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NEW MOBILITY

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The Fine Print: Include your name and contact info. Include photographer's name and contact info. If you are pictured in the photo, make sure you have the photographer's permission to enter. If you are the photographer, make sure you have the subject's permission to enter. We will provide release forms to entrants; entries will not be considered without signed release forms. It is up to the person submitting the photo to distribute prize money to other relevant parties, such as the photographer or subject. United Spinal Association retains the right to use any entered images in future editorial, marketing and fundraising materials.

United Spinal Association

NEW MOBILITY

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Cover and Contents Photos by Kim Fetrow

Getty Images

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NEW MOBILITY

United Spinal Association

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BULLY PULPIT

By Ian Ruder

DO LIFE

Lying alone on an operating room gurney while waiting for emergency surgery is probably not the best time for introspection. Yet when I recently found myself in this situation thanks to some militant hemorrhoids, my mind immediately pulled up a list of Ian's Deepest Thoughts and I started soul-searching.

On top of obvious questions — How the hell did I end up here? How am I going to get through this? — others that kept popping up centered on New Mobility and my job. Specifically, what in the world is the editor of a magazine for "active wheelchair users" doing incapacitated in a hospital? And, am I even fit for this role?

These questions aren't new to my cluttered brain. From the time I stepped into Tim Gilmer's oversized shoes almost three years ago, the same thoughts lingered in my head's deep recesses, coming to the fore most frequently when my health is flagging, or life and the world seem overwhelming.

I've even had friends and family members who've seen me struggle through tough times read the magazine and ask me if its depiction of life with SCI/D meshes with my experience. When things aren't going my way, it's easy to lose focus on all the things I love about my life and I wonder if they're onto something.

There's no question that living with a disability can be difficult, overwhelming and even depressing. We're so conditioned to that portrayal of disabled life by mainstream society that it's easy to lose track of the reality that life without a disability can be just as difficult, overwhelming and depressing.

In hard times, it's easy to forget that nondisabled people don't have a corner on happiness and fun. In fact, I think you could make a pretty good argument that they don't have as deep an appreciation of life as we do.

All of these thoughts were bouncing through my head when the nurses finally rolled me into surgery. As I've written in this space, the operating room was literally the one place I'd been trying to avoid since the arrival of COVID-19. Now I was there, wondering if life was trying to tell me something.

A nurse struck up a conversation about the mask I was wearing, and we quickly discovered that she used to work as a caregiver for one of my closest quad friends. One of the last things I remember before succumbing to the anesthesia is her smiling and saying the slogan for his nonprofit, "Do life."

I didn't really think much about the words of that slogan when I woke up or in the week of recovery following the surgery, but in hindsight it all makes sense. Whether you have a disability or you don't, you have a choice about how you want to live your life. Speaking from almost 23 years of experience, being disabled can genuinely complicate that pursuit in ways nondisabled me could never have understood, but it still always comes back to a choice.

> "Whether you have a disability or you don't, you have a choice about how you want to live your life."

New Mobility strives to be *the* publication for anyone who wants to embrace the possibilities within that choice and live an "active" life to the fullest. Whether "active" means jumping from planes, raising a family or simply trying to get control of nagging medical problems, we get it and we are committed to helping you "do life" the way you want. I'm honored and excited to be a part of it.

BEHIND THE STORIES

With Ian Ruder

Actor **Regan Linton** compared the process of developing her new column, "Own It," to the struggle Lady Gaga faces when deciding what to wear to the inauguration. "I'd make a decision like, 'Yes! This is it!' and then I'd be like, 'Ummmm, maybe not quite there yet,' and I'd explore a few more options. Ultimately, hopefully it'll be expressive and forthright ... with some fun and irreverence thrown in," she says. "I love talking about the things we don't feel we can discuss, even though they are on our minds the most, or what we deal with most."

I've wanted to get **Jerry McGill**'s voice in the magazine for some time now and was excited when he agreed to profile hip-hop dancer Auti Angel for this issue. It was the perfect fit, as McGill's respect and appreciation of Angel shines through the story. "It was fun interviewing Auti," he says. "Often times the subject can be standoffish and reserved, and justifiably so. There is a genuine concern for how they will be portrayed. Auti was jovial, lighthearted and at the same time open and revealing. The kind of person you want to have a beer with."

Leaving the Senate to join United Spinal as director of policy and advocacy was definitely a change of pace, says **Stephen Lieberman**, who was a staffer for Sen. Bob Menendez (D-NJ). "In the Senate, you're constantly fielding requests and taking meetings with various stakeholders about many different issues," he says. "At United Spinal, we know what our issues are. The core mission of equal opportunity and inclusion stays the same. We just keep plugging away, looking to advance the ball further down the field for the benefit of our community." We're grateful for Steve's advocacy update on page 10.

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

NEW MOBILITY

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BROOK MCCALL • TEAL SHERER
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Rollin' RNs features two wheelchair-using RNs who use their experience as health care professionals who live with SCI to write articles that pertain to health topics of interest for the community. facebook.com/rollinrn

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"You are paving the way for so many others."

JANUARY 2021

'NM Person of the Year: Andrea Dalzell'

The Right Choice: You couldn't have chosen a better person. Congratulations, Andrea!

Jackie Wiegert Klotz
Facebook

Lead On: I relate! What an incredible story. You are paving the way for so many others. I wish you didn't have to encounter so many barriers on your path.

E.T. Russian
Newmobility.com

Barrier Busters: I absolutely *love* this! There's no one more deserving. Yay for us wheelchair nurses breaking down those barriers.

Meg Prehn
Instagram

Shattered Ceilings: Sisssssssss! Making me proud. Keep shattering these ceilings people try to place above you!

@nursetiffanyyy
Instagram

'Josh Spencer & The Last Bookstore'

Steinbeck Treasures: I had no idea of The Last Bookstore owner's story. I'm from Liverpool, United Kingdom, but live in Mexico. My partner and I flew to Los Angeles a few years ago and found this bookshop completely by chance while we were out walking one evening. I loved it, spent hours in there and bought some Steinbeck paperbacks that I treasure. I was paralyzed aged 22, albeit in a different manner.

@tommy_coconuts
Instagram

Post-Pandemic Destination: Great article about a place I'm drooling to go to when life returns. I saw the documentary about Josh Spencer and was completely captivated by his quiet charisma and resilience, not to mention his visionary business venture and philosophic worldview that overrides his disability and puts it on the back burner of his life.

Alison Dale
Newmobility.com

Editor: *Watch the documentary at tinyurl.com/ybxejawe.*

'How Tecla Helped Me Romance My Wife'

Tecla Love: The one device that has most impacted my life is the Tecla. I started with Tecla Shield to control my iPhone and upgraded to tecla-e when it became available. I use the head array on my power wheelchair to connect with tecla-e and my phone. Both Tecla Shield and tecla-e are absolutely phenomenal. When I first read about Tecla in your magazine, my rehab specialist at the wheelchair clinic had not heard of it, but was able to arrange a trial for me.

Mostly, I use Tecla to control my iPhone, but I also use it with an iPad. I love being able to make and receive phone calls and text messages and read books, just like everyone else.

Diane Feldman
Via email

'Wheelchair Users' Experiences with COVID-19 Vaccine'

Caregivers are Essential: My mom is 73 and she is a paraplegic with health problems. I am 50 and take care of everything she needs. I have asked about getting a COVID-19 shot for myself and was told I would not have to wait, but if you look at who is eligible for the shot, they do not even mention caregivers. We as caregivers worry what will happen to our loved one if we get sick. I just wanted to put this out there and see if others feel the same. What can we do?

Laura DiFiore
Via email

New Mobility Vision Board: To help me visualize my goals, I create vision boards. I made this one with New Mobility and magazines from Hawaii.

Cameo Perells
Oregon State University

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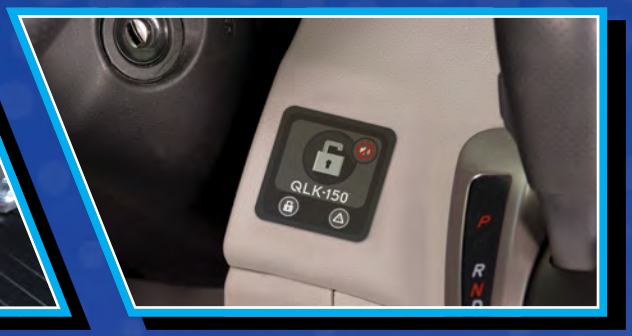

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MOBILITY SPECIALIST @ Q'STRAINT

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POSTS

The World's Most Spacious Accessible SUV

If you need a roll-in vehicle with plenty of room to move around, but vans just aren't your thing, BraunAbility may have the ride for you. The company recently launched a Chevrolet Traverse conversion it's describing as "the most spacious wheelchair accessible SUV ever."

The Traverse comes with an extra-wide, in-floor ramp and the increased doorway height means that even users with the largest power wheelchairs should have no problems getting inside. Both front seats are removable, and there's room for two wheelchair users in the mid-row position as well as a full third-row bench.

Basically, it's got all the size, access and configurability of a minivan, without looking like, well, a minivan. Starting vehicle and conversion MSRP is $77,345. To check out all the options and find a dealer near you, go to bit.ly/37rSbNc

Hong Kong Wheelchair User Climbs (Most of a) Skyscraper

A four-time winner of the Asian Rock Climbing Championship recently climbed 800 feet up the side of a Hong Kong skyscraper in his wheelchair. Though Lai Chi-Wai was stopped by strong winds 230 feet from the top, the media was all over his story, and he raised over $700,000 for exoskeleton research. Chi-Wai says he hopes the climb shows the strength of disabled people, but he mostly seems bummed that he didn't make it to the top.

See a vertigo-inducing video on his climb at bbc.com/news/av/world-asia-55696245.

LISTEN

FROM THE START OF THEIR FIRST EPISODE, JESSIE CHIN, FRANCESCA "FRENCHY MINAJ" KELLISE AND ANTWAN TOLLIVER MAKE NO BONES ABOUT THE GOAL OF THEIR NEW PODCAST, FROM THE THRONE: "WE WANT TO STOP THE STIGMA THAT PEOPLE IN WHEELCHAIRS FEEL SORRY FOR THEMSELVES [AND] PEOPLE IN WHEELCHAIRS DON'T LIVE THEIR LIVES THE RIGHT WAY," KELLISE SAYS IN THE EPISODE'S OPENING MINUTES.

IF THE FIRST THREE SHOWS ARE ANY EVIDENCE, THE THREE CLOSE FRIENDS FROM NEW YORK CITY LOOK TO HAVE A GOOD CHANCE OF HOLDING DOWN THE THRONE. THEIR CANDID AND INSIGHTFUL OBSERVATIONS ARE OFTEN FUNNY AND, MORE IMPORTANTLY, ENJOYABLE TO LISTEN TO AS THEY ARE OBVIOUSLY PASSIONATE ABOUT EDUCATING THEMSELVES AND OTHERS ABOUT DISABILITY. CHIN MAKES A GREAT DE FACTO MODERATOR AND TOLLIVER IS THOUGHTFUL AND COMPOSED, BUT IT IS MINAJ WHO STEALS THE SHOW WITH HER QUICK WIT AND BRASH DELIVERY. HERE'S TO THE REIGN! FIND IT ON FACEBOOK @FROMTHETHRONEPODCAST.

Photo by Lampson Yip/Getty Images

NYC's New Accessible Transit Chief

Quemuel "Q" Arroyo shares a nickname with James Bond's famous gadgetman, and the New York City Metropolitan Transit Agency is hoping he proves just as ingenious at solving the city's longstanding transit accessibility problems. On Feb. 4, the MTA introduced "Q," a United Spinal member and wheelchair user, as its first chief accessibility officer.

Q Arroyo

Arroyo previously held a similar role at the city's Department of Transportation as chief accessibility specialist and ADA coordinator/disability service facilitator. He told CityAndStateNY.com that, as a New Yorker who relies on public transit, he understands "the only way to change is by bringing on people with disabilities, bringing them to the table, and really having that voice be heard."

Read his full interview at cityandstateny.com/articles/personality/interviews-profiles/conversation-quemuel-arroyo-mtas-first-chief-accessibility. For more on the long battle to improve access in NYC, watch *All Riders*, a new 15-minute documentary about the latest generation of advocates who are pushing the Metropolitan Transit Authority to live up to the ADA after decades of delay and slow progress, at vimeo.com/510363377.

The Accessibility App That Finally Sticks?

With a slick interface and a growing user base, iAccessLife is the latest accessibility app to try and establish itself as the "the Yelp of Accessibility." App creator Brandon Winfield doesn't hesitate to call it just that, but only time will tell if iAccessLife can sustain success where so many others have struggled.

Brandon Winfield, left, uses his app to explore the Atlanta area.

Click on a business and iAccessLife gives you all the relevant info — hours, Google rating, and links to call, navigate to or visit its website — along with the option to rate its overall accessibility and specific features like entrance, bathroom, parking and interior.

Since its 2019 launch, iAccessLife has grown to have 4,500 unique locations rated in 45 states and 30 countries. Winfield says they're trying to get to 5,000 users in the next three months and 7,500 by the end of the year. Try it out for yourself by searching iAccesslife on either the App Store or Google Play.

'Interabled?' Yeah, No.

We keep seeing the term "Interabled" pop up on the interwebs, including *The New York Times*. The term, used to describe a couple in which one person has a disability and one doesn't, invokes some strong feelings in our staff. So we decided to see what everyone else thought with a reader poll.

The results are decidedly negative, with over 50% of the 171 respondents either disliking or loathing the term, while only 20% either like it or love it. One response — "Seems unnecessary, why can't they just be a couple?" — sums up our feelings pretty well.

But if this is the way of the world nowadays, we should get ahead of the curve. So what's your best term to describe a couple in which both people are disabled? "Crouple," "Wheelationship," "Friends With (Social Security) Benefits"? Come on team, let's figure this out. Send your brilliant ideas to jbyzek@unitedspinal.org.

WATCH

NETFLIX HAS JUST RELEASED A NEW FILM CALLED PENGUIN BLOOM THAT CENTERS ON A WHEELCHAIR USER. WATCH AS NAOMI WATTS PLAYS A YOUNG, ADVENTUROUS MOTHER WHO HAS TO LEARN HOW TO MANAGE LIFE WITH A DISABILITY AFTER AN ACCIDENT WHILE TRAVELING IN THAILAND. NETFLIX LOSES POINTS RIGHT AWAY FOR CASTING A NONDISABLED ACTOR IN THE ROLE, BUT DO THEY MAKE UP FOR IT WITH A NUANCED PORTRAYAL OF WHEELCHAIR LIFE? LET US KNOW WHAT YOU THINK.

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

BENEFITS INCLUDE:

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***New Mobility* magazine**

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Ongoing Educational Webinars

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

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

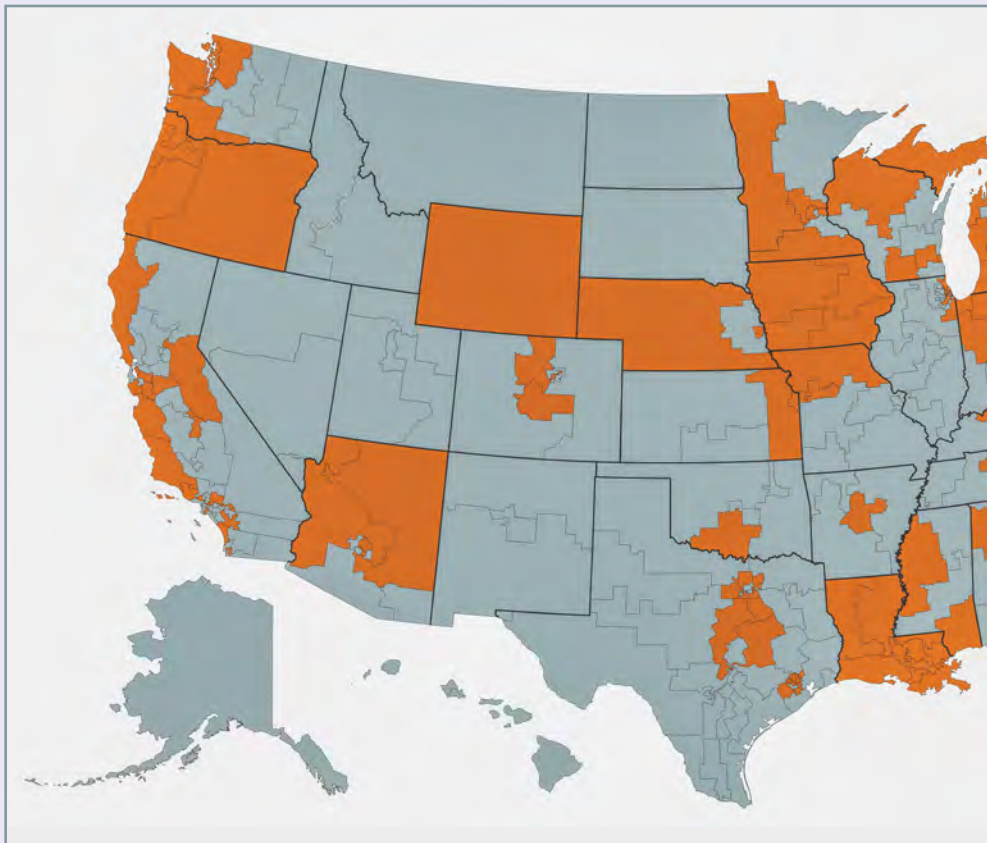
United Spinal Association

CELEBRATE UNITED SPINAL'S 75TH ANNIVERSARY THROUGH ADVOCACY

Throughout our history, people with disabilities have faced barriers of all kinds. While our physical world is now more accessible than ever and the civil rights of people with disabilities are more protected under law than ever before, it is a constant battle to ensure that everyone with a disability has the same opportunities as anyone else. Each instance where a disabled person faces discrimination requires someone to speak up in order to make change — and United Spinal Association wants to make sure that we have an army of advocates across this country ready to fight for it.

As United Spinal celebrates our 75th anniversary in 2021, the Advocacy and Policy team continues to push on many issues of importance to the disability community. From ensuring equal treatment in the provision of medical care related to COVID-19 and getting our community vaccinated against this virus, to fighting for accessible housing and transportation, to pushing for equal opportunities in the workplace, United Spinal is committed to building an inclusive world where all people with disabilities can thrive.

Here in Washington, D.C., we have had very positive engagement with the Biden administration so far. We believe that Congress will include critical additional funding for Medicaid home and community-based services as part of another COVID-19 recovery bill. The Biden administration has committed to including caregiving for people with disabilities, alongside childcare and care for older adults. Also, there is a lot of discussion in Congress about an increase in the minimum wage, which would include phasing out the discriminatory subminimum wage for people with disabilities. None of this would have happened had it not been for all of the advocates who raised their voices and made their elected officials listen to our community's con-



cerns. There remains much to do but see below for how you can help.

To ensure that our message is being heard by all 435 U.S. Representatives and 100 U.S. Senators, United Spinal needs dedicated advocates registered as part of our District Mobilization Initiative. To register, please visit unitedspinal.org/grassroots-advocacy-network.

There's never been a better time to join us. As part of our 75th anniversary celebration, we are holding a year-long Advocacy Challenge that includes several significant prizes, including one for a lucky winner picked at random from our registered advocates!

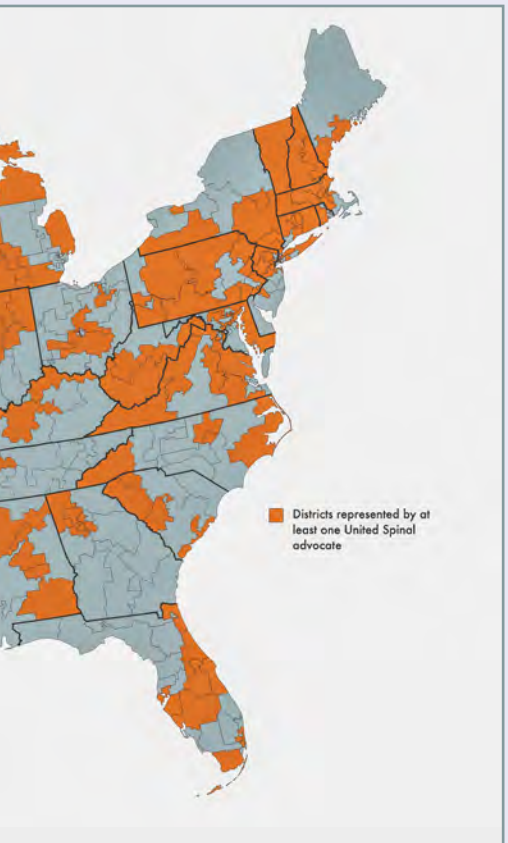
The goal is to have registered advocates in all 435 congressional districts, so that when a critical issue to the disability community is being considered in D.C., every single member of Congress knows that they have constituents back home who want them to take United Spinal's position.

Since this program was launched in the summer of 2020, we now have over 300 registered advocates in over 200 congressional districts across the country. The map shows districts where United Spinal has at least one registered advocate. Anyone, anywhere can participate — a person with a disability, a caregiver, a family member, or anyone who cares about our issues.

We are also holding a Recognition Challenge for chapters and advocates to get state legislatures and mayors around the country to recognize United Spinal's 75th anniversary through official resolutions or proclamations. Please join us today (and bring a friend!) to help us advocate for a truly inclusive world for all.

Email or send questions at advocacy@unitedspinal.org and keep your eyes peeled for updates to our social media accounts, newsletters and website. As always, check our Action Center for the latest action alert messages to Congress: unitedspinal.org/action-center.

— Stephen Lieberman,
Director, Policy & Advocacy



GEAR HACKS

By Seth McBride

GETTING A GOOD SETUP WITH BAD REIMBURSEMENT

In this month's cover story, I write about the various ways that the health insurance wheelchair reimbursement system in the U.S. is broken.

And while you may benefit from an ultralightweight, high-spec wheelchair like a Panthera X, Apex Carbon or TiLite TR, getting an insurance company to pay for one of these can be a tall order. It's undoubtedly worth the battle, but even if your insurance will only cover an aluminum-frame wheelchair, there are options and setup tweaks that can help you make the most of it.

The Forgotten Measurement

Center of gravity, the measurement of where your axle sits in relation to the rear-most part of your seat — typically your backrest bars — is often underappreciated in seating clinics. But if you've only ever sat in a wheelchair with conservative, therapist-approved CG, you'd be amazed at what a difference changing it can make with your push efficiency and ride quality. I can't tell you how many inches of CG is optimal, as it varies for everyone. But for reference, my injury is at C7 complete, and I sit with my axle 3.5 inches forward of my backrest bars, which allows me to pop my front end off the ground by just leaning back.

Ki Mobility's Ethos wheelchair is covered by most insurance companies and has a unique vibration dampening mechanism.

On most wheelchairs, including ones with limited adjustability elsewhere, you can typically slide your axle position forward or backward by loosening a couple of hex bolts. Be careful to get the position exactly the same on each side, though, as clamping your camber tube even slightly off from perpendicular can pull your frame out of true.

The drawback of moving your axle forward is that it makes you chair easier to tip over backwards. The advantages, however, are enormous. For one, sitting farther behind your wheels gives you more wheel to push, increasing efficiency and allowing you to get from here to there with fewer repetitions. Second, you'll have more of your weight on the big, rear wheels, rather than the small, front casters, which decreases rolling resistance. An aluminum frame chair with an optimized CG is easier than to push than a 5-pound carbon fiber frame with your weight over your front casters. Third, sitting with more weight on your rear wheels can reduce vibrations and improve your ride quality by letting your front casters float over cracks, bumps and rough ground. You might feel totally unstable when you first move your axle forward, but once your body recalibrates its balance points, there's a good chance you'll never want to go back.

The Tao of Adjustability

A few months ago, I wrote an article about adjusting your seating position, including front and rear seat height and backrest angle to maximize stability and increase push efficiency ["Dialing in Your Seating Position Without Changing Your Chair," November 2020]. I used to think that highly-adjustable wheelchairs were only for newbies. It is true that adjustability has its drawbacks — adjustable components typically add weight, and over the years they're prone to seize up, rendering them mostly useless. But my most recent wheelchair ordering experience has changed my tune a little. I had multiple chairs' worth of experience when I ordered and the help of two extremely knowledgeable ATPs, but we still got two important measurements just slightly off. It was only because of a manufacturing error that I got a chance at a redo, and the fixes turned a good chair into a great one.

Fine tuning your seating position can make such a big difference in your chair's performance, regardless of frame materials, that unless you know exactly what you want, it's worth considering ordering a chair with high adjustability. Motion Composites makes an aluminum version of its Apex frame, which has fantastic adjustability — including a cool mechanism to bring your caster angle back to neutral

Motion Composites' Apex is hightly adjustable.

after you've changed your front or rear seat height — but still manages to keep its weight in line with other manufacturers' models.

The important point about adjustability, though, is that you have to use it. Give yourself time to get used to a seating position, but don't be afraid to make small tweak after small tweak, even when you think you've got things right. You can always go back if you don't like what you've tried, and you'll never find your perfect position if you don't go looking for it.

Taking Out the Rattle

How you sit in your chair can mitigate some of the drawbacks of aluminum, but there's no getting around the fact that — in addition to their weight savings — titanium and carbon fiber are much better at dampening vibrations. In fact, chromoly steel does a fantastic job at shock absorption, but RGK, a British company, is about the only chair manufacturer I can find making chairs out of the stuff.

There are still some options for reducing the rattle of an aluminum-framed chair, though. Ki Mobility's Ethos wheelchair is covered by most insurance companies and has a unique vibration dampening mechanism. The design separates the part of the wheelchair frame that touches the ground from the part that touches your body and connects them with polymer (fancy rubber) inserts, which stop some of the vibration transfer. The result is a smoother ride without the cost of advanced frame materials or the weight of beefier shock absorbers.

Otherwise, the old standby of Frog Legs front caster forks can take some of the bite out of rough roads. Likewise, wider, lower pressure tires can make for a smoother ride, but they come with their own drawbacks, like increased rolling resistance and a changed rear seat height.

There's no setup that's perfect for everyone, but with a willingness to play around, I hope you can find something that works well for you — even if your insurance doesn't.

Resources

- Ki Mobility Ethos ($2,995 MSRP): kimobility.com/ethos
- Frog Legs Caster Forks: froglegsinc.com
- Motion Composites Apex ($2,595 MSRP): motioncomposites.com/en_us/products/rigid-wheelchairs/apex-a#technical-specifications

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HUMAN-CENTERED COMPUTING RESEARCHER

Madison Russell

Madison Russell, 20, lives with juvenile arthritis and has wanted to make technology more inclusive and accessible since she was 14. When she started using a wheelchair in 2018, she didn't think, why me? She thought, why not?

Making the Virtual World a Reality for Wheel

Making the virtual world a more accessible place has always been an interest for Madison Russell, even before she became a wheelchair user thanks to syringomyelia, a rare disease that causes cysts to form on the spinal cord. She thought she'd devote her life to dancing but quit at age 11 when her juvenile arthritis made dancing too dangerous.

After attending a summer camp for kids with juvenile arthritis, some who used wheelchairs, she became sensitive to how inaccessible and isolating the world could be. "I had friends who had to stay home all the time or couldn't use a cell phone because their fingers were too damaged," she says. "Seeing that is what initially gave me my interest in accessibility."

Her father was a software engineer, so she learned to type before she could write or speak and how to make websites when she was 9. She took a computer science class in high school and realized she had an aptitude for it. "I liked programming," she says. "I was good at it and as I got older, I realized how many things you could do with it. One program can change so many lives."

She knows this firsthand because in high school she created a pen pal app to help closeted teens connect with one another. The app didn't come to market, but it resonated with her as a queer teen fearing she'd lose friends if she came out in her rural southern hometown of Hiram, Georgia.

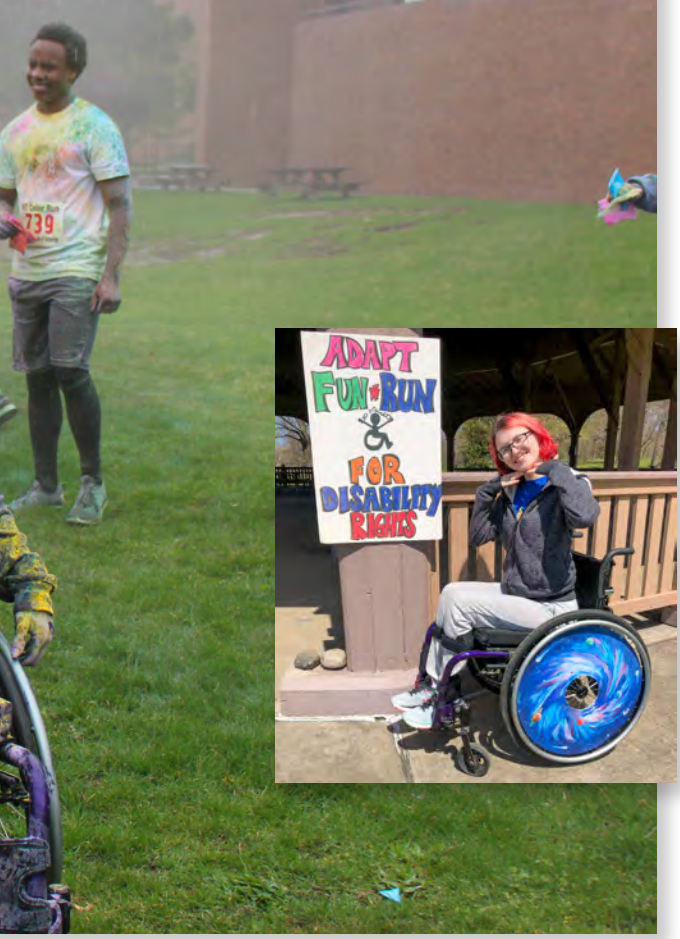
It resonated with thousands more, too. It went viral, gained national media attention, and earned her a scholarship to The Rochester Institute of Technology's first graduating class of the Human-Centered Computing Program, where she focuses on accessible and instructional technology.

She is currently interning at the Center for Accessibility and Inclusion Research at RIT, where she studies educational accommodation for graduate students with disabilities and ways to include wheelchair users in virtual reality gaming.

"I had one roommate who I watched play Beat Saber in the living room. He was standing, turning around, and moving across the room using motion

CAN'T LIVE WITHOUT: I just got an Apple Watch with wheelchair mode, so instead of counting steps, it counts pushes and changes the calorie count for wheelchair users.

WHAT WOULD TELL YOUR PRE-DIAGNOSIS SELF? It's not the end of the world. Life looks great so far, and it's not as bad as I thought it would be.



chair Users

controllers," she says. He asked Russell if she'd like a turn playing the popular VR rhythm game and she reminded him she couldn't. That was the moment she realized game designers don't think about wheelchair users when they design these games with VR technology. She hopes that her research integrating wheelchair users will open a whole new market for systems like Oculus and PlayStation VR.

"Growing up, I saw so much inequality — racism, sexism, homophobia and transphobia. My parents tried to shield me from that as much as they could, but it's hard when you go to elementary school and you have to have the racism talk when you're 8 because Obama got elected," says Russell. "But I think technology plays a huge role in leveling the playing field by giving opportunities for inclusion and access where none may have existed before."

The Universe Fell Into Place

Madison's juvenile arthritis stopped her from dancing when she was 11. But when she began using a wheelchair in 2018, she used her new ride to reclaim movement.

"When I became a wheelchair user, I could dance again because I didn't have to worry about my knees and my hips and the damage dancing did to them. I always say the universe made a mistake with giving me arthritis and making me quit dance and sports, so my wheelchair is the universe righting its mistake. It felt like the universe fell into place.

Dancing feels so freeing to me. I feel like I am in my body again. Being a wheelchair user, sometimes I feel like I'm in a completely different body.

Dancing makes me feel like myself again."

A POPULAR MISCONCEPTION ABOUT ROCHESTER INSTITUTE OF TECHNOLOGY? That because it's home to the National Technical Institute for the Deaf, it's also accessible to hearing people with other disabilities and actually cares about our needs.

WHY I JOINED UNITED SPINAL: My syringomyelia diagnosis was so out of left field. When I found United Spinal, I felt like I'd found an entirely new community I didn't know existed.

Farmer Tim's 10 STEP GUIDE to ACCESSIBLE GARDENING

BY TIM GILMER

Gardening has anchored my life for about 45 years now. More than an activity, it is it also a frame of mind, a way to connect with nature and a calming time that lets you leave worries behind, if only for a brief period each day. It also has a cumulative effect, creating a deeper sense of gratitude for nature and life itself. And it has practical benefits. It can put food on the table and give you a chance to be outside, enjoy the sun and fresh air. Best of all, it can happen in a manageable, accessible environment, like a deck, porch or patio.

1 GATHER THE ESSENTIALS

For me, gardens are a place to raise food, but vegetable plants go especially well with flowers and other plants on a deck. Choose a space with a solid rolling surface and room enough to grow a few or several plants — a wooden deck, porch or concrete slab. A table-like surface you can roll under for starting seeds and potting up plants is necessary, unless you plan on buying starts. A few small tables or other raised surfaces are good for setting up containers at wheelchair level. Your accessible garden space should also have water available close by.

Last spring, at the beginning of the pandemic, I decided to raise tomato plants and lettuce on my deck. I ended up getting carried away and added broccoli, beans, squash, peppers, basil and parsley, just to see if I could grow them successfully in containers. By season's end, my plants and containers took up about 30-40 square feet of space — about a 6-by-6-foot area.

2 CHOOSING YOUR SOIL

The foundation of any plant is its soil or growing medium. For containers, dirt dug from the earth can be heavy, messy and difficult to work with. You can make your own growing medium or buy a packaged mix from a nearby garden center. You can also find good products online. If you grow organically, there are more options now than ever before.

Last year I used a local organic mix called Opus Grows Mix #1. Whatever you use, if the label says "OMRI listed," that means it is approved by the Organic Materials Review Institute. I used that mix for potting all my vegetables, which I grew from seed. The seedling mix should be finer, however. I used Black Gold seedling mix, not to be confused with Black Gold potting mix.

3 GROWING FROM SEEDS, STARTS OR BOTH

Starting seeds requires some hand dexterity, but you can direct a helper, friend or family member to prepare your mix, fill flats and sow seeds. Handling seeds, many of them tiny, can be a problem for anyone. Common seed sowing tools may be managed by those who can hold a lightweight tool in their hand or hands. You may be able to come up with an adaptation that works for you. You can also purchase some seeds in pelletized form — small round balls larger than a BB. These are easier to handle than say, natural lettuce or tomato seeds, which are small, flat and difficult to work with.

Here is an idea you may be able to adapt and improve on. Buy mostly pelleted seed. Start seeds in Jiffy Peat Pellets. All they need is water. Add it from the bottom and they will soak it up and swell. Place your seed or seeds in the center of each Peat Pellet. Using round pelleted seeds is way easier, but you also can use natural seed. Buying starts from a garden center is easier than starting your own seeds but can get expensive. Also, watching those first few seeds emerge in the spring is a joy.

All they ask in return is sufficient water, sun and protection from freezing and wind and pounding rain. When they are newly planted and are outside and vulnerable, it's best to keep them covered with plastic at night. Remove the plastic during the day so they can get air and sun, or when they outgrow the plastic covering.

4 PICKING THE BEST SEEDS

Find a good spring catalog from a reputable company, preferably located in your growing region. Since I live in Oregon, I use two seed catalogs, one from in-state, the other from Maine. Why Maine? Because Northwest and Northeast regions have similar growing seasons. I have used Johnny's Seeds (from Maine) for decades, and I find their catalog to be full of useful products, including tools, as well as a large variety of interesting seed varieties and basic instructions for how to grow each type of plant.

5 SETTING UP THE GARDEN

Each type of plant requires an optimal soil depth. Shallow-rooted lettuce and broccoli can be grown in only 6-8 inches of soil. I used an old stock watering tank for a deck planter. It isn't pretty, but you can grow a season's worth of lettuce and two or three broccoli plants in it. A planter can be plastic, wood or metal, but it must have drainage and be at optimal height for wheelchair use. I like planters that are no wider than arm's reach and four to six feet long.

For larger plants, fill 3-to-5-gallon containers, or larger, with 10-16 inches of potting soil. To have good access, elevate them slightly. Keep in mind that you will have to roll up to a planter and may have to position yourself "sidesaddle," instead of head-on, unless it is built to roll under. I created a makeshift false bottom for my stock tank by putting upturned bins and buckets in the bottom of the tank, laid a simple wooden frame on them and stapled wire mesh to the wood, then placed a weed barrier mat over that before filling it with my growing medium. I used only 8 inches of soil, but the mesh allowed water to drain to the tank bottom, where an overflow port allowed it to escape.

If that sounds like a chore, it was. If I had it to do over again, I would buy or build a simple wooden planter or planters.

6 EXPERIMENT WITH VEGGIES

I had surprising success growing broccoli in my tank planter, along with lettuce. If you want more central heads of broccoli, add a separate planter. It's best to plant your

These photos show tomato plants in various pots and containers, from the young seedlings in peat pods on bottom left to the group of potted tomatoes shown on the top right-hand corner of the next page. New gardeners sometimes worry they need proper containers and pots, but it's OK to be creative and make do with what you've got. Look how Tim Gilmer stakes his tomatoes, though. As the plants grow, keeping them from flopping over requires stakes and twine.

lettuce and broccoli seeds in succession so they don't mature all at once. Three or four different plantings should be sufficient, depending upon the size of your family.

I planted a yellow snap bean variety on a whim and was surprised by the yield from a clump of three plants that I planted together in a wide, 16-inch-diameter pot. Two pots' worth should yield several sizable helpings. Remember, beans need heat (60 degrees or more to germinate), water and fertile soil, or fertilizer added when growing in pots.

Squash is easy to grow but requires a good-sized container and lots of root space and nutrients — and the yield will never compare with field-grown plants. For a deck, I suggest growing smaller varieties like "8-Ball" (smaller, round summer squash). They are prolific yielders.

Basil and parsley — I prefer "Giant Italian Parsley" — are surprisingly easy to grow and should be harvested every week or two to keep them fresh and producing. Bell peppers may only produce four or five fruits per plant, but my yellow variety did better than I expected.

7 STARTING TOMATOES AND LETTUCE

For me, these are a mandatory salad base. I grow mainly small lettuce varieties, like "Little Gem" or "Tom Thumb." They make nice tight heads in little space and are tasty with a good mix of crunchy and leafy leaves. A nice red leaf is good to add, but you can buy quality red leaf at the market, and it goes a long way.

The key to growing successful lettuce starts is exposing them to the right temperature. I like to separate my tomato seedlings from my lettuce seedlings because tomatoes germinate best at 70-85 degrees, while lettuce does best at 55 to 70. Lettuce will not germinate in full sun on a hot day in the high 70s or 80s.

For tomato varieties, there are nearly endless possibilities, but deck space must be considered. I used indeterminate varieties of taller, staked plants to maximize yield and preserve space. It took a lot of care but was worth it. I grew two reliable and tasty cherry tomato varieties ("Sungold" and "Sweet Million"), and for the first time, "Black Krim," an heirloom — on the advice of a good friend — that disappointed me. Too little fruit, spoils easily. This year I will grow an old reliable, "Early Girl," in an indeterminate variety. It also comes as a bush plant.

To stake my tomatoes on my deck, I used 6-7 foot bamboo poles placed on the inside perimeter of the pot (four per pot at 12, 3, 6 and 9 o'clock). When the plants needed help to stay upright, I wound nylon or sisal twine around the poles to support branches when they were laden with fruit (see photo). It worked well, but I needed help in supporting branches while I wound the twine around the poles. I also drilled holes at the tops of containers and secured the poles with zip ties, for stability.

8 WATCH THE WEATHER CLOSELY

Respect Mother Nature and her unpredictability by consulting the latest up-to-date forecasts from an au-

thentic source — like the National Weather Service for your *specific* area. To me, Farmer's Almanacs are about as reliable as astrological forecasts. Stay away from them. Be certain to have a protected space for your plants in the event of sudden wind or hail or pounding rain, especially when plants are tender and most vulnerable. I sometimes had my wife or grandson move plants to a protected area the night before expected bad weather, just to be safe.

Bad weather and disease often go hand-in-hand. Most diseases are either soil-borne, which you can limit with good quality, soil-less growing medium, or the result of excessive moisture and poor air circulation. If you have healthy plants, disease will not harm them to the point of affecting the fruit. Seedlings are especially vulnerable to too-high humidity. Be certain they always have air.

9 KEEPING COSTS DOWN

Space, time and money. These are the main factors in growing a garden, wherever you grow. If you own the space, it's free. If you have the time, you are fortunate and highly likely to succeed. Out-of-pocket expenses vary, but a good rule of thumb is only pay for what you cannot do yourself with a little more effort or ingenuity. Most wheelchair users have learned this lesson as a way of life. I save seeds from season to season so I don't have to buy them every year.

You can make seedling and potting mixes yourself if you get the basic ingredients separately, mainly peat moss and well-composted garden soil. Garden centers sell soil if you don't have your own. Be sure to get something that adds good aeration, like natural pumice, perlite or coir fiber, which comes from coconut shells and is resistant to bacteria and disease. Moisture retention is boosted when you add vermiculite.

Seedling mixes can be simpler. I have raised healthy seedlings in a simple home-made peat moss, vermiculite and perlite mix. The seedlings will get started without nutrients but should be placed in potting soil that has nutrients after two or three weeks for best growth.

10 HARVEST AND PLAN FOR NEXT YEAR!

The payoff for all your work, attention and care comes with the fruit of the harvest, the good feeling you get knowing you are eating healthy veggies, a feeling of accomplishment and, as I mentioned before: reduced stress. The time and love you give your plants each spring and summer return to you multiplied in late summer and fall, if not before.

If you have a little disappointment at harvest time, try again the next growing season. Spring in all its wonder is a reliable and trustworthy friend, and gardening will boost your spirits each year.

MORE GARDENING RESOURCES:

Here are resources that will answer just about any question you can think of about how to start your garden:

- gardenerspath.com/plants/vegetables/best-container/
- gardenerspath.com/plants/vegetables/grow-tomatoes-containers/
- newmobility.com/2018/03/accessible-gardening/
- thegardeningcook.com/vegetable-garden-on-a-deck/

Using peat pellets

- ugaurbanag.com/using-peat-pellets-for-seed-starting/
youtube.com/watch?v=PmyGBrKvzbs

Easy organic fertilizers

- rexius.com/collections/wholesale/brand-opus-grows
oldworldgardenfarms.com/2017/02/02/simple-organic-fertilizers/
- gardeners.com/buy/organic-compost-for-containers/31-571.html?SC=XNET0349#q=organic%2Bfertilizer&start=7

THE QUEST TO FIND THE RIGHT WHEELCHAIR

BY SETH MCBRIDE PHOTOS BY KIM FETROW

"That's a really nice chair," said the vendor rep, when I rolled into my local seating clinic almost three years ago. "We can't get you anything like that."

Nice to meet you too, I thought.

I knew the chair I was pushing — a TiLite TR with an ADI backrest, bolt on sideguards and a jerry-rigged cushion — was nicer than what a lot of people had, but it sure didn't feel extravagant. The frame itself was of unknown age. I first got it in 2008 when a rugby teammate, Mark Zupan, tired of watching me push around a 2-inches-too-wide chair with a duct-taped backrest and offered me his old frame. The fit wasn't perfect — it was a little too short, with too little dump — but it was better than what I had, so I adjusted where I could and otherwise made it work.

In 2013, a small wheelchair manufacturer built me a custom chair. That chair fit better than any I ever sat in, but the frame was aluminum and rattled me to pieces on anything but the smoothest of surfaces. Plus, they made it out of thin-walled material to save weight for a handcycle tour. After two years, the frame started deteriorating and I was forced to switch back to the TR. Having experienced a well-fitting chair, I now knew what I was missing; having experienced aluminum, I wasn't going to get a new frame unless it was made out of titanium.

Fortunately, I got married, and in 2017 I went onto my wife's work insurance after a decade on Medicare/Medicaid. Finally, I thought, I can get a new chair. I made an appointment with the seating clinic, only to have the rep shoot my dreams down before I'd even had the chance to open my mouth. I went in there knowing exactly what would work best for me: a custom-fit TiLite TR. I rolled out having ordered a new cushion — the therapist's multi-thousand-dollar, insurance-approved method to keep me making do with the chair I already had. I was pissed — even more so when my left foot started swelling, my spasms worsened, and my low back and neck pain increased.

So began a three-year quest to obtain the right chair for me. On a personal level, the quest proved successful. I sit here today in a chair that is lightweight, durable and well-fitted to me and my lifestyle. It is, without a doubt, the best chair I have ever pushed. But that doesn't mean this story has a happy ending. How I got the wheelchair and who ultimately paid for it reveal a system that is more broken than you could ever imagine.

THE PROBLEM

I first met Dave Knight at a brew pub in Eastern Washington. My editor, Ian Ruder, and I were there to visit the TiLite factory the following day and Knight was showing us around. After an unobjectionable beer, we got to talking about wheelchairs. I told Knight the story of my indeterminably old chair, and how, roughly two years after the beginning of my wheelchair quest, I had gotten nowhere. I'd started working full-time, gone onto my own private insurance and tried everything with them. Could I use an outside vendor? *Sorry, no.* Could I buy the wheelchair and equipment I needed out-of-pocket and have them reimburse me? *Sorry, no, we don't do that.* I was told that my plan had an exclusive contract with the same vendor who'd already shot me down. [see "Vendor Consolidation" sidebar]

Knight is an assistive technology professional with 26 years of experience in the mobility industry, and he's worked for Permobil since 2011. He lives the same problem on the other side of the equation — increasingly getting stonewalled by vendors and insurance companies when he recommends

“When I asked him what it would take to get my insurance to pay for the wheelchair I needed, it touched a nerve. Over his career, he says, ‘I’ve seen technology get better, and at the same time funding keeps getting worse.’”

McBride peruses the goods at the TiLite factory in Pasco, Washington.

anything more than a base model chair and components for his clients. When I asked him what it would take to get my insurance to pay for the wheelchair I needed, it touched a nerve. Over his career, he says, "I've seen technology get better, and at the same time funding keeps getting worse."

He's right that it hasn't always been this bad. Back in the '80s and '90s, there was an innovation explosion in the U.S. wheelchair industry. This was driven partly by better technologies — many of which were adapted from the bicycle and aerospace industries — and also by the recent emancipation of wheelchair users to live more freely in their communities. But there was a financial aspect to it as well. Companies could make money from innovative designs and small wheelchair startups were being bought up, sometimes for significant sums, by major wheelchair manufacturers. Back then, reimbursement from insurance providers wasn't based on a set fee for a certain category of chair — it was based on what that chair cost. "Both Medicare and private insurances would pay for the chair you needed as long as you could show it was medically necessary," says Bob Vogel, a T7 para who has worked in and around the wheelchair industry, both on the manufacturer and the vendor side, since the early '80s.

> "It wasn't just Medicare saying, 'We aren't going to pay for this.' It was them saying, 'We did pay for this' without paying any extra."

But in the 2000s, Medicare significantly tightened up wheelchair reimbursement. Part of it came alongside system-wide cost cutting measures, and another part was due to a couple of high-profile scandals in the industry (damn you, Scooter Store!). For manual wheelchairs, one of the biggest changes was the elimination of a billing code that applied to most chairs more advanced and expensive than a basic, lightweight wheelchair. Codes are the basic unit by

which insurance providers categorize which different products and services are reimbursable.

At the time, TiLite, Quickie and Top End all offered titanium frames because there was consumer demand and because insurances would pay more for a chair made out of titanium. When Medicare eliminated the code that applied to titanium, it lumped all the chairs that were previously in that code into a different one that had a lower reimbursement amount. Not to worry, Medicare said, vendors could still add on upgrades — they just need to bill for those separately. It was annoying for vendors because they had to change how they did things, but they still got reimbursed more for better equipment.

But around five years ago, the Centers for Medicare and Medicaid Services issued a memo stating that way back in 1993, when they originally created all of these codes, they'd already taken titanium into consideration. So providers were no longer allowed to bill for the additional expense. "It wasn't just Medicare saying, 'We aren't going to pay for this.' It was them saying, 'We did pay for this' without paying any extra," says Knight.

By the time I started my new wheelchair odyssey, most private health insurers in the U.S. had already followed Medicare's lead in regard to reimbursement amounts for wheelchairs. Advanced frame materials, custom modifications and upgraded components were becoming rare. The exceptions these days are people who get a wheelchair through workers' comp, or, sometimes, those who have insurance through a union (collective bargaining is a thing) or through a Fortune-500 level corporation with a contract big enough to push back. I didn't have any of those. I needed help.

THE PLAN

Fortunately, I had Dave Knight fired up. And he already had the start of a plan. The idea was to figure out everything I needed, not compromise on quality or what we thought in-

Every chair starts out as long pieces of tubing that have to be cut, bent and welded into form. Titanium generally takes more skill and time to work with than aluminum.

surance would approve, and then have my vendor bill each individual piece separately. If we could force them to deny specific pieces, then we could put the full court press on the health insurance appeals process. With the right team willing to put effort into a lengthy battle, maybe we could get my insurance to pay up. If it worked, for the first time in my wheelchair-using life, I would have a chair perfectly setup for me — and Knight and my vendor would have precedent for the next time someone needed similar equipment.

First step was getting me measured. The next day, after Ruder and I had toured the TiLite factory, we went with Knight and another longtime ATP into a conference room. On the wall were a row of old, framed marketing photos, one of which showed Mark Zupan mean-mugging the camera in a frame that was decidedly newer than the one he'd given me. With Zupan looking down, we started the process, going over every measurement and every component with an eye to how each would affect my day-to-day life.

Caster position was just one example. I currently live in an old house with a teeny, tiny bathroom. To be able to maneuver, I need a frame that is as short possible. But a short frame makes it easier for the chair to tip forward. Multiple times a day I bend over my lap to play with my son on the floor and I'm building a house in the country, where I spend a lot of time wheeling in the dirt. With a chair that's too tippy, I'm likely to wind up sprawled on the ground a lot more than I'd like. One solution is to bring the casters forward, closer to front of the frame, instead of sitting a few inches back like they normally do. This lengthens the wheelbase and reduces forward tippiness without making the chair any longer.

There are dozens of these types of little tweaks that can maximize a chair's safety and performance, and they all vary based on a person's body, injury-level and lifestyle (see "Getting a Good Setup with Bad Reimbursement," page 12). But the manufacturer has to be willing and able to make these modifications — some (though not all) of which require additional time, skill and money.

The less a person knows about chair setup, the more vital it is to find a quality team that can help guide them through the process. I had a lot of experience and came into this with a solid understanding of what I did and didn't want, and I still found it incredibly valuable to collaborate with two knowledgeable ATPs. For that hour we spent dialing in my perfect setup, I felt like I was in wheelchair Shangri-La — choosing equipment based entirely on my body and my lifestyle instead of how much it cost.

But we weren't in Shangri-La, we were in Pasco, Washington, and this fabulous, theoretical chair we'd configured was going to cost a lot of money. We still had to find someone to pay for it.

A box-style frame with fixed back posts is both lightweight and durable, but the only adjustability is in the center of gravity.

SHARING INFO ON LETTERS OF MEDICAL NECESSITY

Have you and your clinician successfully submitted a letter of medical necessity to receive the features and requirements you needed for your wheelchair? United Spinal is collecting stories like yours so we can build a library of language and guidance to help other wheelchair users get what they need.

The letter of medical necessity is a letter written *after* your wheelchair assessment that justifies your need for the specific chair requested to the insurance company paying for your wheelchair. The letter is supposed to be very descriptive about what equipment is recommended for you and why.

We will post a library of language and guidance that will help wheelchair users know what to highlight. Please email your story with the subject line "Letters of Medical Necessity" to advocacy@unitedspinal.org.

THE SQUEEZE

The next step was getting a therapist involved. I'd ditched the seating clinic after my previous experience, and on a friend's recommendation, had found a new PT. I met with my new therapist, and then all together with Knight and the vendor rep. We made a few minor changes based on the therapist's recommendation, and overall, the process was a breath of fresh air. I felt empowered rather than dictated to. It helped that the vendor was already on board as well, knowing the plan to shoot for everything I needed, and be prepared for a long appeals fight with my insurance company.

The appeals process is another reason that it's so valuable to find a therapist who is both knowledgeable about spinal cord injury and passionate about getting you the equipment you need. Insurance appeals are designed to make things tedious and opaque, to take forever and grind you down until you just accept what they're offering. A therapist is usually the grunt worker through the process because they have the knowledge to argue about "medical necessity." To be an effective advocate, they have to have an in-depth knowledge of both SCI and your individual situation, as well as the willingness to engage in a protracted battle.

A month or two after the appointment, my insurance did approve the base items — aluminum frame with no custom modifications, aluminum ROHO backrest and a ROHO quattro cushion, plus a seat belt that I didn't even ask for. But they denied *everything* else, from the expected (like the titanium frame charge) to the WTF (like my casters and basic metal pushrims). The letter gave boilerplate insurance denial speak:

"Your benefit plan covers the basic items needed for your mobility needs. The request for some of the items do not meet your health plan criteria because they are considered beyond the basic need or are not mobility related."

How pushrims and casters could be considered "beyond the basic need" or not "mobility related" was beyond me. I mean, I suppose I could get around pushing only on my tires, but going without casters was going to require some damn impressive wheelie skills. The letter gave no indication of how to appeal, instead offering a peer-to-peer support number that my "physician or

Aluminum wheelchairs account for the vast majority of complex wheelchairs sold in the U.S. Titanium frames like the one McBride is sitting in are increasingly rare.

health care professional" could call to discuss the decision.

When my PT called, they told her that it had to be a medical doctor making the call. This took some wrangling, as my doctor had written me a wheelchair prescription months before but hadn't at all been involved in the specifics. So my PT had to fax the letter of medical necessity to my doctor and then go over all the details. My doctor let insurance know that her being forced to call was ridiculous, as the PT was the expert here. Insurance was unmoved. They wouldn't even discuss medical reasons for why items had been denied, instead telling her that really the problem was with the vendor submitting an unbundled claim.

To understand bundling, we have to go back to Medicare, which first started the policy. The stated intent of bundling was to protect consumers, to make sure that DME vendors couldn't give you a wheelchair frame and then say, "Sorry, Medicare didn't pay for wheels, you'll have to buy those separately." Bundling meant that Medicare gave a provider a set amount, and for that money they had to give you everything associated with the chair: frame, wheels, pushrims, wheel locks, etc.

Today, most private insurers also follow Medicare's bundling policy. This is why my insurance was denying casters and pushrims, because they said that reimbursement for those, along with everything else we'd submitted for, was already included in the base wheelchair code they'd approved.

The problem with bundling is that in the all-consuming

ABOUT THAT BILL

If you ever look at the bill from your CRT vendor, you've probably asked yourself, why is this wheelchair, cushion or backrest listed at more or less double its MSRP? Like everything in the industry, it's complicated, but the short story is that nobody actually pays the price that's listed.

As one source told me, you can think of it as a game between the vendors and health insurance providers: Health insurance companies are always looking to reduce costs. Vendors are afraid that if they list the price of a piece of equipment too close to the existing reimbursement amount, insurance companies will have justification to further reduce payments. That's how I wound up with a manual wheelchair and components with a list price of $19,000.

I'm sure there's some sort of formula that went into that price, but essentially it's just a made up number. What really matters is the number that's listed as "Insurance allowable." That's what insurance pays your vendor and is what your copay amount should be based on. As with anything though, it's worth double checking *before* you sign that bill.

quest to reduce costs, insurance companies base reimbursement amounts for bundles on the most basic items they contain. So the more complex and expensive the options a vendor submits for, under a bundled system, the bigger the loss they take if they provide you with those items. It's like Medicare's memo stating that they'd already paid for titanium without paying any extra, only at a system-wide level.

"If you're going to set pricing on groups of products, you have to do it in a way that's rational," says Don Clayback, the executive director for the National Coalition for Assistive and Rehab Technology, which represents both complex rehab technology manufacturers and suppliers. Clayback says that an insurance company gives vendors a set price. The vendor might be willing to take a $20 loss on a specific item because they can recoup the cost elsewhere, but when the difference is hundreds of dollars or more, they start to say, "I can't do it." In this case, it's hard to fault them — they are businesses after all. Try going into Best Buy and asking them to give you an 80-inch TV for $50 and see what happens.

Now, you could blame manufacturers, but manufacturers have already been squeezed in this system as well. Margins are slim and keep getting slimmer. TiLite is owned by Permobil, a Swedish company that is owned by a big Scandinavian investment company. Quickie is owned by Sunrise Medical, a German company that is owned by a different Nordic investment company. Invacare, based in Ohio, is a multi-billion-dollar, publicly-traded company owned primarily by private equity firms. Wheelchair manufacturers are part of enormous, global corporations because if you're going to do business with the U.S. health insurance industry, the economics of scale are the only economics that work. Manufacturers know exactly how much an insurance company will reimburse for a chair, which leads to a world, as Vogel puts it, "where instead of designing a wheelchair to maximize ability, sadly you're designing it to fit into a funding category."

THE KICKER

As we tried to figure out how to appeal the insurance company's decision, they threw another wrench in my spokes — sending me a letter stating that starting in a few months, they would no longer cover me as my primary insurer because I was eligible for Medicare Part B. I was shocked. I had gone off Medicare because I was working and would have to pay out of pocket to retain it. I didn't currently have Medicare Part B, but because I was disabled enough to qualify for it, insurance was refusing to be my primary coverage. Seriously?

However legally dubious this policy was, I didn't have time to fight it before I got kicked off coverage. My employer, United Spinal Association, agreed to cover my Medicare premiums while we figured out what to do, but once July 1 came, I would be back on Medicare, and there was no way Medicare was going to pay for the wheelchair we'd submitted for. It was already the beginning of May and we couldn't appeal my current insurance company in time to still get a chair. I threw in the towel and asked the vendor to get me an out-of-pocket price for all the upgrades.

SELECTING A NEW MANUAL WHEELCHAIR? THERE'S AN APP FOR THAT.

When it comes to selecting a manual wheelchair, one size does not fit all. My Wheelchair Guide mobile app makes choosing the right wheelchair easier by guiding you through your self-assessment and maintenance checklists, and it also includes customizable to-do lists and helpful wheelchair skills videos.

The app was created by United Spinal and University of Pittsburgh, with the help of a grant from the National Institute on Disability Independent Living and Rehabilitation Research. Look for Manual Wheelchair app 2.0 to come out this year, and power wheelchair information will be released soon, as well. If you would like to assist with accessibility and usability testing, please do not hesitate to contact the advocacy team at advocacy@unitedspinal.org.

Search "MWG Manual" in Google Play or Apple's App store to download and learn more at unitedspinal.org/my-wheelchair-guide.

A few days later, I got an email from the vendor, telling me that "due to contractual obligations" they have with my insurance company, they had to get upper management involved. A few days after that, I got a call from the vendor's vice president, who apprised me of the situation: a few years ago, they signed a contract with my insurance company agreeing to the bundled pricing. My insurance company claims that this pricing pays for everything a user needs, so they are not allowed to charge me private pay for any upgrades. Even though there was a multi-thousand-dollar difference between what my wheelchair cost and what insurance would be paying, they would provide me with the chair. [See "About That Bill" sidebar]

Wait. What? I was really getting the chair? Yes, it was true.

Three years after starting the process and 15 years since I'd last had insurance pay for a wheelchair, I was finally getting a chair configured to maximize my function and maximize my daily life. The messed-up thing was that I felt dirty about it. Sure, it was great for me. But would any of this have happened if I wasn't a writer for a national magazine for wheelchair users — someone who had both connections and a platform? In fact, I already knew what happened when a member of the general public goes into a seating clinic and asks for the good stuff: The vendor says, "Sorry, your insurance won't pay for that."

But as I've talked to people in the industry, I've learned that while "your insurance won't pay for that" is often true, it can also be misleading. Many of the major CRT vendors across the country have been forced to sign something of a devil's bargain. Insurance companies claim they're paying for everything you need, and major CRT vendors have signed contracts saying as much.

Find a PT and an ATP who are willing to fight for what you need. Don't let the vendor dictate the process. ATPs have to sign a code of ethics that puts your welfare, not the vendor's, paramount. If a vendor tells you your insurance won't pay for something, make them prove it. Tell them to bill your insurance for what you need and see what happens. Cushions and backrests can be billed separately and are subject to different rules, but frame materials and modifications, wheels, pushrims and casters are typically all included in a bundle. As a vendor source, picking his words very carefully, told me: "If [a therapist] wants particular products, we have to meet those products."

VENDOR CONSOLIDATION

It's hard to miss: There are a lot fewer complex rehab technology vendors than there used to be. Similar to the reasons why wheelchair manufacturers are part of behemoth corporations, consolidation of vendors can be traced back to shrinking profit margins. As CMS and private insurers have reduced reimbursement amounts, smaller vendors have had a hard time staying afloat. Many have either gone bankrupt or been bought up by bigger vendors. At this point, we're at the stage where wheelchair users in many markets only have the "choice" to use one or two of the big, national CRT vendors.

With fewer and fewer companies left, and those that are left having to continually tighten their operations to make a profit, it's no wonder that customer service satisfaction continues to decline, while sales and repair wait times continue to rise.

THE RIGHT CHAIR

On June 30, a single day before my insurance deadline, I finally got my wheelchair. The moment I first transferred into it was surprisingly anticlimactic. After the mythical proportions this quest had taken on, I would have expected a revelation. Instead, it felt like, well … a wheelchair. It didn't even feel perfect. That would come later — after I fine-tuned the pressure distribution in my cushion, tweaked and retweaked the backrest height and angle, and tried, unsuccessfully, to raise my front seat height after falling face first into a pile of Transformers. After so many years of making do, it felt a little weird, but I called Knight for help.

He came over with a vendor tech, and after some mucking about, he realized that his usual tricks didn't work and there was something off with my caster position and seat height, likely due to an error in the customization process. A few days later, he called me back and let me know that any potential solutions would cause problems elsewhere, so TiLite would be making me a new frame.

Even with a few errors, the first frame felt good. But the remake is everything I could hope for. It's comfortable to sit in. I can push miles in the city without my shoulders or neck hurting, and the front casters float over grass and dirt when I'm out in the country. When I run errands, I can lift the frame into the car without my bicep feeling like it's about to detach from my shoulder. Titanium and carbon fiber may seem like a luxury, but not when you're trying to keep your body from imploding by the age of 40.

Some wheelchair users really only need basic equipment. But for many of us — active wheelchair users who are trying to squeeze as much out of our limited function as we can — lighter components, more durable materials and customized seating can make all the difference. Maybe someday our medical system will recognize this. Until then, we're going to have to keep fighting for what we need. NM

VetsFirst is a program of United Spinal Association that assists veterans and their eligible family members in obtaining the benefits they are entitled to, deserve and need.

Our Mission

VetsFirst leads the way in advocating for veterans living with disabilities and ensuring they achieve the highest level of independence and quality of life.

Our History

As a program of United Spinal Association, VetsFirst has a long and illustrious history assisting and representing veterans and their eligible family members. United Spinal—a VA recognized veterans service organization—strives to ensure the organization remains an instrument for veterans.

About VetsFirst

VetsFirst brings to bear seventy years of expertise in helping America's veterans with disabilities, their spouses, dependents, survivors and other eligible family members receive health care, disability compensation, rehabilitation and other benefits offered by the U.S. Department of Veterans Affairs. We supply direct representation, proactive legislative and regulatory advocacy, individual support and counseling services, guidance on education and employment, timely news and information and valuable self-help guides.

VetsFirst advocates nationally for all generations of veterans, including individuals living with post-traumatic stress disorder and traumatic brain injuries. Our advocacy efforts go far beyond offering words of support and encouragement. We take this fight to Capitol Hill to bring attention to issues that matter most to the men and women who proudly served our country.

Timely Support

We connect with thousands of veterans and active military servicemen and women annually through our call center and online help desk, **Ask VetsFirst**. Our staff takes the time to address each inquiry, offering guidance with questions on military separation, claims appeals, and state benefits. Visit http://helpdesk.vetsfirst.org/ to submit your questions and receive quick response from our knowledgeable staff.

Valuable Resources

In addition to providing individual support and counseling services, VetsFirst offers timely news and information across the spectrum of issues presently impacting the veterans community, including state benefits, separating from the military, as well as exclusive feature stories on military health care and VA funding and compensation.

Our Core Beliefs

VetsFirst's priorities are based on three core principles that will improve the lives of veterans with disabilities.

Community Integration and Independence— We support policies that help veterans with disabilities reintegrate into their communities and achieve independence.

Timely Access to Quality VA Health Care and Benefits— We support improved access to VA health care and compensation and pension benefits that are the lifeline for many veterans with significant disabilities.

Rights of Veterans with Disabilities— We believe that discrimination against disabled veterans that produces barriers to housing, employment, transportation, health care, and other programs and services must be eliminated.

AUTI ANGEL

IN HER OWN WORDS AND ON HER OWN TERMS

BY JERRY MCGILL

When Auti Angel and I meet for this interview, it is via Zoom, and she instantly reminds me of a character out of a futuristic superhero movie. She wears a sleek black blouse, and her hair is fire red. I get the impression that she might be going out clubbing after our talk, but she assures me it is all for her Instagram appearance later that evening.

A review of her Instagram account shows her offering online hip-hop dance classes, appearing in a music video for Demi Lovato, photos of her posing with mega-stars like Snoop Dogg and references to the critically-acclaimed reality show she's best-known for, *Push Girls*.

Like many celebrities today, she is continually developing her craft.

BORN TO DANCE

It was always Angel's plan to be in show business, but as with so many of her contemporaries, her path was filled with unexpected potholes and valleys. She was born in San Diego and grew up in Torrance, California. She came from a family that, although not without its flaws, was loving and stable. Her mother was English and her father was Peruvian and Mexican. He was a huge follower of Bruce Lee and instilled that "always be a fighter" sensibility in his daughters.

Auti Angel attends the Sundance Channel's "Push Girls" Pop Up Event at Times Square on May 31, 2012 in New York City.

Photo by Cindy Ord/Getty Images

Angel had a flair for dance as far back as she can recall, doing salsa at 2 years old. When she was around 6, she saw a beloved uncle dancing vivaciously to disco singer Sylvester's "You Make Me Feel," and that was when she knew dancing was her passion — and she pursued her profession with vigor. "There was no plan B," she says.

Although her family was loving, they couldn't protect her from harm. "I was very insecure as a young girl, going through child abuse," she told HuffPost's Elizabeth Kuster in 2012. "Physically and sexually." When Kuster expressed sympathy, Angel assured her that, "It's OK! That's what made me who I am today. Had my life been so peachy keen, I would not have learned how to fight through all of my obstacles — including becoming paralyzed."

Angel moved out of her family home at age 18, and the next couple of years were a mixed bag of mild successes and great disappointments. A woman close to her told her she had such a great body that she would make a good stripper. Needing the money, she gave it a go, but that career only lasted about a week and a half. "I hated it," she says. A few months later she married a man who constantly abused her. In one harrowing experience, he damaged her face so badly that she hid it with extra makeup for an audition she had the next day.

THE ANGEL FALLS

One morning she realized she could not continue on with the abuse and found the strength to leave her husband. As she struggled to find her way into the music entertainment world, she made a few connections in the industry. She gained major headway by touring with Eazy E, NWA and LL Cool J, while also dancing in music videos. "I loved that lifestyle, and we were every bit like a real family," she says.

It was difficult for her to pay the bills consistently as the member of a touring dance crew, and Angel recalls an extremely low point in her life occurring right around that moment. "I really needed only $500 to pay my portion of the rent, and I went to a guy who was a trusted friend at the time

Photo via Instagram @Autiangel

to borrow it. He wound up offering to give me the money, but only if I slept with him. Feeling stuck between a rock and a hard place, I did it," she says. "I did what I needed to do to make sure my roommates didn't get evicted because of me."

That moment was heavy on her mind the afternoon that a hit-and-run driver struck her vehicle, causing it to spin out of control, hitting the center divider head-on and injuring her spinal cord at T10. She was 22 years old. Soon after, she lost her mother — who she says was the most important person in her world — to breast cancer.

Angel recovered physically in good time, but the emotional wounds were profound and enduring. She soon returned to much of her previous routine of clubbing and socializing, but she had chronic pain and severe bouts of depression after losing her mother. She also worried her romantic life might be severely affected, and that others would no longer find her attractive. She started hanging out with the wrong crowd, was introduced to crack cocaine and remained addicted to the drug for nearly two years.

"It's funny because all that time touring in the hip-hop world, you know weed was around me a lot, but I was never really that into that," she says. "But after my car accident and losing my mother, I had all of this pain, physical and emotional, and I needed something to help me through it."

FINDING FREEDOM IN JAIL

Eventually her drug abuse landed her in county jail, where someone handed her a Bible. The first passage she opened it to was Romans 8:18:

"I consider that our present sufferings are not worth com-

Photo Courtesy of Sundance

From left to right, the original Push Girls are Mia Schaikewitz, Auti Angel, Angela Rockwood and Tiphany Adams.

paring with the glory that will be revealed in us."

This verse proved to be a veritable life-changer for her, and she embraced the concept of self-determination. She recalled her father's fighting spirit, and she willed herself to turn her life around. At the same time, she opened her heart to the presence of God in her life and attributes any successes she has had to God's love for her.

While speaking with Angel, I find religious references sprinkled throughout her conversation, but I never get the sense that she is trying to convert me. The presence of a higher power is clearly a strong motivator in her life, and one in which she takes great value and pride. "God gave me a gift to teach with love and compassion. I have personally witnessed many miracles and I am forever thankful," she says.

Angel has numerous opportunities to reach a wide range of people through a motivational speaking platform, and she encourages those she meets to "push the limits of life." She genuinely believes, "No matter what obstacle you face in life, they are all able to be overcome. If you have a heartbeat and breath in your lungs, artificial or not, you have purpose!"

THE PUSH GIRL YEARS

One of the brightest moments of Angel's career came with a starring role in the 2011 romantic comedy, *Musical Chairs,* directed by the *Desperately Seeking Susan* director Susan Seidelman. At first Angel was dismayed with the film when she realized it called for several characters who use wheelchairs but that few of the parts would go to actors who had true disabilities. She met with the director to voice her concerns and coached the actors portraying wheelchair users, including her friend Laverne Cox – who is known for her starring role as a transgender woman, Sophia Burset, in *Orange Is the New Black.* Angel believes it was a meaningful learning experience for all involved.

The following year brought her breakthrough, as *Push Girls* began in April 2012. During the two-year run of the groundbreaking reality show about four women wheelchair users seeking the good life in Los Angeles, it became clear early on that all of the women on the show were intriguing and appealing in individual ways. For Angel, it was her slick fashion sense, engaging backstory, and intriguing personal life that compelled viewers to eagerly tune in and follow her on a weekly basis.

The show came about from her authentic friendship with creator Angela Rockwood, and co-stars Tiphany Adams and Mia Schaikewitz — three other women with SCI who shared a common goal of changing the world with their experiences. It was originally entitled *Chairlie's Angels* (get it — Chair-ly?), and it was unlike anything else on television at the time. Its odds of success seemed unlikely, but once a few producers at Sundance got hold of the concept, they decided it was too unique to pass up. They renamed the show *Push Girls*, which was a natural fit for both its literal and symbolic reference to life from a wheelchair user's perspective.

During the course of the reality show's two-season run, Angel was all the things we've come to cherish in this medium — she was brash, outspoken, daring, charming, sexual, confrontational, vulnerable, pulsing with vitality and confidence. It was hard to look away whenever she was on the screen.

While *Push Girls* was on the air, LL Cool J called her out on stage at one of his concerts. "Once I finished, I rushed off to tweet about my awesome experience," she said in the comments of her August 6, 2013, YouTube clip. "All of a sudden, he called me out once again and whispered in my ear, 'I'm so

Auti mugs for the camera with legendary rapper Snoop Dogg.

Photo via Instagram @Autiangel

proud of you!' and that will forever ring in my soul as God's confirmation that I am on the right path!"

She seemed to have everything — booming personality, flashy wheelchair, great fashion sense, admirable career as a choreographer and her own wheelchair dance team, Colours 'n Motion, that she founded in 2003. Not to mention she also had a handsome, extremely supportive partner at home, her husband, Eric. Today, although Angel and her husband have separated, they are still friends and she remains optimistic and confident about her future in this ever-shifting landscape of modern entertainment.

At age 51, some 28 years after her accident, Angel is still in the game. Despite having had recent surgery to repair a collapsed disc, she is in the studio working on a hip-hop album that she hopes will debut sometime this summer. But, as many can attest, aging is rarely easy or graceful.

"It sucks aging at any ability level, yet it *really* sucks aging with a disability," she says. "My advice to the next generation is take care of your bodies as much as possible. Appreciate what you have, while you have it. Balance — and everything in moderation — is key."

For the woman who once referred to herself as "JLo before there was JLo," there simply is no time to slow down. As she once philosophized in a moment from season one of *Push Girls*: "If you live for hope, life passes you by ... so dance 'til the wheels fall off."

AUTI ON INSTAGRAM

@AutiAngel: Auti Angel's Instagram is where some lucky fans scored invites to a Zoom party with Angel and the other Push Girls at the end of February. Watch it regularly for info on how to sign up for hip-hop classes with the wheelchair dancer and, if you love '90s hip-hop, you'll want to see her dancing to Salt 'N' Pepa and the classic photos of her with Jamie Foxx, Usher, Snoop Dogg, LL Cool J and many more. This account is a GenX who's-who without the grunge.

Although Angel keeps up a presence on Twitter, Facebook and YouTube, her Instagram account is the most active and fun to follow. Be sure to visit her website, autiangel.com, as well.

RESEARCH IS BETTER WHEN PEOPLE WITH SCI HELP DESIGN IT

BY STEVE WRIGHT

Jen French

Bonnie Richardson

Anita Kaiser

Photo by Chris Chapman

For far too many years, spinal cord injury researchers have failed to include disabled people in their studies as anything but subjects. Fortunately, that's changing as more people with SCI/D participate in consumer advisory boards and other human-focused approaches. They are designing surveys, focusing on goals and giving key input *before* a solution that impacts them is completely designed and ready to submit for approval.

Whether it's creating products, designing treatments or collecting data, people with SCI are increasingly involved in all aspects of research. Their vast experience, expertise and real-life knowledge are informing approaches — before funding is wasted or unrealistic conclusions are reached.

IT TAKES A TEAM

Bonnie Richardson, a C5-6 incomplete quad from Sequim, Washington, is not a scientist. But she is listed as an author on a study that appeared in the November 2020 *Spinal Cord Series and Cases* journal that looked at how people with SCI access information about experimental therapies and clinical trials. She worked alongside scientific researchers whose careers are built on studying SCI, helping to create a survey and analyze the results. "The goal was to gain a better understanding of how people living with SCI get their information," she says about the North American SCI Consortium-sponsored research.

Richardson praises NASCIC's engagement program, which connects projects requesting input or involvement from people living with SCI to willing participants. This human-focused approach allows those who will benefit the most from the research to play an active role in designing the studies, "rather than just be data that is measured and manipulated," says Richardson. "When considering our individual abilities and challenges, we are the experts. When researching something for our community, collectively we have invaluable real-life experience to contribute."

It takes a team to make a successful product, treatment or service — and teammates who will be end-users play an especially important role in making the end result a success. "People with SCI are living the life every day. We know what has and has not worked for us in the past. We also usually have a good understanding of what would have made it more usable," says Richardson. "If designers utilize an advisory board of people with SCI, they can save tremendous time and money by not repeating these same design issues. The earlier the board is consulted, the greater the success and savings."

More professionals need to be open to having an advisory board of people with SCI at their disposal, Richardson said, noting most participants are willing to donate their time to improve products and services for their community.

This is where advocacy groups like Unite 2 Fight Paralysis come in. Its network has directed, trained and supported advocates in multiple states to push for legislation to fund community advisory board-based clinical studies. These studies have resulted in more than 40 people with SCI receiving interventions to pursue functional gains.

"Laypeople gain a deeper understanding of the research and the researchers gain a deeper understanding not only of the lived experience, but also the end goals articulated by representatives of the SCI community," says Matthew Rodreick, the group's executive director, about how including people with SCI from the ground up benefits all involved.

FOR BEST RESULTS, CONSULT END-USERS FIRST

Dennis Bourbeau, a research investigator at the Cleveland FES Center, asserts that including people with SCI at all stages of a study is effective problem solving. Also, it could save investors a large amount of time and money.

"As an engineer, I think in terms of first developing a good definition of the problem, and then understanding the elements of what would be considered

Jeff Weldon

a successful solution to that problem," says Bourbeau. "Developing the solution itself should come after these first two steps. It is critical to include all stakeholders, especially individuals with SCI, at all points of this process, not just with evaluating a potential solution that was defined by the other stakeholders."

For example, the FES Center wanted to better understand how mild electrical stimulation of certain nerves can improve bladder and bowel function. "Before investing a large amount of time and money in this direction, we asked individuals with SCI about how they manage their bladder and bowel, what their priorities for functional recovery were and whether they were even interested in an approach that used nerve stimulation," says Bourbeau. "An independent advisory board helped craft the questions and helped us interpret the feedback that we received."

The results were published in the *Spinal Cord* journal, where clinicians can find them and potentially use them to improve the quality of life of people with SCI they see in their offices.

Bourbeau believes that including people with SCI in the research enterprise, along with asking them to assist defining the problems and parameters for successful solutions, is key to achieving research and clinical breakthroughs. "The community of people living with SCI is savvy, motivated and well-organized," he says.

HOW TO BECOME INVOLVED WITH NASCIC

BY JANE WIERBICKY

United Spinal Association is a Principal Member of the North American Spinal Cord Injury Consortium, whose mission is, "to bring about unified achievements in research, care, cure and policy by supporting collaborative efforts across the spinal cord injury community."

NASCIC advocates for the involvement of people with SCI in all aspects of research — care, cure and policy. For example, in research, NASCIC aims to include the perspectives of people living with SCI not only as research subjects, but also to help inform study design, study implementation and dissemination of results. The consortium allows for stakeholders to work collaboratively to bring about change. One of the ways this is done is by working together for projects approved by the project review committee, on which I currently serve. We review proposed projects to ensure they meet the following criteria:

- Form relationships between the individuals and organizations representing SCI;
- Exchange valid, trustworthy and useful information, experience and knowledge;
- Promote best practices in research, treatment and care;
- Create or strengthen a unified voice for SCI in North America;
- Promote collaboration among experts in the fields of research and/or clinical care and/or advocacy;
- Impact the lives of people living with SCI;
- Meaningfully and actively engage people with SCI.

If the PRC approves a project, it is sent to the executive council for a vote. If the proposal is accepted, NASCIC expects to be fully involved and an equal partner in all project activities and decisions.

There are three types of NASCIC memberships: Principal, Patron or Partner. There is no cost for people with spinal cord injuries to join NASCIC as Patron members. Since United Spinal Association is a consumer organization, it is a Principal member. You can learn more about these levels, including a link to join NASCIC at nasciconsortium.org/membership.

Patron members can register for NASCIC's Project Engagement Database to be considered as an advisor/advocate on SCI projects that NASCIC is involved in at nascic.wufoo.com/forms/nascic-project-engagement-database. By serving on a project, Patron members ensure that the perspectives of individuals with SCI are included. A list of some of the projects that NASCIC is, or has been, involved with — including one proposed by United Spinal Association — can be viewed at nasciconsortium.org/projects.

Patron and Principal members are also engaged in other ways, such as through involvement in the PRC. The majority of the PRC members live with spinal cord injury or are family members. Fellow United Spinal Association employee Jose Hernandez, C5, recently joined the executive council. Each Patron member has the right to attend the annual meeting of NASCIC members where they have one vote, which is self-representing.

Jane Wierbicky is the nurse information specialist for the United Spinal Resource Team.

"Funding agencies and regulatory institutions are actively seeking their input and encouraging researchers to include individuals with SCI as important stakeholders, which helps to incentivize the researchers. I think that researchers should see more examples of how an inclusive research model is successful and be given the expectation of adopting this research model if they plan to conduct translational work." Translational work describes projects intended to actually benefit real people, rather than satisfy a scientific curiosity.

PEOPLE-BASED TRIALS

Jennifer French wrote the book on what it's like to participate in a clinical trial. Called *On My Feet Again,* the 2012 publication includes her experience of testing an implanted neuro-prosthetic system that enables her to stand. French, a C6-7 quad, is vice president of the North American SCI Consortium and executive director of the Neurotech Network.

"When you think about how smart phones were designed, they have a full division of experts focused on the user," says French, who lives in St. Petersburg, Florida. "Before anything is done, they gather input from the people who are going to use the finished product. Contrast that with traditional medical research, where they rarely talk to the end user until clinical trials."

French says the $6.3 billion 21st Century Cures Act, enacted in 2016 and allocating $4.8 billion to the National Institutes of Health for precision medicine and biomedical research, helped shift the model from old-guard exclusionary research to present-day end-user input from the ground up. Pharmaceutical companies were among the first to embrace the concept of participation by people for whom the products and treatments were designed because there is a financial gain in avoiding expensive trials that fall apart from lack of enrollees.

"When you design a trial, if it is not

7 WAYS LIVED EXPERIENCE IMPROVES SCI RESEARCH

Much has changed in the 10 years since Anita Kaiser, a doctoral candidate at the University of Toronto and a research trainee in the SCI Mobility Lab, first entered graduate school. Then, she received pushback from her advisors who feared her C6-7 complete SCI would bias her data collection and analyses of that data. But now, "Research has been slowly shifting to include individuals with lived experience of a specific illness/disease/condition in the decision-making process from start to finish," she says.

Kaiser said this positive shift is an important step forward because building a strong partnership between the SCI and research communities can enhance the quality of the research and improve outcomes.

"People with SCI are experts in our own right by virtue of our lived experience. What we have to say matters and can directly influence the direction of research priorities, as well as how projects are designed and administered," she says. "I recognize the dual role and unique perspective I bring as a person with lived experience and the value of that in producing high quality research that reflects the priorities and needs of the SCI community."

Kaiser says when people with SCI drive research, they focus on reduction and treatment of secondary complications, improvements to quality of life and accessibility as well as finding a cure for paralysis. Here are seven ways she says incorporating the lived experience of people with SCI makes research better:

1. We add relevancy, helping to define research questions. Our presence ensures research is focused in areas of importance to us and that it addresses a need or gap in care or service or explores a novel treatment or therapy that leads to neurorecovery. NASCIC and the SCI Alliance are made up of multiple stakeholders, including people with lived experience of SCI whose mandate is to set priorities for research.

2. We can assist with recruitment of participants in studies, which is something many scientists struggle with. An interesting study on a relevant topic with potential to benefit the participant sells itself and can spread like wildfire through our community.

3. We can aid with research design and implementation so that the project is feasible and researchers can collect the data they need. We can identify flaws in a research design that could lead to lost, missing or unreported data. A well-designed study would make recruitment/retention/compliance less challenging. This can be the difference between a successful study and a failure — particularly when developing devices or products that align with needs.

4. We can help interpret results. A well-designed study means the results would be meaningful and applicable. Whether it's an early-stage study that tells us which direction to focus on, or late-stage research where we can take something and apply it to practice, even negative results are successful because they tell us what not to do.

5. We can disseminate results so others learn about the latest research and help advocate for policy change, or implementation of new treatments/therapies.

6. We can advocate and move research along at a faster pace. Rather than wasting time investigating every nuance, the research can take what we need and move on to the next step.

7. We can support fundraising efforts to secure research dollars.

Learn more about the SCI Mobility Lab, located at the Toronto Rehabilitation Institute's KITE Research Institute, at sites.google.com/view/scimoblab/home. And go to kite-uhn.com to follow KITE.

Photo by Tyler Croat

The Unite 2 Fight Paralysis team includes wheelchair users (L-R) Kelsey Peterson, Mary McMenamy and Jake Beckstrom.

people-based, it has a higher probability of failure," says French. "Embedding the voice of experience can totally change the way therapies, devices and delivery of biologics is done. It's about understanding the way we live our lives."

Jeff Welden, a C3 quad from Long Island, New York, agrees. "I'm on a community advisory board developing a brain-machine interface," he says. "The CAB's brainstorming and troubleshooting forges a relationship where the project's team manages advanced planning rather than corrective reaction. Utilizing the skills we have acquired as natural problem solvers is a surefire way to improve result efficacy, community acceptance, available usefulness and impact of the project's result." NM

RESOURCES

- Canadian Spinal Research Organization, csro.com
- FES Center, fescenter.org
- Neurotech Network, neurotechnetwork.org
- North American SCI Consortium, nasciconsortium.org
- On My Feet Again: My Journey Out of the Wheelchair Using Neurotechnology, by Jennifer French, available at most online booksellers.
- *Spinal Cord Series and Cases* journal, nature.com/scsandc
- *Spinal Cord* journal, nature.com/sc
- Unite 2 Fight Paralysis, u2fp.org

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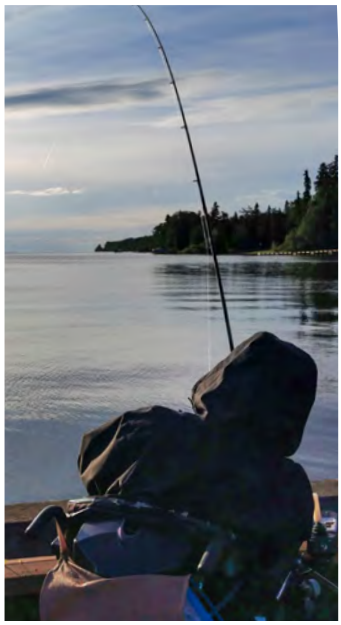
By Kary Wright



Kary and Terry Wright (above) caught 15 walleye on their first spontaneous trip after a life-changing fire destroyed everything they owned.

WILD ABOUT WALLEYE

In July, after a few months recovering from a devastating fire that took nearly everything we had, my wife Terry and I were just starting to get back to a sense of normal. We purchased a wheelchair-accessible van, and although I couldn't drive it yet, the freedom was incredible after being so immobile for so long. I had started to replace my things and had just purchased a spinning rod. I was dreaming about fishing and more normal days in the future.

As if on cue, Terry heard from her friend Danelle. She was camped on the south side of Slave Lake in Northern Alberta, Canada. She said the walleye were biting incredibly well right from shore, and there was a pier that was great for wheelchair access. A quick Google check confirmed that we were a four-and-a-half-hour drive from Slave Lake. It was already 3 p.m. on a Friday afternoon, a little late for us under normal circumstances, but level-8 boredom was setting in.

Terry suggested we book a hotel near the lake for the night, noting she could have us packed in 10 minutes. One thing about owning next to nothing, it makes the nomad life easy. We had nothing going on, nothing to lock up or put away. We were basically in limbo with not much to do and nothing to do it with.

By 3:30 p.m. we had our one fishing rod, a change of clothes, bathroom bag and dog packed, and we were heading North. We really needed a break.

"Well, this is spontaneous," I said with a grin.

"Yes, feels like fun!" replied Terry.

We had hardly thought about having fun since the fire, and a spur-of-the-moment trip was just what we needed.

Memories and Anticipation

The drive was so refreshing after not going anywhere for a long while. Green scenery lined the road, as heavy rains had obviously helped farmers' crops. As we got farther north, the land gradually changed from farmland to a more rugged landscape with coniferous trees and rolling hills and more wildlife, including bald eagles and deer.

As we approached the lake, the scenery reminded me of a fly-in fishing trip that I went on with my father and a friend. I daydreamed about the landing in the town of Slave Lake, where we proceeded to refuel and take off to a more remote airstrip. We caught so many walleye and northern pike on that trip that we had to fillet them so we didn't overload the plane. I reflected on how

grateful I was for those wonderful times with my dad, and I wondered if the fishing was still as good 35 years later.

We pulled into town, checked into our room and got back on the road for the 20-minute drive to Danelle's campsite. We turned at the sign and pulled in to see the lake. It was huge! The campground was on the left, with a boat launch and breakwater that I could fish from just beyond. It looked perfect.

We exchanged hellos with Danelle, unloaded from the van, and walked down to the breakwater. Unsure of local protocol, I asked where we could fish.

"Right here, you can park wherever you want. We'll fish by the van," said Danelle's daughter Kacie.

"Do they bite well?" I asked.

"Yes, people catch walleye and pike all day."

"What time should we come?"

"At daybreak, then you'll get the good parking," said Kacie.

"And you'll be up?" I asked sarcastically.

"No problem," she replied with a grin.

We visited at the campsite for a bit, then headed back to our room to set the alarm and go to bed.

Early Morning Success

The alarm woke us up at 4:30 a.m. We grabbed a muffin and coffee at the drive-through shop next to our site and set out. By a little after 5 we had arrived at the breakwater and secured the choice fishing spot. There was nobody around.

We assembled our tackle as Danelle and her partner, Ken, pulled up. Soon Ken had a pickerel-rig tied to my line. With a weight on the bottom, it suspends two minnows above the lake bed. Walleyes love minnows.

"Can you cast mine? Then it'll get out farther and I won't lose the bait," I asked.

"No problem," said Ken as he grabbed my fishing rod.

Terry strapped the rod to my arm. Then Ken set her up with a fishing rod that had the same rig.

There is something about the anticipation of getting a tug on your line. We kept the line a little tight, so it held the bait off the lake bottom. I was on high alert watching the rod tips for action. My tip straightened and slowly bent as the line tightened, a sure sign of a bite. I waited a few seconds to make sure the fish had it, and then sharply raised the rod to sink the hook. A solid tug, and the fight was on.

I tried to grab the reel, which wasn't quite adapted correctly for me yet, and slowly started reeling in.

"Sorry I'm slow, there's a little work needed so I can reel better," I said.

"No problem, you can enjoy the fight longer," said Terry.

I eventually got my catch close to shore by pumping the rod and reeling in on the downstroke. Kacie finally showed up to much teasing and helped me net the fish — a walleye weighing several pounds. She took the fish off, baited my hook, cast out and strapped the rod to my arm.

In all, Terry and I caught about 15 nice walleye, and I can say they are the best-tasting fish ever. What an incredible day. I'm ready for more action.

OWN IT

By Regan Linton

> "I sometimes wonder, what if my friend's first reaction had been one of affirmation and curiosity? What if she said, 'Omigosh, you are going to have such an amazing opportunity to explore your sexuality.'"

OUR BODIES AREN'T BROKEN ... JUST UNIQUE

People said a lot of things to me after I was paralyzed in a car accident 19 years ago. But amid *how sad* and *God has a plan for you*, the comment that left the biggest impression came from one of my closest college girlfriends: "I'm so sorry you'll never get to orgasm with a guy." Her immediate layperson assumption was that paralysis would negatively impact my physical stimulation and therefore obliterate any future chance for the genital response we call "orgasm."

At the time, it felt like a gut punch. In just a few unplanned words, my friend, however unintentionally, had effectively planted a seed in my mind that my future sexual experience would be diminished. Less than. Never as fulfilling as it would have been if I hadn't been injured. And looking back, it pisses me off that just a few uninformed words had so much power over determining how I would proceed through the next several years to view myself as a sexual being.

Now mind you, sexuality had never been my greatest priority as a young person. Sure, it was on my mind, but for several reasons my teenage self wasn't particularly drawn to sowing oats. I felt uncomfortable with sexual objectification by teenage boys, instead asserting my value of intellect, humor, and, well, everything else. The Eastern philosophies to which I was drawn regarded physical desires as rather ephemeral and superfluous. I was very protective of my body, and the concern about STDs or sexual assaults outweighed my desire to satisfy curiosities. And with a busy schedule of soccer, theater, choir ... let's just say it was not *Fast Times at Ridgemont High*.

But since I was surrounded by hormone-charged adolescent culture, my lack of interest in sexual experimentation often made me feel rather alien. Deep down I knew that what I was seeking just wasn't what was being offered in a high school context. But social messages made me feel like I was the problem ... I must be broken.

So it was icing on the shitcake when, at age 20, I found myself feeling even more broken, perhaps irreparably. Like so many in my position, I was bombarded with disempowering narratives that implied that bodies like mine — with atrophy, scars, catheters, ventilators and wheels — aren't desirable, and therefore we and our partners can never have a *truly* fulfilling sex life post-injury ... it will always have a handicap. There will always be some supreme version of sex that is now unavailable to us.

The problem is, the external sources dictating what is possible come from a nondisabled perspective — people like my friend, who have no idea what it actually *is* to be paralyzed, disabled, etc., and can only imagine it and fear it. They are themselves being fed a "standard" version of what sexuality and intimacy look like, which, let's be honest, is predominantly crafted around the profit that can be derived from people feeling inadequate. Alternative narratives get drowned out.

We're told that our "way in" to sex, orgasm, arousal, and sexuality has been cut off — that we can no longer be sexual beings, because our bodies don't fit what sexuality looks like. And sadly, we often accept this assessment. We judge ourselves, thinking we are broken and inadequate if we don't get wet like we're "supposed to," aroused like we're "supposed to," or can't move the same way, respond the same way. Adding a partner to the mix makes it even more complicated, as partners can get overwhelmed and discouraged by what they don't understand. The unknown territory can make us all feel like failures. It can be tiring, and we just want a "simple" and familiar response.

But our sexuality *is not broken*. We just don't have the right popular models to illustrate what it can look like when we have to adapt or when things change. And our popular understanding of sexuality, pleasure, intimacy, arousal and the like has been consistently bastardized over time, leaving us with a substandard and incomplete understanding of the full complexities of what is possible for our bodies.

As Emily Nagoski lays out in *Come As You Are* — a book every person should read, disability or not — we have all been duped in how we think about our bodies and their sexual capacities. Too many of us believe we are broken simply because our pathway to pleasure doesn't look conventional. Through a scientific lens, she reminds us of something we often forget: The ultimate goal is *pleasure*, and pleasure manifests differently for everyone. Despite what various social narratives will tell you, different doesn't mean "less than." It just means different.

Post-Traumatic Possibility

Unfortunately, aside from books like *Come As You Are*, there aren't many roadmaps for us. Nondisabled people who have no firsthand, lived experience of how our bodies feel, react, or behave aren't going to be able to tell us what we need. There is a woeful lack of models or examples of empowered, bold, fulfilled, expansive, nontraditional sexuality.

But we have the power to explore for ourselves. Our different version of sexuality could, in fact, be *enhanced*. After all, we are not relying on the same ho hum, surface, simplistic physiological responses that are the default for other humans. If we could get past barriers of judgment and comparison, we might inhabit our sexuality in a way that is elevated, expanded and advanced beyond what folks with conventional bodies will ever know or could ever imagine. We can throw out genital orgasm as the gold standard and discover the many ways that we can achieve — as Nagoski terms it — the "sudden involuntary release of sexual tension."

Over a number of years, I ultimately discovered the ways in which my paralyzed body was uniquely liberated from the expectations imposed on nondisabled bodies. As a paraplegic, I felt more free than I'd ever been before my injury — free to discover my sexual identity in all of its uniqueness, to chart my own road map, to discover forms of arousal and pleasure that were my body's alone.

I sometimes wonder, what if my friend's first reaction had been one of affirmation and curiosity instead of negative judgment? What if she said, "Omigosh, you are going to have such an amazing opportunity to explore your sexuality in ways that so many people don't get to. Your body is going to be like no other. I wonder what you will discover. I'm so jealous!" Perhaps it would have saved me several years of fighting against something that didn't need to be fought.

Our trauma, in the end, could be the thing that opens us up the most. Researchers talk of post traumatic growth. Why can't this concept extend to sexuality? Perhaps our disabilities actually force us to leave behind the carcasses of our previous lives and discover new possibilities, simultaneously shedding expectations we had carried with us. We get a unique opportunity that so many people will never experience in their lives. If only we could spend less time fighting against it and more time loving within it, and realizing we aren't broken … just unique.

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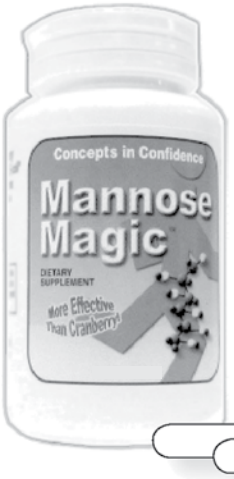

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What is the one product you couldn't live without? The roll of Velcro I use it to strap my feet down to my footplate to keep them in place when navigating rough terrain like cobblestone, gravel or cracked sidewalks.

If you could change one thing in the world to improve quality of life for wheelchair users, what would it be? I would make it easier to acquire a new wheelchair. It is very hard to get a new wheelchair due to cost and insurance barriers. Being able to get a new wheelchair quickly would immensely improve wheelchair users' lives.

Meet other members or join United Spinal at unitedspinal.org

NM LIVE *with Teal Sherer*

MARCH'S GUEST: TRAVELER CORY LEE

Cory Lee, a power wheelchair user, has visited 37 countries and all seven continents and documented everything on his award-winning website, Curb Free with Cory Lee. He recently published his first children's book, is a regular contributor to New Mobility and was our 2018 Person of the Year. Though Lee's next international trips are postponed because of the pandemic, he's been exploring destinations in the U.S. In our interview, he talks about the COVID-19 precautions he takes and when he plans to hop back on a plane. He also shares three travel tips for wheelchair users and details on an upcoming adventure. Here are five quick Q's for Lee:

What is a travel highlight from this past year? Visiting the Florida Keys surpassed my expectations with its accessible beaches, beach wheelchairs and good food.

Dream travel companion? President Barack Obama. I lived in Washington, D.C., in 2008 and remember celebrating outside the White House when he won. I was also a 2009 Presidential Inaugural Committee volunteer.

Best meal you've had abroad? Anything in Spain. Paella and churros — I could eat it all day, every day.

Favorite piece of adaptive equipment while traveling? I have a wheelchair battery charger that I use here at home that is 110 volts but when I am traveling to places like Europe, I bring a separate charger that is 240 volts. That way I don't have to take a converter, as they often don't mix well with wheelchair battery chargers.

Best advice you've gotten from a fellow wheelchair user? To be your own advocate and know your rights. I think this is especially important when we are traveling. For example, I know the Air Carrier Access Act — the law airline carriers must abide by regarding disabled travelers — like the back of my hand.

For more of Cory Lee's travel tips, insights and writing, visit his site at curbfreewithcorylee.com

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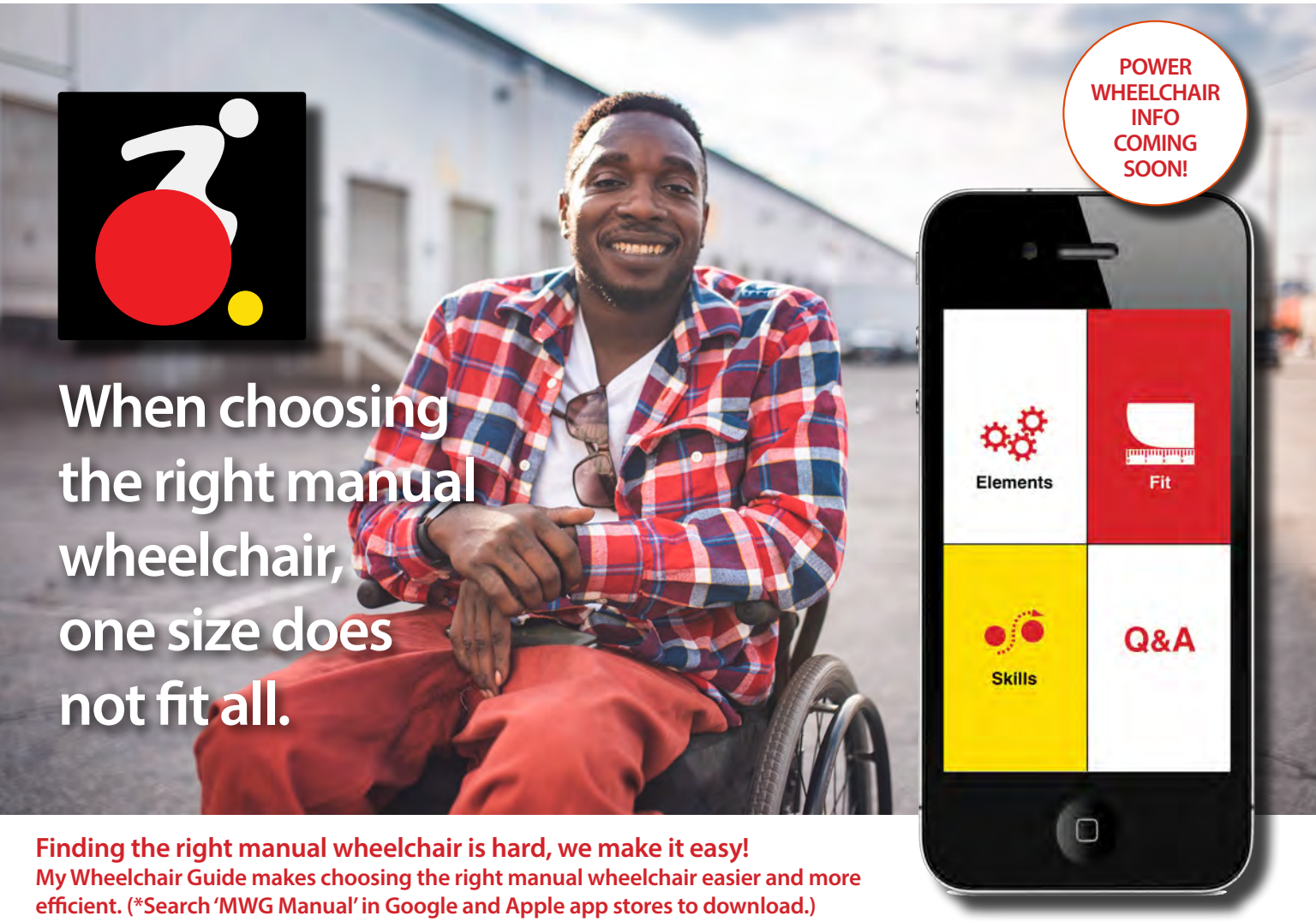

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