embarrassing. This was my moment to swoop in and save the day. “Do you want to use me like a step stool?” I said. “That other tree has a branch that's a little lower.” He happily agreed to try. He climbed up on my lap and then onto a part of the trunk that he could sit on. After sitting there for a few moments, he was ready to get down but was afraid of falling. Again, Mama to the rescue. I assured him I was still right there to support him as he slid onto my lap. Then we agreed to try a higher branch on a day there weren't so many kids around watching.

Sure, we might do things a little differently, but sometimes different is just what your child needs.

NAVIGATING AN INACCESSIBLE WORLD WITH MY SON

BY TEAL SHERER

My 9-year-old son, River, pushes a shopping cart at Trader Joe's, and I push my wheelchair beside him. When we get to the produce section, I grab a few apples and a bag of Persian cucumbers, and try to snag the last container of strawberries but it is out of reach. Without missing a beat, River stands on tiptoes to pick it up and place it in the cart. As we head to frozen foods, he leads the way and I watch him. "He's getting so tall," I think. I know it's cliché, but kids grow up so fast.

After we check out, I take one of the grocery bags on my lap and River carries the other. We load them into my Subaru Outback and I transfer into the driver's seat. River takes my manual wheelchair and lifts it into the trunk.

On the drive home, I ask River how he feels about helping me. "I love doing it because it makes you smile, and that's all I care about," he says. It's a sweet answer, but I'm suspicious. He might be buttering me up to buy him Robux online game credits — which I totally will. I'm a pushover. Then he adds that he likes going places with me because one day I might be in danger. "Someone could easily knock you out of your wheelchair and steal you," he says. "I've got to be very cautious about that. If that happens, I will knock them out and save you." I think we've been watching too many superhero movies.

THE EARLY YEARS

When River was a baby, I never took him anywhere on my own. Getting him in and out of his car seat was difficult. And the thought of having to carry him and navigate my wheelchair once we got somewhere made me anxious. I tried different baby carriers and wraps, but River was a big baby, and I struggled getting him into them. Also, having to deal with people's stares and weird comments felt exhausting. "I hope you get better soon. I'm praying for you. You're my hero," are things I normally hear. I could only imagine what they'd say if they saw me with a baby.

I hated that I couldn't be fully independent with River. I've always placed so much value on being able to do things on my own, especially



after I became disabled from a car crash when I was 14. I broke my back and have an L2 spinal cord injury. Before River was born, my husband, Ali, and I put a lot of thought into what I'd need to be able to take care of a newborn. Ali built a custom changing-table that I could roll my wheelchair under, which gave me better leverage when I was changing and picking River up. We found a crib with a side gate that folds down to make it easier for me to get River in and out.

After River was born, Ali was only able to take one week off work. I treasured the alone time with River, but the days were long and exhausting. I had postpartum anxiety, was sleep-deprived and had trouble breastfeeding. I felt isolated and stuck. I longed to connect with other moms and researched "mom groups" in our area, but they met at parks where they would push their babies around in strollers. I didn't think I would fit in. We hired a nanny to help with River a couple days a week, and that helped. I enjoyed her companionship and our outings together. She would push River's stroller around our neighborhood while I rolled beside them with our German shepherd.

PEOPLE HELPING PEOPLE

The thing with babies is that they don't stay babies forever. River was continually growing and developing, and for him, me being disabled was the norm. He learned to pull himself up by grabbing onto the front bars of my wheelchair, and learned to walk by holding onto the back bar and pushing me around the house. At the same time, I was becoming more confident as a mom. I adapted and learned tips and tricks, like keeping a breastfeeding pillow on my lap to make it easier for me to hold and transport River around the house.

With time, getting River in and out of his car seat grew more manageable, and I remember the first time I took him somewhere by myself. We went to our local library, and River sat on my lap while I pushed us around to pick out books.

Now that he is 9, he doesn't physically need me the way he used to. Now, he helps Ali and me by bringing in groceries, taking out the trash and helping with yard work. Currently, the most challenging part of being a mom has nothing to do with my disability — it's keeping River fed because he's always hungry, and managing his screen time. River grew up surrounded by technology, and if it were up to him, he'd watch YouTube and play video games all day long. My parent-friends and I are always telling the kids they need to "touch grass," meaning that they are spending too much time online and need to get outside to reconnect with the world.

There will always be things I can't do with River. I'd love to be able to take him to the

"I LOVE GOING PLACES WITH YOU, MOM," SAYS RIVER. "WE HAVE SO MUCH FUN TOGETHER, AND SOMETIMES WE SEE WEIRD STUFF THAT MAKES US LAUGH."



Ali, River and Teal enjoy Victoria, B.C.

beach park next to us so we can play in the sand and splash around in the lake, but it isn't accessible. Instead, a mom in our neighborhood offers to take him with her kids, and I know he'll have a great time. I also find comfort in all the cool things that Ali and River do together. They go mountain biking and snowboarding, and Ali is very involved in River's lacrosse team.

I ask River if he ever wishes I weren't disabled. "Yeah, sometimes. I would love to run, and race, and play tag with you," he says. "But I love having a mom who has a wheelchair, because if my legs break, I can always borrow one of your wheelchairs."

I don't take for granted all the things I can do with him, like cuddling and reading to him in bed; going on rolls together around the neighborhood, pushing my chair while he pedals his bike; building Legos; and being silly while listening to music and dancing around our house.

Next week, River and I are flying to my dad's and stepmom's house. I don't worry about taking him places on my own anymore. In the airport, I'll have my backpack on the back of my wheelchair, and River will wear his while he rolls our luggage and lifts it up onto the belt at security. If I need help with anything while we travel, I know who I'll ask. We can't wait to spend time with family and swim together in their pool. "I love going places with you, Mom," says River. "We have so much fun together, and sometimes we see weird stuff that makes us laugh."

MI



When her son, River, was a baby, Teal Sherer found it difficult to take him places independently — a dynamic that quickly changed as he got more functional.



60 Years Paralyzed and **GRATEFUL FOR ANOTHER DAY**

BY TIM GILMER

At first all I saw through the rainy windshield were two legs — no body attached — moving on to the winding road in an easy jog. I slammed on my brakes, pulling hard to the right, fearful I would crash into the drainage ditch. His 20-something face turned and froze. Terrified, wearing headphones, a dark shirt and no reflective clothing at all, he realized I was going to hit him. There was no crosswalk, no intersection and no earthly reason to try to run across a 45-mph curvy country road at 7:30 a.m. on a dark wintry day. The rest was up to

God, fate, or blind luck. We were both trapped. No way out.

I say “we” because I felt as much a victim as he must have. I was on my way to a wound care clinic after a large, growing sore on my right calf was diagnosed as a rare autoimmune condition. I’d been bedbound for an entire year — as if 60 years of paraplegia was not enough — completely immobile for the first six months with a scrotal wound where an abscess had been removed. Then came this disease that the doctor described as “white blood cells gone haywire.” I had lost the ability to

transfer into my unadapted minivan and drive because of aging, diminished lung capacity and fading strength. Rolling up a short ramp had become an exhausting marathon.

Medical bills were piling up and my future looked scary. Despite all this, I was beginning to make progress. I was getting up in my wheelchair three hours per day now, and had purchased a cheap used rampvan that I could use with great effort. I had plans for the future — getting into physical therapy and making a late-life comeback at age 79 after three rewarding careers.

Then this jerk runs in front of me.

Sounds unfeeling and insensitive, I know. But even a chicken knows not to cross a road wearing headphones without looking first. I could see the headline on the back pages of our local newspaper: “Elderly Cripple Driving with Hand Controls Kills Young Jogger.”

AT THE SCENE

I missed making full-on contact by a hair’s width. The jogger hit the left side of my minivan, smashed into my driver’s mirror, slamming it back against my car door, and caromed off wildly, sprawling on the road before I came to a near stop. Cars were coming from both directions, so I had to keep moving forward to avoid being rear-ended. I wanted to keep going but my conscience put on the brakes. I found a narrow lane, turned around and headed back to the scene of the crime.

He was sitting on the pavement on the other side of the road, hunched over, bleeding from one side of his face, holding a bloody rag. A security guard who had been nearby was comforting him. A bystander directed traffic. I pulled over after passing him but had no way to exit my van. No space to deploy my ramp and roll out in my wheelchair. I wanted to at least identify myself and see how badly he was injured. Another security guard passed next to me in a hurry. I honked. He reluctantly came to my window. “I’m the guy who hit him. I can’t get out of my car. I need to go to a doctor’s appointment. Can you take my info or something?”

He scowled at me. “You wait right here or **YOU WILL BE ARRESTED!**” I was the assumed don’t-give-a-damn perpetrator. I called into the wound care clinic and left a message saying I would be late.

In five minutes, a sheriff’s deputy arrived, then another. Then came the ambulance. I sat and waited, a prisoner in my cell, muzzled, eager to tell someone, anyone, my side of the story. Finally, after about half an hour, a deputy came to my window. He took out his notepad, wrote down my license plate, vehicle and insurance info, looked at my driver’s license and listened as I told him what happened. “How is he?” I asked.

THE HARDEST THING IS JUST MAKING IT FROM ONE DAY TO THE NEXT. YOU NEVER KNOW WHAT IS LITERALLY AROUND THE NEXT CORNER.

“He’s on the way to the hospital. I don’t know the extent of his injuries. You say you were going 40? Were your lights on?”

“That’s right, I always drive with lights on in the rain.”

He told me I’d have to make an accident report on the DMV website within 72 hours. I told him I was concerned about my lack of a driver’s side mirror, which was intact but disconnected, dangling out of its housing like a popped-out eyeball. I was still shaken from the accident, nervous about driving without a side mirror. He and another deputy secured the mirror into the housing with accident tape.

“Were there any witnesses?” I asked.

“A man passing the other direction saw what happened and stopped,” said one deputy.

I was relieved. At least someone besides an elderly cripple driving with hand controls had seen the jogger bolt in front of me. But he saw it from his viewpoint, not mine. I had the ringside seat, the only one.

‘YOU’LL HAVE TO RESCHEDULE’

When I finally pulled into the parking garage at the hospital for my wound care appointment, my cell phone rang. “This is the wound clinic. Don’t bother to come in.”

“I’m here in the parking garage. I’m here now. I’m coming in. I need to be seen. My leg —”

“No, please don’t come in. We’re double-booked with three appointments ahead of you. Don’t come in.”

“I’m already here. I can wait! You have no idea what it took just to get out of bed, get put together and drive an hour from my home in the country to get here. ... It’s not easy.”

“I’m sorry, we can’t see you today. You’ll have to reschedule.”

I sat in the parking garage for a minute and considered getting out of my van and entering the hospital to see the jogger, who made it here before I did —

without an appointment. I imagined myself at his bedside wishing him well, but deep down something wanted to poke him in the side with a sharp stick.

The next day I called the deputy who talked to me at the scene and asked about the jogger again. He said he didn’t think the jogger’s injuries were serious, possibly a broken collarbone from his fall.

Three months later I received a letter from my insurance company saying the jogger’s claim against me had been settled. Settled? No one told me the jogger had even made a claim! Did this mean a jogger wearing headphones ran in front of me where there was no crosswalk or intersection without looking before running across the road — and now *my* insurance rates would go up? *I* was the one at fault?

I called my insurance company and ranted. Thirty minutes later I received an email from them explaining that “settled,” in this case, meant the claim was dismissed. An investigation had found the jogger was at fault.

NO TIME TO REST

The hardest thing about aging with paralysis — or any disability — is just making it from one day to the next. You never know what is literally around the next corner. People like us wake up each day paralyzed, always paralyzed, no time off. Still having to make unwanted but necessary adaptations to whatever physical or cultural insult comes our way. Still having to deal with so many people who have no idea what it takes for us to keep moving, keep trying, keep smiling.

But after the dust clears at the end of each day and I’m alone in my hospital bed in the safety of my home, with loved ones nearby, I say a prayer of thanks. Sometimes our grit is rewarded. The day’s messiness and disappointment fade in the rearview mirror — and my crippled body and side mirror are still functional, accident tape and all. ■■■

DRIVING AS A WHEELCHAIR USER

If you want to learn how to drive as a wheelchair user, there are two distinct paths you can take: the way you're supposed to do things, and the way people often do things. My driving experience as a wheelchair user fell in the latter, "just figure it out" category. There were three main reasons for this: cost, time and lack of access to services. I came to my disability by way of a spinal cord injury when I was 17. To me, as with many young people, driving meant freedom and independence.

Getting back behind the wheel was one of the first priorities after getting home from rehab, but there were no adaptive driving instructors or evaluators in my town in Alaska, and I certainly wasn't going to spend the time or money to fly to Seattle, go through evaluations, have a mobility dealership install hand controls and then have the car barged back to Alaska. So, I had my father — a mechanic by trade — install a set of hand controls and a spinner knob. I relearned how to drive the way I learned before my disability: by driving.

Of course, there are problems to this approach. Most people don't have a mechanic in the family who can properly install a set of permanent hand controls. "There are a lot of people who go online and buy the cheap, \$150 temporary hand controls because they don't want to [go through a dealer] or can't afford it," says Jemal Mfundshi, a wheelchair user and C6-7 quad who works for United Access, a mobility equipment dealer in Portland, Oregon. "For some people it works well and they're safe. There are many people who have done that and didn't choose the right product or didn't install them properly. I've seen people wreck because they just shouldn't be driving, period."



Jemal Mfundshi

Mfundshi is obviously coming from a dealer's perspective, but he does make an important point: If you get the DIY approach wrong, your safety isn't the only thing compromised, because it also affects the safety of passengers, pedestrians and everyone else on the road. The safest option — and most expensive — is to go through a full evaluation (often \$200-400) with a certified driving rehabilitation specialist, and to work with a licensed mobility equipment dealer so you can see what kind of vehicle and equipment options are best for you and have them professionally installed.

Jane Wierbicky goes into the details of what the evaluation/dealer route entails on the next page. But whatever your path back to driving, don't let words like "accessible," "specialist" and "certified" suck the soul out of your automotive fantasies. Remember that evaluations and hand controls are a means to an end: a world where you get to drive where you want, when you want.

— SETH MCBRIDE

MEMBER TIP

“ There are more interesting choices today than there ever have been for people who want to roll into their vehicle. A great way to start is by attending an Abilities Expo where you can talk with vendors and check out an array of accessible minivans, SUVs, pickup trucks and more. ”

— Randall Duchesneau, Philadelphia



UNITED SPINAL RESOURCE CENTER MOST FREQUENTLY ASKED QUESTION

HOW DO I GET STARTED WITH DRIVING AS A WHEELCHAIR USER?

RESOURCE CENTER SCI NURSE SPECIALIST JANE WIERBICKY:

Many people want to know if they'll be able to drive after spinal cord injury or other neurological diagnosis. With the right adaptive equipment, driving is possible for many wheelchair users, including people with limited arm/hand function. If you want to get on the road, discuss your driving goals with your health care provider(s) to determine if you're ready from a medical standpoint — for example, your spasticity is under control, and your medications will not interfere with your driving.

When you're ready, ask your doctor for a referral to a Certified Driver Rehabilitation Specialist for a driving evaluation. A CDRS will:

- Evaluate your potential for driving by assessing your abilities and limitations and develop a driving plan.
- Help you identify appropriate adaptive equipment for your needs, and the vehicle features that best support your driving goals.
- Provide a written prescription for needed adaptive equipment.
- Create a training plan.
- Help you navigate the driver's license requirements for people with disabilities in your state, which vary by state.

To find a CDRS, contact your local rehabilitation facility to see if they offer a driver rehabilitation program. The Association of Driver Rehabilitation Specialists offers a resource for locating specialists. There are many advanced assistive technology options available to suit your wheelchair and function. If you're able to independently transfer into a driver's seat, you may also be able to independently load a manual wheelchair into your vehicle. Various wheelchair lifts can help you stow your wheelchair. If you're unable to safely transfer or you use a power wheelchair for mobility, you may need a vehicle that allows you to drive or push the wheelchair into the vehicle. Some wheelchair users drive the vehicle from their wheelchair and use power lock downs to stabilize the wheelchair. Some examples of adaptive equipment:

Steering: Spinner knobs make steering easier with one hand, such as the tri-pin spinner for people without finger function.

Gas/Brake: Hand controls can be mounted on the left or right and can be individualized by using different motions such as push-pull, push-twist and more.

Secondary driving controls: Wipers, headlights and other controls can be operated in different configurations depending on need, such as touch pads, headrest or elbow switches, voice activation and more.

The National Mobility Equipment Dealers Association website (nmeda.org) provides consumer information on adaptive driving equipment.

The process of getting back on the road is costly. We recommend contacting your state vocational rehabilitation agency to learn about financial assistance if your vehicle will be used for work/school. If you're a veteran, contact the U.S. Department of Veterans Affairs to learn about available benefits. Many people use grants, loans and fundraising to cover costs.



RESOURCES

UNITED SPINAL RESOURCE CENTER RECOMMENDATIONS

Driving After Spinal Cord Injury, MSKTC

Published by the Model Systems Knowledge Translation Center, this fact sheet is full of answers and breaks down the basics of returning to driving into simple bullet points and handy photos.

msktc.org/sci/factsheets/driving-after-spinal-cord-injury

BEST NEW MOBILITY ARTICLES

Baja or Bust

Kirk Williams (left) recounts his first international road trip in "Spock," a Ford Transit van that he had converted into an accessible living quarters and adventure-mobile. He explains his vehicle setup, the how-tos of undertaking a multimonth road trip as a quad and why he was glad he took the plunge.

newmobility.com/baja-or-bust

Motorvation: All About Hand Controls

Our late automotive columnist Michael Collins goes over a range of hand control options, from the basic to the complex, and talks with many drivers about how they adapted to driving post-disability.

newmobility.com/all-about-hand-controls

Everyday Advocacy: Changing Hand Controls

Mike Collins uses an inquiring letter from a reader as a jumping-off point to tackle a number of questions on the legality of setting up hand controls.

newmobility.com/changing-hand-controls

VIDEO RESOURCE

Go to youtube.com/newmobilitymedia to view "Driving as a Wheelchair User," which shows different wheelchair users' driving setups.



PRODUCTS

By Michael Franz



OMNICUFF REVIEW: UNIVERSALITY AND FUNCTION ... AT A COST

Most people with limited hand and arm function are probably familiar with using a universal cuff. The standard universal cuff is typically a beige cuff that wraps around the hand with Velcro and has a slot that holds items like forks and toothbrushes. It's not sexy, but it's easy to use and highly functional.

ReachAble Technology has introduced a new iteration of the universal cuff – the OmniCuff – a cuff-based system that promises to expand the range of possible uses. I was interested to test the OmniCuff and see how it delivers on this promise and whether it works well enough to make me change the way I do my everyday activities as a C6 quad.

More Than a Cuff

The OmniCuff system consists of three main parts that work together to make it easier for users to access and swap adaptive devices: the Adapter, the Connector and the Basemount. At the heart of the system is the Adapter, a cuff with a magnetic adapter in the palm of the hand. Instead of sliding devices into the small slit of a traditional cuff, which can be tricky and limiting depending on the size of the device, the magnet aims to make attaching things easy.

ReachAble Technology has designed an array of magnetized products, including a fork, spoon, knife and cupholder that have the magnetized Connector allowing for easy connec-

tions with the Adapter, along with a kit that allows users to attach magnets to other everyday items like a hairbrush or even a phone.

In addition to being magnetized for easy connection with the Adapter, the Connector is designed to slide onto metal poles that mount on the Basemount for swapping and storage. The Basemount can hold up to six devices for easy selection while you are eating a meal or doing tasks. The Basemount comes in two sizes, the larger of which rotates. All the meal products (fork, knife, etc.) and the three main components can be purchased independently or in one of three bundles.

I received a demo of the largest

bundle, the \$899 Meal Kit Premium, which comes with the full range of ReachAble Technology's products: fork, spoon, knife, cup holder, large and small Basemounts, a mount to attach the Basemount to a wheelchair, an Adapter with three sizes, and the universal connector kit.



How It Works

The Adapter and Connector can be a little tricky to perfectly line up, but provide a very strong connection once you figure out how they work together. I found it easier to take the utensils off the Basemount and to attach the Connector to the Adapter directly off the top of the table.

The OmniCuff fork and spoon have an adjustable neck that allows the user to change the angle of the utensil. This made it easier to get leverage to stab food with the fork and to find a good balance point with the spoon to avoid spillage. I found the knife to be useful with its upright pizza cutter design. I had an easier time cutting with the knife than most other adaptive knives I have used. The cupholder is bulky, which

is probably necessary because of the design, but I found myself using both hands to stabilize it. Considering that I use both hands to pick up cups and bottles anyway, I can't imagine many scenarios where I would use the cupholder.

The quick release clamp connected easily to the frame of my manual wheelchair and seems like it would work as well on a power chair. The Basemount can then be positioned for easy access to whatever devices you might need. However, I found having the Basemount attached to my wheelchair limited my ability to get under tables and countertops.

The Verdict

Although the OmniCuff works as advertised, I would give it a mixed verdict. The bundles are expensive, starting at \$139.99, and many people may already have adaptive equipment that works for them on hand. The bulky Basemounts are not ideal for those of us who prefer our adaptive equipment to be as inconspicuous as possible. Aside from the knife, I have adaptive utensils that I prefer and would not replace with the OmniCuff. Additionally, the cupholder doesn't make it any easier for me to pick up cups, so I would pass on it as well.

I found creating my own adaptive devices with the universal connector kit to be the best way to use the OmniCuff. A single Adapter can be purchased for \$49.99 and individual connector kits can be purchased for \$19.99. I think that it would be worth it to make a one-time investment in the Adapter3 and to purchase connector kits as needed.

The universal adapters come with double-sided tape and Velcro straps that allow you to connect them to virtually anything. I connected adapters to my hairbrush, toothbrush and iPhone. I could see many other potential ways to use the universal adapters including makeup applicators, small gardening tools, or even sporting equipment like a billiards cue stick or ping-pong paddle.

Learn more about the OmniCuff and its accessories at reachable-tech.com.

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TRACKS & HACKS

By Kary Wright

A FAREWELL TO PRINT

NEW MOBILITY magazine has been a big part of my life. As a columnist for more than a dozen years, every few months I'd write about my latest adventure or something cool I was working on for Outdoor Tracks or Gear Hacks. As I went scrolling through the articles I've been fortunate enough to share, fond memories came flooding in ...

... Learning to fly sailplanes brought back the feeling of freedom that one experiences while soaring. In a sailplane you are silently sailing the sky from cloud to cloud, a mile or more above the ground. You are looking for lift, following birds, watching the tractors in fields and dinky toy cars creeping along the highways. The last thing on your mind is that you live with a disability.

You feel that satisfying kick-in-the-pants as you find a thermal — rising air — then bank and circle to stay in the lift as long as possible to extend your flight even more. A few hours later you return and land at the glider field, and then reality hits. You are no longer a pilot, blending in seamlessly with the other glider pilots high above. You are now, once again, the person in the wheelchair, but you will remember that freedom forever.

... An epic, although hilarious, kayaking fail. A fellow quad friend had set out with me, but she was smart and didn't ignore the multitudes of warning signs that the trip was destined for failure. She cancelled her turn to kayak; I did not. In my defense, the excitement of trying to kayak may have slightly dulled my usually keen (?) observation skills, and being a guy, I just couldn't back out at the last minute. Lesson learned. I ended up sitting in the kayak upside down, with my face underwater in the gravel bottom of the pond, listening to splashing footsteps as my wife scrambled to get me upright. The camera was running; the evidence is on YouTube.

... Fantastic camping trips to the mountains, my favorite place. We went for countless walks and bike rides, taking in the incredible scenery and mountain fragrance. It brings a smile to my face when rereading those stories, but it is also bittersweet. I'm also reminded of how some of the great people I shared those times with are no longer with us or can no longer enjoy camping trips.

I remember sharing my favorite trails with my trusty dog. As a young dog she would want to run and walk for hours. As the years went by, the walks got shorter, and later they were



Clockwise from top left: A moment of serenity before Wright found himself upside down, underwater in the kayak; burning up the fields in adapted ATVs; Wright and his wife, Terry; three trusty dogs have been invaluable companions; of all the scenic destinations, nothing tops the majesty of the mountains for Wright.

“NEW MOBILITY has been a way to connect with others that are on a similar journey and helps keep faith that our world will be better. Thank you, NEW MOBILITY, for sharing a great and positive side of humanity.”



only a few hundred yards. I celebrate that she was such a fun part of my life but am saddened that she is gone. Now I'm on my third dog. She's in her later years, so we enjoy our short walks. I'm amazed at how fast time has flown by and how short a dog's life is in hindsight.

... Racing around the field in a 250cc buggy with friend and fellow quadriplegic, Landon, in his Yamaha Rhino; both machines adapted for quadriplegics by Landon and his team. It was so fun to chase each other, slalom around bales and watch Landon burn doughnuts in the field. It sounded like a racetrack and the neighbors even came over to see what was going on. Landon got a thumbs-up when he explained that we were a couple of quadriplegics burning up the field on adapted ATVs.

There were so many adaptations that my friends and I came up with in the stories. We built cuffs on a 3D printer so that I could drive a zero-turn lawnmower. We made mouth-activated trigger pullers for a crossbow and rifles. We made hand controls for computer joysticks and even for driving vehicles, and joysticks to run radio-controlled aircraft and drones. We built camera mounts for action cameras.

All the things I get to do and all the adaptations and inventions have one thing in common: They are only possible with the help of my team. I may write the stories, but there would be no stories without them. I have lived an amazing, fulfilling, fun and loving life to this point. My wife, Terry, has worked so hard for so many years to make my world more normal, and has supported many hairbrained ideas, and a few good ones too. Along with Terry, my family and friends jump in immensely to help make things happen, to which I am eternally grateful. The effort they put in can't be overstated — I only hope they get something back that makes the effort somewhat worthwhile. I get to do fun things only because of their hard work.

Living with a disability invariably means requiring assistance. Some people require very little help and live life independently, and some require a lot of help. In reading other people's stories in NEW MOBILITY, I'm reminded that many others have a similar team of support. There are a lot of great, caring people out there, that may get overlooked at times. As a recipient of so much assistance, and someone who realizes how it makes my world so great, it inspires me to help others wherever possible to help brighten their world. It has been such a privilege to share ideas in the magazine in hopes it'll help others.

NEW MOBILITY has allowed me and countless people a way to showcase this bright spot of our communities. It has been a way to connect with others that are on a similar journey and helps keep faith that our world will be better. Thank you, NEW MOBILITY, for sharing a great and positive side of humanity: It helps to remind us of all the good in the world.

See all of Wright's columns and articles at newmobility.com/author/kwright.

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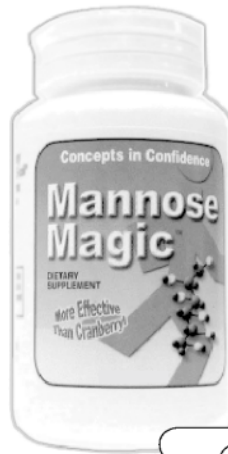
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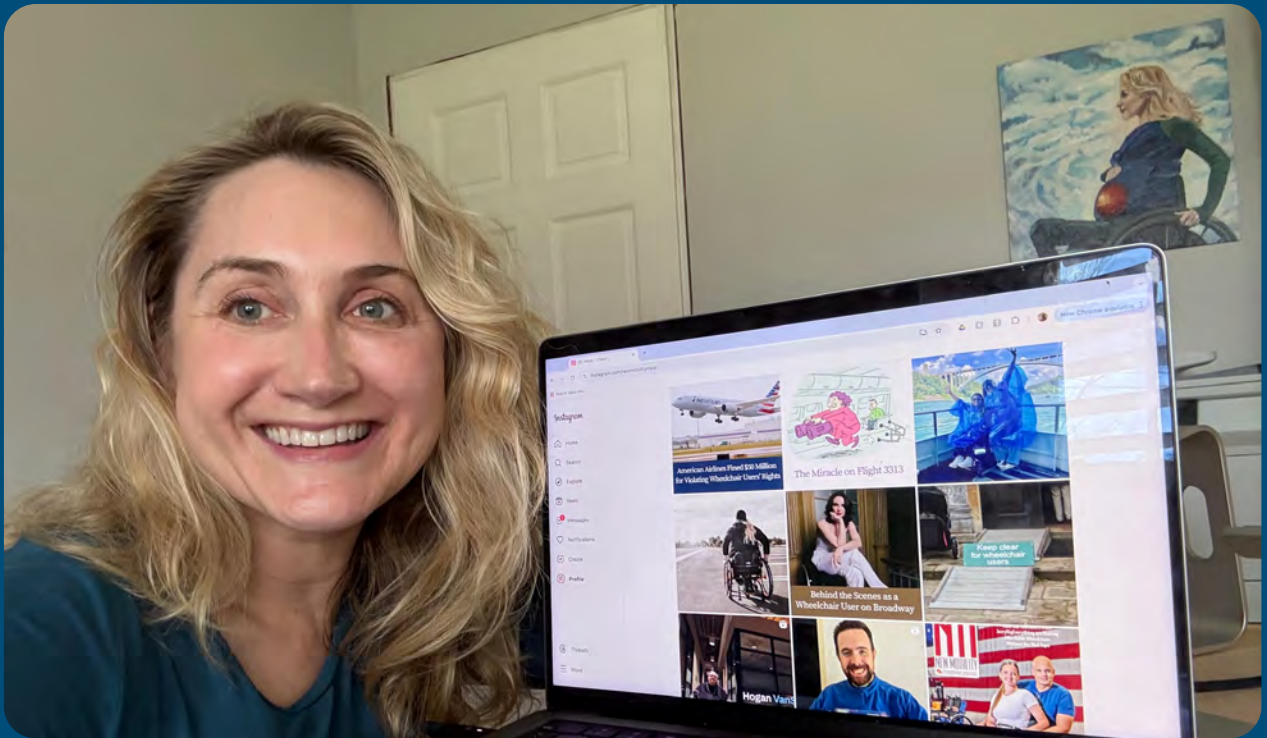
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LAST WORD

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I started New Mobility's Instagram page five years ago, and it has been so rewarding to watch it grow. I love when a post — like how inaccessible medical offices are — garners a lot of comments from our community. And it is exciting when something I share goes viral — like the video that caught airline workers mishandling wheelchairs, letting them fly down the baggage ramp, crashing into the

tarmac. And I get a lot of enjoyment when I post a funny meme or laugh-out-loud comic. Social media also allows us to share news as it breaks and get immediate feedback from you. If you are not already following us, I hope you will. See you online!

—TEAL SHERER
NM Social Media Manager

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