

NEW MOBILITY

The Pandemic: Struggle, Resilience and Unexpected Gifts



TO
SUBSCRIBE,
CLICK HERE

Looking for a catheter that's easy to use?

Meet **Onli**.

Hydrophilic Intermittent Catheter



Onli catheters are easy to use.

- No need to apply lubricant! Prehydrated and ready to use right out of the package.
- Funnel length and sliding gripper* help provide control during insertion.
- Easy to open packaging.

Call to request a sample today! 1.888.808.7456

www.hollister.com/onli

* Sliding gripper is only on 16" catheters

Prior to use, read the Instructions for Use for information regarding Intended Use, Contraindications, Warnings, Precautions, and Instructions. Rx Only.

The Hollister logo and Onli are trademarks of Hollister Incorporated.

© 2020 Hollister Incorporated.



Continence Care

Aquila's SofTech Healing Results Amaze the Medical Community

The SofTech Seating System has drastically improved even chronic pressure sores by combining custom fabrication with alternating therapy.

Every cushion is custom built for each client to provide the best possible outcome.



Aquila Seating Systems have more clinical data than any cushion on the market.

Insist on the Best, Insist on Aquila.

If you suffer from pressure injuries, call today for details.

We have 21 years of expertise to help you.

SofTech Cushion
Completely Self-Contained
with Wireless Remote



Shown without cover

AQUILA CORPORATION
Seat Cushion Systems

Medicare HCPCS code E2609

AquilaCorp.com



866-782-9658



Support, advice and tools to *help you feel empowered* every day of your cathing journey

Adjusting to cathing can be tough. You may find yourself dealing with a range of practical, physical and emotional challenges. me+™ Support from ConvaTec brings you the products and support you need, tips and advice you can use, and an inspiring community you can grow with.

Visit learntocath.com to create a personalized video guide with tailored instructions to help you feel comfortable with your approach to cathing.

90%
of patients rated
GentleCath™ Glide
better than their usual
catheter for comfort
during use.*

GentleCath™ Glide

FeelClean™
Technology



ENROLLING IS FREE. Contact us today to join me+™, request free samples or speak to a nurse.

Call 1-800-422-8811, e-mail cic@convatec.com or visit gentlecath.com

CONTENTS

Issue 326 - November 2020



COVER STORY

LIFE ... HALTED. 22

In the spring, COVID-19 exploded across the world, insinuating itself into every aspect of our lives. Eight months later, the pandemic refuses to go away, while a host of other issues have flared up to further complicate the craziest and most trying year anyone can remember. SETH MCBRIDE talks with wheelchair users across the country to find out how they are coping and where they see opportunities in the chaos. JESSICA FARTHING catches up with elite athletes who'd hoped to participate in summer's cancelled Olympic and Paralympic Games.

Cover and Contents Photos by Jacklynn Lomeli



FEATURES

14 'THE QUAD GODS' Competitive online video gaming is one of the fastest growing entertainment industries in the world. A group of quad friends in New York is capitalizing on the boom and has its eyes on a possible Olympic future. ALEX GHENIS reports.

18 FIXING YOUR EQUIPMENT Tired of waiting for your wheelchair to get serviced? Want to repair it yourself but not sure how? We turned to three longtime wheelchair users — SETH MCBRIDE, BOB VOGEL and JENNY SMITH — to get tips and tricks to help you take charge of your chair.

32 SITTING PRETTY Author and Instagram influencer REBEKAH TAUSSIG's new memoir, *Sitting Pretty*, is a poignant, beautifully-written reflection on growing up disabled and the insights, insecurities and issues raised by her experiences. In this excerpt, Taussig delves into her romantic history.

DEPARTMENTS

- 4 BULLY PULPIT
- 5 BEHIND THE STORIES
- 6 SHARE
- 8 POSTS
- 10 UNITED NEWS
- 11 REFRAMED
- 12 HOW WE ROLL
- 36 JOSH ON JOBS
- 37 DAILY DILEMMAS
- 38 MEDIA
- 41 ERVIN
- 43 CLASSIFIEDS
- 44 LAST WORD



NEW MOBILITY IS THE MONTHLY MAGAZINE OF UNITED SPINAL ASSOCIATION

**PRESIDENT & CEO: JAMES WEISMAN
VP OF PUBLICATIONS: JEAN DOBBS**

EDITORIAL

**PUBLISHER: JEAN DOBBS
EXECUTIVE EDITOR: JOSIE BYZEK
EDITOR: IAN RUDER
ASSOCIATE EDITOR: SETH MCBRIDE
EDITOR EMERITUS: TIM GILMER
SENIOR CORRESPONDENT: BOB VOGEL
CORRESPONDENT: AARON BROVERMAN**

CUSTOMER SERVICE

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

ADVERTISING SALES

718/803-3782
MANAGER, CORPORATE RELATIONS:
MEGAN LEE, EXT. 7253
AD MATERIALS: DEANNA FIKE, EXT. 7250

PRODUCTION

PRODUCTION MANAGER: DEANNA FIKE

CIRCULATION

CIRCULATION MANAGER:
BEVERLY SMITH

POSTMASTER: Send address changes to New Mobility, 120-34 Queens Blvd, #320, Kew Gardens NY 11415. Subscription rates: \$27.95/year; \$35.95/year in Canada; \$67.95/year international via airmail. New Mobility (ISSN 1086-4741), Volume 31, Issue 326, is published monthly by United Spinal Association, 120-34 Queens Blvd, #320, Kew Gardens NY 11415. Copyright 2020, all rights reserved. Reproduction without permission of any material contained herein is strictly prohibited. We welcome comments; we reserve the right to edit submissions.

Periodicals postage paid at Flushing, NY and additional mailing offices.

www.newmobility.com
www.unitedspinal.org



BULLY PULPIT

By Ian Ruder

ME AND LINK

After eight months of Zooming, isolating and social distancing, by the time 5 or 6 p.m. rolls around every day, I am ready for a break — some way to clear my head, leave everything behind and relax. In healthier times, this is where I'd meet a friend for dinner or go for a roll outside. But with those options mostly off the table, my new hobby has been exploring the picturesque highs and lows of Hyrule.

In Hyrule, I can meander aimlessly for hours, traipsing across verdant grasslands, stream-laden riverbeds or forested mountainsides. Sometimes I'll just watch the sun set or follow a herd of deer roaming the fields. Wherever I go, I'm surrounded by the sounds of nature — an owl's hoot, the rustle of the grass in the wind, or even the soothing pitter-patter of rain falling.

If you've been to Hyrule, you're probably laughing and nodding your head at this point, and if you haven't, you're probably torn between thinking I'm insane and wanting to know where this magical land is. The good news is, Hyrule is accessible to everyone; the bad news is, it only exists in the world of Nintendo's Zelda video games.

High on the short list of "good things" to come out of the pandemic has been the re-introduction of console-based video games to my life. While I had played the occasional game on my iPad or computer in the 22 years since I was paralyzed, I'd avoided diving fully back into the pastime I'd so enjoyed as a teenager.

I used all the excuses. At first, the actual logistics of using a controller seemed out of reach. I'd seen the early sip-and-puff controllers, but that was more of a commitment than I was willing to make. Then, as technology improved to the point I knew I could jerry-rig a working set up, I told myself I had better things to do. I told myself video-games were for kids, not 40-year-olds.

It took a global pandemic and the prospect of untold hours at home alone for me to finally stop making excuses and take action. I reached out to a friend to help me build a controller and I starting researching exactly what I needed to play the games I wanted.

When I finally got my controller in early April, I eagerly plugged everything in, fired up the system, and quickly realized that

“High on the short list of ‘good things’ to come out of the pandemic has been the reintroduction of console-based video games to my life.”

I sucked. The hand eye coordination I'd used to dominate my friends in high school had faded and the prospect of relearning everything seemed daunting. But I didn't quit, and over week after week of COVID nights, I got better.

Instead of worrying about which button was where, my quad fists instinctually moved wherever they needed to be to make Link, the hero of Zelda, do whatever I wanted.

One of my friends once told me that exploring Hyrule provided some of the same feelings and emotions he'd drawn from riding his mountain bike through the countryside prior to his spinal cord injury. Immersed in Hyrule's luscious anime graphics and sounds, I understood what he meant.

Now, more than ever, we all need to find ways to stay sane and escape the often-overwhelming realities of our day-to-day lives. I never would have thought I'd find that escape in Hyrule, but I'm not complaining.



BEHIND THE STORIES

With Ian Ruder



COLUMNISTS

MAT BARTON • JOSH BASILE
SHERI DENKENSOHN • MIKE ERVIN
MIKE FRANZ • BROOK MCCALL
TEAL SHERER • TODD STABELFELDT
REVECA TORRES • KATE WILLETTE
KARY WRIGHT

CONTRIBUTORS

KIM ANDERSON • CHRISTIAAN BAILEY
LAWRENCE CARTER-LONG
MICHAEL COLLINS • RORY COOPER
DEBORAH DAVIS • JENNIFER FRENCH
ALEX GHENIS • RICHARD HOLICKY
GARY KARP • PAULA LARSON
REGAN LINTON • LILLY LONGSHORE
KATE MATELAN • BEN MATTLIN
ASHLEY LYN OLSON • KENNY SALVINI
ERIC STAMPFLI • MITCH TEPPER
ANTHONY TUSLER • KIRK WILLIAMS
CORY LEE WOODARD
LOREN WORTHINGTON

WEB PARTNERS

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

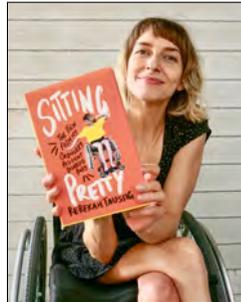
FEATURED WEB PARTNER:

CURB FREE WITH CORY LEE
An award-winning travel blog devoted to sharing the world from a wheelchair user's perspective. Featured in National Geographic and on the Travel Channel.
Curbfreewithcorylee.com



UNITED SPINAL BOARD OF DIRECTORS:
unitedspinal.org/our-story

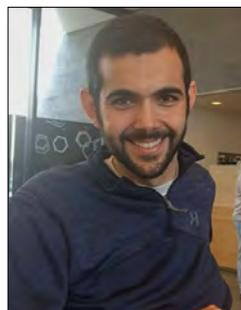
I'm notoriously bad at Instagram, so I was late to finding **Rebekah Taussig** (@sitting_pretty), but boy am I glad I finally did. We are fortunate to have an excerpt from her new memoir, *Sitting Pretty*. Baring your soul for the world is never easy, even when you have 40,000 ardent followers on Instagram. "The book came out on a Tuesday, and I think it was Sunday night when I was like, 'Oh my God, people are going to read this book,'" says Taussig with a laugh. "How do I take it back?" I think you will be glad she didn't. Her candor and voice make her stories and insights instantly relatable, and her ability to blend disability theory and history into her anecdotes makes for an enjoyable read that is also educational without ever feeling preachy.



Jenny Smith's contribution to this month's feature on maintaining your wheelchair marks her first time writing for New MOBILITY, but I'm hoping it won't be her last. Smith's 31 years of experience on wheels is evident in her writing and her confidence. With her master's degree in psychology and an impressive resume of global travel (Afghanistan, anyone?), it's clear she has plenty of learned wisdom to share. "SCI is a full time job in and of itself," she says. "When you add in a couple of things like taking care of your wheelchair, it can easily get overwhelming." Read more of Smith's writing at jennysmithrollson.com.



As an editor, assigning a story to a writer who has a personal interest is always a plus. When I approached **Alex Ghenis** about writing about the growing presence of adaptive video games and the emergence of competitive adaptive esports, I knew I'd found a good match. It turns out he was a gamer prior to his SCI, with a love of racing and flying titles. Reporting the story helped inspire him to grab an Xbox Adaptive Controller and get back to his pre-injury passion. "I was interested in playing," says Ghenis. "Since I started writing this, I've given it a try. Setting everything up right has been slower — and more expensive — than I would have liked, but it's been fun and now I can beat some of my friends."



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

SHARE

“Bravo to NM for covering the best of our progress.”

Wheeling Forward

Fantastic stories! I'm blown away by how far the disability community has come. Million-dollar grants, photos of us, by us on stock websites, etc. Bravo to NM for really covering the best of our progress!

Terri O'Hare

Via email

Framed Perfectly

Thank you for all of your wonderful photo tips (“Pro Tips to Turn Your Wheelchair Into a Mobile Photo Booth,” September 2020). I can't wait to try them!

Robin Mazzuca

Newmobility.com

Great photo issue! Please pass along to Kirk that he stirred my enthusiasm to start carrying a camera and shooting again.

Anonymous

Hands-free Help

Is there a way to give voice direction on iPhone to change to video? For example, I have my iPhone camera set to photo while holding the camera with one hand. The other hand is on or near my power chair control. I'd love to say “video” and have instant video coverage. Thanks.

Joan McKniff

Newmobility.com

Editor: Kirk Williams recommends you check out this Techbout post on using Siri for photo/video: techbout.com/take-photos-selfie-video-using-siri-19307.

Real Insight

I love your black-and-white pictures because they gave me a deeper imaginable story of life (“The Work of Nolan Ryan Trowe,” September 2020). Great work, and keep up with your amazing work as a photographer.

Sylvia Luna

Newmobility.com

This is a wonderful show! Do you by chance have a website with more pictures? Also, I tried to find the podcast *The Juggernaut Show* and couldn't find it — do you know what the problem is?

Barbara Fields

Newmobility.com

Editor: Try facebook.com/a76juggernaut for *The Juggernaut Show*. For more of Nolan's work, nolanryantrowe.com.

Un-Contested Success

Fantastic stories and very inspirational (“New Mobility Photo Contest Finalists,” September 2020). Keeps me interested, thanks.

Michael Quinones

Newmobility.com

Congratulations to all the winners! Keep striving ahead.

Mike Malec

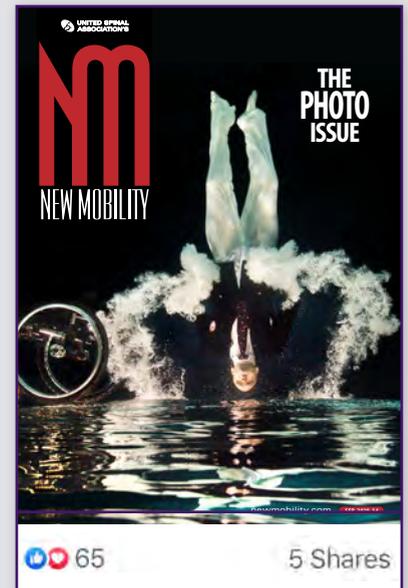
Newmobility.com

Photo Motivation

I see I have let my disability completely dictate my life and shut me out of everything. Thank you for such inspiring pictures and stories.

Amy Estes Potter

Newmobility.com



Rolling From the Ashes

Powerful, well-written narrative on the true priorities in life! (“The Reset,” *Outdoor Tracks*, September 2020.) So very sorry this happened to you and yours, but your tenacity to rise above the ashes in true phoenix style is truly inspiring. Stay strong, this too will pass!

Lorri Loshny

Newmobility.com

Zoom Star

I have the same history — everyone sees that I have short arms right away (“Embracing ‘The Reveal,’” *Reframed*, September 2020). But not when I'm online. I have to think about this — maybe dazzle them with brilliance and then, at the end, wave goodbye! Except that I usually gesture when I talk, anyway.

Michael Herzovi

Newmobility.com

Loving this perspective, Rebeca Torres. I've only done backgrounds in Zoom meetings using COVID art that I have done. But as you say — my wheelchair is not visible so my disability is not known. But like you, I'm proud of who I am.

Chuck McAvoy

Newmobility.com

ALLTRACK³ SERIES HYBRID

WHY COMPROMISE?



Outstanding outdoor performance & stability

Optimal comfort & maneuverability

The one and only **TRUE HYBRID DRIVE**

- Best in class turning radius as low as 21.75"
- Patented Dual-Action Suspension:
Fully independent 6-wheel interactive suspension with vertical shock absorption
- Complete line of R-Net expandable and non-expandable electronics
- Available with center mount articulating foot platform
- Multiple frame, drive wheel, and caster options



NO COMPROMISE!



SEE THE
R³
HYBRID
PERFORM



Run to Hulu

What better way could there be to spend Mother's Day than in a movie theater watching a thriller about a creepy mom who has kept her wheelchair-using daughter completely isolated from the world and controlled her every move? Prior to the pandemic, that was the thinking that led Hollywood to schedule *Run* for a May 8 release to coincide with Mother's Day weekend. Now, six months later, you can finally see whether the film's buzz was deserved.

Photo by Allen Fraser/Lionsgate



Real-life wheelchair-using actor Kiera Allen takes direction from Aneesh Chaganty.

The film stars Emmy and Golden Globe winner Sarah Paulson (*American Horror Story*, *The People vs. O.J. Simpson*) as the mom and newcomer Kiera Allen — a real wheelchair user — as the daughter, and finally gets its worldwide debut Nov. 20 on Hulu. Disability writer Emily Ladau says not to miss Allen's breakthrough performance. "To know that Kiera Allen wasn't performing disability, but rather that she was performing a character, made it feel as though watching *Run* was a radical act," says Ladau. "There's power in witnessing authentic disability representation on screen."

Make sure to visit Newmobility.com in the days leading up to the release for Ladau's interview with Allen.

Photo by Allen Fraser/Lionsgate



A New Way to Stand

It seems like there's a new prototype wheelchair popping up every few weeks, and the latest to generate online discussion is the modified Segway stander built by United Kingdom architect Suzanne Brewer. Brewer, who does not use a wheelchair, has been working on the prototype for two years.

"Standing wheelchairs at the moment are bespoke, they are made for that person," Brewer told *Architects' Journal*. "That doesn't make them accessible to

enough people, unfortunately, and it makes them very expensive." Most run around £25,000 in the U.K., which spurred Brewer to create a generic model that is more affordable and usable by most anyone who needs it.

Check out bit.ly/2SG3GZs to see what you think.



Suzanne Brewer and her non-disabled son Jarvis demonstrate her Segway-based stander.



Robot Car Legs

Forget wheels and ramps — maybe the accessible transportation solution we've all been waiting for is ... a car with robotic legs? As crazy as that may sound, this September Hyundai announced it is pursuing that technology in a line of new Ultimate Mobility Vehicles:

A car with robotic legs could save lives as the first responder in natural disasters; or, people who do not have access to an ADA ramp could hail a car to walk up to their front door, level itself, and allow wheelchairs to roll right in.

To read more about Hyundai's vision, and to see more renderings, visit hyundai.com/en-us/releases/3152.

Disabled Voting Bloc Grows

A September study confirmed that people with disabilities form an increasingly large, powerful and potentially decisive percentage of the electorate. The report by the Program for Disability Research at Rutgers University projected that 38.3 million eligible voters have a disability — a 19.8% jump since 2008 — and more than 25% of the American electorate may be motivated by issues affecting the disability community.

"The sheer size of the disability electorate makes it clear that people with disabilities and their family members have the potential to swing elections," said Lisa Schur, director of the Program for Disability Research at Rutgers University. "While their partisan split is similar to that of other citizens, people with disabilities put a higher priority on health care and employment issues, so how candidates deal with those could be decisive."

- At 38.3 million people, the number of disabled people who will be eligible to vote in the November 2020 elections exceeds the number of eligible voters who are Black (29.9 million) or Hispanic (31.3 million).
- The study projected 21.3 million eligible voters with a mobility disability. For the full report, visit tinyurl.com/y5qlbxqf.

Wheelchairs for Cows?

Ruby Sue just wanted to run and play like all the other calves, but thanks to "curly calf syndrome" her back half was paralyzed. Committed to leaving no calf behind, New Hampshire-based Walkin' Pets designed and built a custom wheelstand to allow Ruby Sue to live an active life. Find out more about Walkin' Pets on Facebook: facebook.com/HandicappedPets.



WATCH

THE NEW DOCUMENTARY **RE-INVENTING THE WHEEL** FOLLOWS A PEER SUPPORT GROUP OF ACTIVE WHEELCHAIR USERS IN CANADA'S OKANAGAN VALLEY AND ITS EFFORTS TO HELP ONE MAN ADJUST TO HIS FIRST YEAR AFTER SCI. THE FILM DEBUTED IN SEPTEMBER AT THE LUNENBURG DOC FEST IN CANADA. FOLLOW THE FILM'S FACEBOOK PAGE FOR INFO ON WHERE TO WATCH: [FACEBOOK.COM/REINVENTINGTHEWHEELMOVIE](https://facebook.com/reinventingthewheelmovie).



Stick-to-It with CatTongue Grip Tape

Anyone reading this knows how annoying it is to have a cell phone or tablet constantly slip off your lap. CatTongue Grips makes one of the grippiest adhesive pads we've ever had the opportunity to try, and last fall the company launched a new product that should be even more helpful for those with limited grip strength. Its non-abrasive grip tape is made out of the same waterproof, dishwasher safe material as its phone pads, but comes in roll form so you can cut and stick it onto your footplate, workout equipment, favorite water bottle, tools, handcycle pedals, and pretty much wherever you could use a little extra friction.

Grip Tape is available for \$19.99 and cell phone pads are \$12.99 from cattonguegrips.com.



MEMBER BENEFITS

unitedspinal.org

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:

Personalized Advice and Guidance

Peer Support

Advocacy and Public Policy

Veterans Benefits Counseling

Accessibility Advocacy

Local Chapters

New Mobility magazine

Informative and Educational Publications

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.



NEWS FROM UNITED SPINAL

STARING DOWN DISASTERS

On the heels of a busy hurricane season, with an uncertain pandemic forecast heading into winter, United Spinal Association is implementing an emergency preparedness campaign to help people with SCI/D address the devastating effects and risks associated with natural and human-caused disasters.

United Spinal's Ready to Roll initiative is a comprehensive effort to enhance the independence and wellbeing of wheelchair users with information and checklists that can aid in unexpected disasters and emergencies. In addition to helping members of the SCI/D community, Ready to Roll aims to equip professionals, municipalities and local agencies to improve the service they provide to individuals with SCI/D by examining and adjusting their emergency procedures to consider the specific and crucial needs of our community.

"Whether it's fires, hurricanes, floods or something else, disasters pose enhanced risks to people with spinal cord injuries," says Abby Ross, United Spinal's chief operating officer. "Coordinated, proactive planning can save lives. Sadly, time and again we've seen local governments and civic leaders lacking the knowledge and/or ability to help our community in these situations. Ready to Roll fills in the gaps in service and empowers the SCI/D community and the people in positions to help."

The initiative will be rolled out in three phases over the next two years. The first phase — which is already underway — focuses on creating resources for individuals with SCI/D, their families and caregivers, while the second targets professionals who serve individuals with SCI/D, and the third focuses on outreach to municipalities, agencies and local governments.

For more, including helpful checklists, best practices and video and podcast resources, visit unitedspinal.org/ready-to-roll.





REFRAMED

by Reveca Torres

A YEAR OF RECKONING AND REFLECTION

I took another look at the Reframed article I wrote for *NEW MOBILITY* in January 2020 where I talked about the prospect of change this year. Although the events that unfolded since then were not what I envisioned, I do see them as a catalyst for change. Our community has been faced with further isolation from a pandemic, struggles with in-home supports, and fear around the seemingly easy decision to go to a hospital or clinic for needed medical care. Those fears have been further complicated by racism, political divides, and difficult decisions about schools and workplaces reopening. It has taken a toll on our mental health and there's no doubt it's been difficult.

All these events have also exposed inequalities, injustice and areas where we are failing each other as a society and as citizens of the world. Yet, I continue to be hopeful that change is happening, as I have seen the disabled community come together, using our problem-solving skills and ability to adapt to form mutual aid groups, share our resources and supplies, and make space for voices that need to be heard.

As we near the end of 2020, I think we should take time to grieve the things and the people we've lost, but also reflect on the things we can be thankful for, including our support systems — family or chosen — and the changemakers who continue to push forward even when the fight gets hard, energy is depleted and spirits are exhausted. My hope is that we rest, recharge and refuel. I look forward to witnessing the birth of new disabled leaders and holding them up high so they can feel supported and shine!



“We should take time to reflect on the things we can be thankful for, including our support systems and the changemakers who continue to push forward even when the fight gets hard.”

PODCASTER

Rhonel Cinous



Four years after sustaining a C5 injury, Rhonel Cinous is using his podcast to rediscover who he is through conversations with others from the SCI community.



Ramping Up

As a Haitian-American, Rhonel Cinous always wanted to go to Haiti, but when he finally got his opportunity, things did not go as he had hoped. Cinous, a Miami native, went to Haiti in 2016 to promote the morning radio show he hosted and see the country, but on a snorkeling trip during his second day, he broke his neck on his first dive. “I don’t know if I hit a sandbar, but I rolled over my neck and it was like someone hit pause on my life,” he says.

Prior to his injury, Cinous lived a high-paced life: working two jobs, going to events and doing the radio show while remaining extremely social and upbeat the whole time. Now, he found himself lying in bed, waiting for his power chair to be delivered.

“All those activities came to a screeching halt. I was stuck at home in bed and I’m very private, so having people around me 24/7, touching my stuff and touching me was very weird for someone so independent,” he says.

But having all those people around also gave him a sounding board for everything he was feeling and helped him get a grip on

his situation. He realized he wouldn’t be able to work or attend events like he used to, but he recognized the pause would give him a chance to re-evaluate who he was. “Slowing down is still helping me figure out who I am and what I want to do with life, and I think I’ve sort of answered it,” says Cinous.

Since his injury, Cinous has always wanted to find his way back to radio. His spot on the morning show on the nation’s only Haitian-American radio station was always open for him — he even guest-hosted occasionally — but being on air at 8 a.m. everyday and maintaining his rehab schedule wasn’t feasible. Without Cinous, the show went another direction, and the station owners eventually canceled it.

The first year of his injury, Cinous realized the challenges of SCI were more mental than physical. Focusing most of his time on physical therapy was fine, until a pressure sore laid him up for another six months. And to make matters worse, he and his girlfriend had split up only months before.

“That had to be my lowest point mentally and emotionally,”

BEST ADVICE FOR HIRING AN ATTENDANT: Get to know them first. Get references from people you may know from therapy or healthcare providers, be forthright and be your own best advocate.



MOST PIE-IN-THE-SKY ASPIRATION: I’m a huge mixed martial arts fan and one of my dreams is to call a fight or be a color commentator on the side.

BEST DATING STRATEGY: Be willing to put yourself out there. If you’re comfortable with who you are and how you present yourself, people around you will be comfortable.



Support Without Standing in the Way

Rhonel Cinous recounts how a nervous-but-game personal care assistant made all the difference when he wanted to go waterskiing.

“ I didn’t tell anyone where we were going. As soon as my care aide realized we were going to the lake at Amelia Earhart Park in Miami, and that this wasn’t typical pool therapy, I had to come clean: ‘I’m not going to lie to you. We’re about to do something crazy. You don’t have to join me, but you’re here to support me.’ She was a bit concerned and worried because I’d gotten hurt in the water and waterskiing was my first water activity since then. She was like, ‘You’re crazy!’ and I said, ‘You are correct, but this sounds like a cool idea.’

My aide was freaking out the whole way, but she was 100% on board. It was really cool and I appreciated that she understood I needed to do that. One, to feel like myself again and two, she didn’t stand in the way of it. She just let me enjoy myself and have fun. ”



says Cinous. “I realized that the person I’d known as Rhonel was changing as I sat alone in my room, and I broke down in tears.”

He sought advice from a psychologist who helped him realize he had to recast himself. Those conversations led Cinous to start his own podcast, *Ramp. It. Up!*, in which he interviews others with spinal cord injuries and shares lessons from his own journey.

“The podcast gave me an outlet to talk and became a way I could share stuff with other people. Personally, I want to gain as much information as I can about living with a SCI, whether that’s finances, employment, relationships or recreation,” he says. “I’ve been fortunate enough to receive advice from some amazing peer mentors, and I thought I should probably be doing the same thing in my own way.”

Since starting *Ramp. It. Up!*, he’s already learned so much from those with SCI. “I see my career in podcasting because I love it and whether it becomes a monetary endeavor or not, I want to be able to help my community. And maybe if I help them, I can help myself to further my own independence.”

ROLLING WHILE BLACK:

I’ve been looked at as a threat, but now I’m an afterthought — that hurts too. At least when I was a threat, I was relevant.



WHY I JOINED UNITED SPINAL ASSOCIATION:

It’s invaluable to hear from people going through the same thing and hear they’ve overcome many of the same challenges.

QUAD GODS OF GAMING

BY ALEX GHENIS

When asked if he is prepared for the top levels of competition, Jose Hernandez, a C5 quad and one of the Quad Gods captains, exudes confidence. “What I can say is that I may not be able to beat you down the street, but when I play games I can match or defeat you,” he says.

Hernandez’s team is attracting big-name sponsors like Logitech, which kitted them out with high-end PCs and an array of adaptive gear. And although the players participate because it’s fun, they say gaming with others who live with SCI/D makes the experience more special. “You have that camaraderie,” says Hernandez, 40. “You know that your teammates understand what you’re going through.”

The problem-solving and competitive scenarios players master in order to win matches or in-game achievements often have real-life applications, so it’s logical that the sport found a home in a rehab setting like Mount Sinai. “Those skills and experiences even transfer into work and day-to-day life,” says Hernandez. “If I can beat something in the game, then I can do quality work on par with other professionals.”

Hernandez started playing video games when he was a teenager. After his diving accident at age 15, he continued playing as form of hand therapy as well as recreation. He adapted to growingly-complex controls by building his own PC setup that allowed him to keep up with other gamers.

When he heard about the quad gaming team in Mount Sinai Hospital’s transition group, he was all in. “I got in-

involved because of Angela,” he says about Angela Riccobono, the senior clinical psychologist at Mount Sinai and the group’s facilitator. “In one way or another, the whole team has worked with her.”

The first Quad God was Chris Scott, who acquired a C3 spinal cord injury from a parachute accident in Long Island six years ago. “Scott, who passed away, is the reason the team got created,” says Hernandez. “He rehabbed at Mount Sinai and was extremely depressed, and Angela didn’t know how to help him.”

titles, and fell on a few favorites, including the ever-changing NBA basketball series.

Although gaming was a fun escape, Scott became lonelier and spent most of his time at home. He had hit a rut. “He missed participating in activities like skydiving,” says Riccobono. In February 2019, she introduced Scott to a coworker of hers, David Putrino. He’s the director of rehabilitation innovation for Mount Sinai Health System and has a lab dedicated to new rehabilitation technologies, including video games.



The Quad Gods esports team plays out of Mount Sinai and hopes to one day make it to the Olympics.

IN THE BEGINNING

The mouth-operated QuadStick hit the market the same year Scott was injured. With the sip-and-puff device mounted on his wheelchair, he could play games ranging from first-person shooters to racing

When the two men realized they were both gamers, Scott had Putrino grab a well-used QuadStick out of his backpack. Putrino mounted the device on Scott’s arm rest, plugged it into an Xbox, and it was game on. Basketball

Photos by Jess Jacklin

The Quad Gods esports team runs out of Mount Sinai Hospital in Manhattan, where they train on video games like Fortnite, Rocket League and NBA2K. There is talk of esports becoming an Olympic category, and if that happens, the Gods want to be ready.



Richard Jacobs smiles in the background as Alejandro Courtney games with an adaptive controller.

was Scott's specialty and Putrino had played his fair share over the years, so that was the first contest. "He started to play NBA2K," says Putrino. "And then he started to kick my ass."

When he and Riccobono realized that gaming was successful for Scott, they collaborated with him to start an esports team. The trio fundraised to purchase adaptive gaming equipment and found other quads to game with them, with Scott as the team captain.

Once the project was ready to be announced, Riccobono invited members of her biweekly transition group to join. Within two months, "about 12 other quads showed up and wanted to be a part of it," says Putrino. Eight of those stuck with it to form a competitive team. By July 19, 2019, the players officially launched as the "Quad Gods," and in October, the popular website CNET wrote about the team in a prominent feature.

Sadly, Scott had passed away from

a chest infection on July 27, barely one week after the Quad Gods officially launched. Though it was hard to work through their grief, the team continued with Scott's memory and goals.

BUILDING A TEAM

Competitive gaming — sometimes one-on-one, sometimes teams-against-teams — started moving online in the 1990s and became more well-known with the establishment of the Cyberathlete Professional League in 1997. By the 2010s, large, in-person tournaments handed out millions of dollars in prizes, with famous players landing top-dollar sponsorships. With the possibility of esports becoming an Olympic sport someday, the Quad Gods didn't just want to play together. They wanted to compete on the world stage.

The Quad Gods' remaining seven members met at Mount Sinai at least once per week for practice and team-

building until the COVID-19 crisis hit New York City. Then they switched to playing and practicing from home. They secured sponsorships and resources from developers and donors. In addition to Logitech's donations, the New Jersey Nets basketball team donated a physical gaming space, and a foundation affiliated with billionaire Mark Cuban provided \$60,000 in funding for technology, development and travel.

These donations opened even more possibilities for the team and each of its members. Thanks to the high-end gaming computers that include eye-trackers, Nyree Stevens, 29, a C3-4 quad, can play games on PC. Like the others, she also played video games before her injury, although she wasn't obsessed with them.

Stevens uses a QuadStick. "I was playing a shooting game where you have to aim, and it was pretty hard at the beginning," she says. "But after a couple times, I was able to aim well, which is pretty

COOL CUSTOM CONTROLLERS

For gamers with limited to no hand function, a customized controller can be the difference between having fun and running into a virtual wall. Jose Hernandez used a soldering iron to build his own controller for his PC about 10 years ago. “I wanted to be able to use more than the six buttons that came on the standard, arcade-style joysticks,” he says. The controller he built gave him 15 configurable buttons. Back then, homemade solutions like Hernandez’s kept adapted gamers on the cutting edge, but the advent of the Microsoft Xbox Adaptive Controller in 2018 upped the bar for creativity and adaptation.

Fellow gamer Spencer Allen is one of the many innovators using the Xbox Adaptive Controller as a base for next-level controllers. Unlike Hernandez, who games solely on PC, Allen, a C5 quad with a background in engineering, wanted a controller he could use for gaming on consoles. He prototyped a semicircular lap tray that sits on his power chair with one joystick on each armrest and an array of buttons he hits with his hands and elbows. All the buttons and joysticks plug in neatly to the Xbox Adaptive Controller, making configuring the controller for different games a snap. Multiple iterations later, Allen finalized a sleek design with a plexiglass top. Microsoft recognized his ingenuity by featuring him in a promotional video touting the controller.

Allen hopes to show other people with disabilities that they, too, can play video games. He recently launched Infinity Gaming Shop to manufacture and sell custom controllers. “I don’t want anyone to feel like video games have been taken away from them because of an injury or disability,” says Allen. “Hopefully my solution can help others enjoy games the way I do.”

For more on Allen’s story, or to purchase one of his controllers, check out infinitygamingshop.com.



amazing.” Soon she entered the fray of racing games, holding her own against both friends and foes.

She says she’s in the minority on a couple fronts. “There are only two of us that play with the QuadStick,” she says. “And it’s pretty crazy I’m one of only two girls on the team.” She hopes that more women and high-level quads will join in the future.

READY TO COMPETE

While playing in the Olympics is their ultimate goal, the Quad Gods train to compete in both disabled and nondisabled tournaments. Although they play competitively online, their goal is to beat nondisabled teams at in-person events.

Sometimes when competing against random teams online, the Quad Gods will be upfront about their paralysis, especially when opponents ask about the team name. Other times, they’ll keep their disabilities hidden, go on to win a competition, and get a well-earned boost from the fact that their opponent had no idea they lost to a team of quadriplegics.

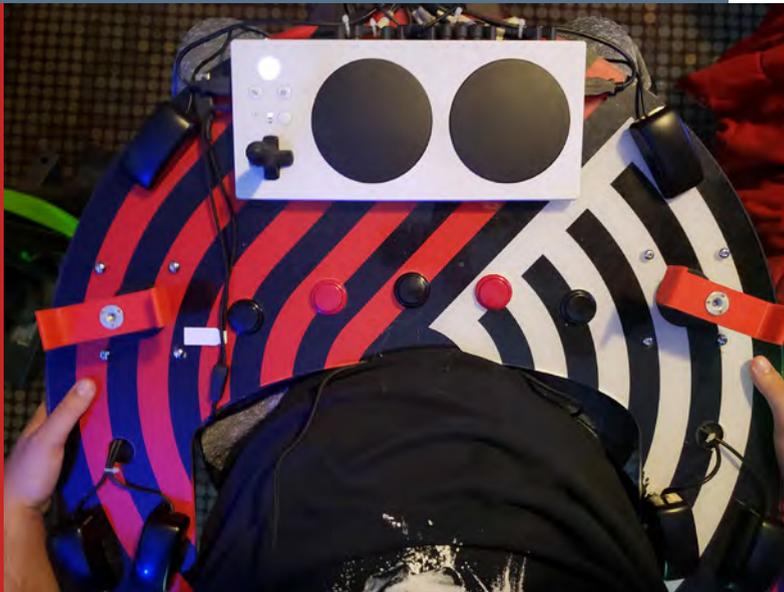
“It’s incredible that in 2020 individuals with disabilities can play competitive video games with other players and they take us seriously,” says Hernandez.

Richard Jacobs, a C7-T1 quad for nearly five years, agrees. “We’re just another gamer to them. Even though we have certain restrictions that hinder what we do physically, we show everybody else we are on the same level as them.”

Like many of his teammates, Jacobs, 37, grew up playing video games. He didn’t explore his gaming options right away after rehab because, “it’s mainly in my hands where I have a loss of dexterity and fine motor skills,” and a conventional joystick didn’t cut it. Then Riccobono mentioned the Gods as something that could boost his spirits.

He showed up to see the team in action and sat next to Blake Hunt, a C5-6 quad using an adaptive joystick. “I saw him playing the game. If you didn’t see him and just saw

Spencer Allen (above) engineered this setup that features one joystick on each armrest and an array of buttons he can hit with his hands and elbows.



NO HANDS, NO PROBLEM FOR ESPORTS STAR

Rocky Stoutenburgh got his first QuadStick video game controller in 2008, two years after sustaining a C3-4 spinal cord injury. He remembers being excited to get back to playing video games but unsure how big an impact the device would have. "I thought it would be something fun to do," says Stoutenburgh, who lives in Southgate, Michigan. "I thought it would be one of those things you try. You know, the kind of things people give you and say, 'You should try this!' or 'This would be cool to use for your life,' and then they just collect dust in your closet and you never use it again."

Twelve years later, Stoutenburgh's mastery of the QuadStick and competitive video games has led him to two Guinness World Records and a professional contract with one of the world's most prominent esports organizations. "I got addicted to using [the QuadStick]," he says with a laugh. "Now I'm just over-packed with too many people to play with and not enough time in the day."

His schedule is likely to get even busier thanks to the contract he signed with Luminosity Gaming this summer. Since its inception in 2015, Luminosity has grown into one of the most recognizable organizations in esports, fielding teams in all the most visible games and sponsoring some of esports' most high-profile personalities.

Stoutenburgh's skill with the sip-

and-puff-based controller has earned him a legion of fans and the nickname "Rocky No Hands." He has over 68,000 followers who regularly tune in to watch him play live on Twitch, and almost 55,000 subscribers who enjoy highlights of his exploits on his YouTube channel. He also posts regularly on Instagram, Twitter and TikTok.

Until recently, Stoutenburgh created, edited and posted almost all of that content on his own, working on his iPad from bed into the wee hours of the night. Signing with Luminosity means he will have access to a team of talented content producers who can help him grow his brand and improve his videos.

"The most exciting part to me is all the help and advice I'm getting from them," he says.

Additionally, he'll have the chance to play with celebrities like NFL stars Richard Sherman and Darius Slay, and take part in high-profile tournaments and competitions.

For now, Stoutenburgh is honing his craft at Call of Duty: Warzone, the leading battle royale game in the esports world right now. He already has two Guinness records in Fortnite, and would like to add to that total by setting more in Warzone. He's excited about the year to come.

"I'm hoping that I grow a little bit more," he says. "Hopefully I'll re-sign next year and keep growing bigger."

Follow Stoutenburgh at RockyNoHands on YouTube, Instagram, Twitch and Twitter.

— IAN RUDER



Rocky Stoutenburgh is the first quad to sign a professional gaming contract.

the TV, you never would have guessed he was a quad," he says. "I thought, he's doing it, why can't I?" He signed up for the Quad Gods right away.

FROM SCREEN TO REAL LIFE

Team members find that playing has real-world benefits. Hernandez drives his own van using the adaptive Scott Driving System. Now that racing games are a part of his repertoire, he says, "Video gaming made me better at driving," because the regular hand-eye coordination made

those movements feel more natural.

Stevens, a QuadStick gamer, now paints by holding a brush in between her teeth. "It's better than when I painted with my hands," she says.

And Jacobs finds the small movements he uses to manipulate a controller have improved his function. "My hands got better, just enough to grip a cup," he says. The cup is still heavy, but he can lift it with one hand now.

Mental health and socializing are arguably the biggest benefits to gaming. "You get to immerse yourself in

the game and be in a totally different world," says Jacobs. He finds video games to be a great bonding experience with his daughter, who now has the entire Mario collection alongside other adventure titles.

Ultimately, gaming is another great hobby for quads who have fewer options than their nondisabled peers. Stevens put it best when she says every piece of gaming, from hand-eye coordination to socializing, has its own value, "and it's the little things that make people happy." **MI**

HOW TO GET YOUR OLD EQUIPMENT RUNNING LIKE NEW

Good wheelchairs don't come cheap, and neither do service visits. Learning how to keep your chair in tip-top shape, including how to make adjustments and fixes when needed, can save you tons of money and spare you the interminable wait for a repair person, all while prolonging the life of your ride. With that in mind, here are three guides — two for manual chair users, and one for power chair users — to save you time and money taking care of your chair.



TUNING YOUR MANUAL CHAIR FOR MAXIMUM PERFORMANCE

BY BOB VOGEL

With a little maintenance, a manual chair should retain top performance indefinitely. I have friends that are styling around in chairs that are over 25 years old and still perform like new thanks to their owners' TLC. In addition to making sure the upholstery, screws, nuts and bolts stay snug, here are tips I've learned to keep your chair at maximum performance for the long haul.

TIRES

The easiest, and most noticeable, way to maximize chair performance is to regularly check your tires' inflation. Under-inflated tires are one of the worst ways to undermine your chair's performance. I keep my tires at the maximum suggested pressure — expressed as PSI and listed on the side of the tire. I prefer a rechargeable, automatic pump for inflation, because it makes topping off a snap. I use a Campbell Hausfeld CC2300 pump — it's fast, has a built-in pressure gauge and can fill high pressure tires.

The next tire item to keep an eye on is wear. When the performance-robbing flat spot develops and the middle of the tire starts growing wider, it's time to change tires.

When purchasing replacement tires, be sure to get the proper size tire for your rim. The size should be listed on the side of your tire, either 24 inches (540), 25 inches (559), or 26 inches (590). When ordering tires, I include an extra set of tubes in case of a flat or other problems when removing the old tire.

You will need to get a set of tire levers to remove the old tire.

I prefer using plastic levers because they don't scratch the rim. I also keep a set of stainless steel levers for removing stubborn tires. For easier tire mounting, I use a tire bead jack, which easily pulls the new tire bead over the rim.

REAR WHEEL CARE: SPOKES, AXLES & BRAKES

Once your tires are properly inflated, the next thing to check is spoke tension. Spokes should feel firm, and any loose spokes should be snugged, something that is easy to do with a spoke wrench. If you notice one or both wheels are out-of-round — warbling from side to side — it is time to take it to a bike shop and have them trued, or straightened, which requires a truing stand. Note: Spinergy wheels require a Spinergy spoke wrench, which comes with a new set of wheels. Replacements are available directly from Spinergy or from SpinLife.

The next rear-wheel task is keeping your quick-release axles clean. Clean the axles with a dry cloth and wrap a cloth around a screwdriver to clean the axle receivers. I find a dry cloth doesn't make my axles and receivers spotless, so I use a light spray of WD40, let it sit for a minute or two and then wipe it off, which leaves the axles and receivers spotless. In moist or salt water environments, a thin coat of Teflon-based spray or a silicone lubricant spray with Teflon, helps keep corrosion at bay.

After the axles, move on to the rear wheel bearings to be sure they spin freely. Rear wheels use half-inch sealed bearings. I always order eight bearings at a time because they are the same



ones used in front caster fork stems.

Last but not least, check to be sure your wheel locks are snug, usually as simple as finding the right Allen key set. Check your manual to see if you need a metric or imperial set.

FRONT CASTER FORK

The first thing to check here is the area between the caster fork and the wheel, which, in my experience, has a unique power to pull carpet fiber, human hair and dog fur into its vortex. If it makes its way into the bearings, it can cause them to prematurely fail. The best way to remove bearing crud is with tweezers or a thin set of needle-nose pliers. Between my German shepherd service dog and my daughter's Australian shepherd, I find that hair removal is a several-times-a-week task.

This is also a good time to be sure caster bolts are snug and to give each one a spin to check the bearings. Most wheelchair caster bearings are 5/16 inch and cost around \$5 per bearing. Note: TiLite chairs with single sided forks use a different size "R6" bearing.

Prior to replacing caster bearings, check your casters for performance-robbing wear: if there is a sizeable flat spot in the center, now is a good time to

replace them. Casters are available online, often for less than market price, and as a bonus, many come with caster bearings installed.

To replace just the caster bearings, loosen and remove the caster bolt and pull the wheel off the bearing. Be mindful of spacers outside the caster wheels as well as a spacer sleeve in between the bearings — I lost a few in my early repair days. Bearings generally come out with a couple taps of a rubber mallet on the end of a straight slot screwdriver placed against the bearing. I use a double-faced soft mallet. When re-assembling the caster, make sure the bolts are snug and don't come loose.

RESOURCES

- How to Replace Caster Bearings: [youtube.com/watch?v=ipLgkE-5gaE](https://www.youtube.com/watch?v=ipLgkE-5gaE)
- Caster Fork Bearing: Removing a bearing from a standard fork mount: [youtube.com/watch?v=OzouBVixLuw](https://www.youtube.com/watch?v=OzouBVixLuw)



Your local bike shop is a great option if you don't feel up for tackling these tasks or want to see them done to learn, says Bob Vogel. "I've found bike shops are happy to change a tire for a nominal fee while you wait. However, most bike shops don't carry high-pressure tires in wheelchair-rim size, so order your tires in advance. Replacing rear wheel bearings is another task I prefer to have experts at a bike shop handle. Fortunately, they are the least likely bearings to go bad."

DIAL IN YOUR SEATING POSITION WITHOUT CHANGING YOUR CHAIR

BY SETH MCBRIDE

The right seating position in a manual wheelchair can make the all the difference in your everyday functionality and your long-term health, affecting everything from balance to skin and shoulder health. The ideal seating position is different for everyone — an interplay between your body's dimensions, your function and your day-to-day life. It's a process to find what works best for you.

Fortunately, if you're in a wheelchair that doesn't feel right, there are a number of adjustments you can do and components you can swap that can make a big difference for your seating position.

Warning: Changing your seating position can significantly alter pressure distribution. Check your skin religiously whenever you make changes, and if you are at risk of skin breakdown, consulting a physical therapist with experience in pressure mapping may be a good idea.

CHANGING FRONT SEAT HEIGHT

If you have room to spare between your knees and a typical table top, raising your front seat height is worth considering. A discouraging percentage of physical therapists have people sit in a minimum of dump. It's usually out of the belief that a flat seat reduces pressure on the sit bones. But what this doesn't take into account

is that in real life, someone without strong core muscles who sits in a flat-seated chair will likely slouch to maintain balance. This puts extra pressure on the coccyx and can lead to pressure sores. Not having any core, I've found that the only way to maintain an upright seating position without falling over my lap every time I try to move is to sit with a lot of dump — as in a 4-to-5-inch difference between front and rear seat height.

One option is to raise front seat height and put bigger front casters on. My go-to casters are 4-by-1.5-inch soft roll casters, but in my previous chair I went

MAINTENANCE KIT

You can find the majority of tools you'll need to take care of your chair online.

There are a number of DME retailers, many of whom offer prices below market value. I've had particularly good luck with DME Hub and Sportaid.

- Backup tubes, \$6.25
- Campbell Hausfeld CC2300 pump, \$89
- Park Tool plastic levers, \$6.50
- Tragoods stainless steel levers, \$8.99
- Tire bead jack, \$10.99
- Spoke wrench, \$6
- Half-inch sealed bearings, \$6.50
- Caster bearings, prices vary by model.
- Tires start at \$39 per pair.

to 5-inch casters to increase my dump by an inch. Make sure you have clearance for the larger casters to rotate without hitting your feet or footplate and that your fork has room to fit them as well. Websites like SpinLife and DMEHub have soft roll casters starting at about \$45 each.

Additionally, you can put more spacers, which are found at most hardware stores, under your caster housing to raise your front end up. How much you can raise using spacers depends on the specific model of your chair. If you can't raise it enough using spacers, looking online for a taller fork can do the trick. Note: Raising front seat height changes the caster fork angle and can cause caster flutter or sticky spots when turning. The more you raise your seat height, the more noticeable the difference. If your caster fork barrels are adjustable, check them with a pocket level or square to make sure they are at 90-degrees and adjust as needed to keep them in line.

REAR HEIGHT

If you have a chair with an adjustable rear seat height, play with it. Sure, it's nice to be able to reach high cabinets, but in addition to balance and posture benefits, a lower rear seat height — sitting down in your wheels rather than on top of them — can give you better leverage to push your chair.

If you have a fixed rear seat height, unfortunately there aren't many ways to alter it other than changing your rear wheel size, and going from a 25-inch rear to a 24-inch rear wheel only changes your seat height a half an inch. But, changing your rear wheel size can have another effect on your pushing that's worth considering.

If you live in a flat area with little need to push hills on a daily basis, larger wheels like a 26-inch can give you more distance per push, making it quicker and easier to cover distance. If your day-to-day includes a lot of hills, going down to a 24-inch could make it a little easier to get up the steep stuff. Personally, I have good arm strength but live in a hilly area, so 25-inch wheels hit the sweet spot.

DIY ERGO

Ergo seating is a still-fairly-uncommon seating setup where the frame rails extend straight out for 4-to-6 inches before they



Dialing in the right seat dump can help compensate for a lack of core strength.

angle up. This creates a bucket that holds your pelvis in place better than traditional dump. If you're active and don't have core strength, I can't recommend it enough.

For a preview of what ergo feels like before you fork over thousands of dollars for a new frame, you can make a DIY version using a foam wedge under the front of your regular cushion. A few years ago, I made a wedge using strips of gym flooring mats duct taped together, which made it easy to play with dimensions until I found something I liked. If you'd prefer a premade (and less janky-looking) version, Stimulite sells a 2-inch-high wedge cushion for just under \$100.

Another option is to get a Roho Quattro cushion, which has four air compartments and

a valve that lets you seal off the air flow between them. Slightly overinflate the cushion and sit down with the valve open. Put your feet up on a couch, bed or other high surface — which will put more of your weight on the back of the cushion. Let the compartments adjust and then, while your feet are still up, lock the valve.

It may take a few tries to figure out the best amount of air in the cushion. In the end, you should wind up with the rear compartments deflated to your normal Roho pressure, while the front two compartments will be overinflated, pressing up into the back of your thighs, where you have enough meat to handle the extra pressure. This is similar to what a Ride cushion does. Quattros are available from your local DME supplier or a variety of online retailers.

BACK ANGLE

If you change your dump, you're probably going to need to change your backrest angle along with it. Many chairs come with angle-adjustable back rest bars, but there are options even if yours is fixed. Many backrest shells offer angle-adjustable hardware. My personal favorite is the Roho Agility Active, as it's adjustable without clunky, heavy hardware and has an air insert in the middle of the backrest to better protect the skin over my bony spine. If you use an upholstery backrest, adjusting the individual tension straps — tighter at top, looser at the bottom, or vice-versa — can effectively change your backrest angle.

SIMPLIFYING LIFE WITH POWER CHAIRS

BY JENNY SMITH

With the complicated electronics and seating systems on modern power chairs, maintaining my chair — my life — can feel overwhelming. I'd rather avoid problems than have to fix them. But issues still arise. Whether it's a cushion, a small part, or a major fix, always expect a long wait with DME providers and insurance. I try to avoid the long delays by practicing these tips:

- Know the terms of the warranty: What is covered under the warranty and for how long? If your chair is "glitchy," have it checked before the warranty expires. Repairs made under the warranty seem to happen faster since insurance isn't involved.
- Always have a backup cushion available: Most insurance companies will pay for a new cushion every three years, so even if you don't need one quite yet, stay ahead of the game.
- One-stop shopping: When I ordered the new cushion, we requested new batteries, armrest pads, a lumbar support, and upholstery for the backrest. It was more convenient to do everything at one time since we needed to get an order from my doctor, a letter of medical necessity and go through the long wait of insurance approval.
- Get to know your tech: I'll often call my tech first, and he can tell me what to do to avoid a service call. But for this re-

lationship to work, direct your frustration over slow response times at the DME provider or insurance company — *not* the tech, who is just doing his job.

- Just ask: For example, as a quad, I couldn't remove a broken lock on my armrest by myself. Learn to be willing to ask for help.
- Learn from others in the SCI/D community: I asked members in an SCI support group on Facebook how to disassemble the broken lock. With the instructions I received, I walked my helper through the steps of removing the part. I had a functioning, albeit non-locking, armrest until the new part arrived.
- Do your research before you order: Find the owner's manual and order form for your chair online. Get familiar with the available options, such as the seat width and depth, turn radius, base width, tilt or recline features, or ground clearance.

MM

WHERE TO BUY ONLINE

Sportaid, sportaid.com
SpinLife, spinlife.com

DME Hub, dmehub.net
1800wheelchair.com

The Safe, Practical and Convenient way to travel wherever and whenever you want.

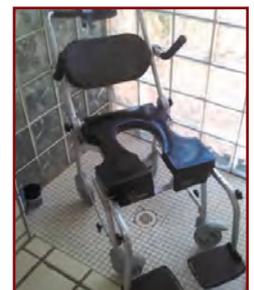
No more waiting for accessible facilities.

- Different models to meet specific needs!
- Simple to assemble; no tools required.
- Safe and easy to use.
- Seat and footrest heights are adjustable.
- Casters have "total-lock" brakes.
- Lightweight and durable, high-quality aircraft-grade aluminum.
- Compact, convenient, and PORTABLE!
- Won't Rust or corrode; easy to clean.
- Virtually maintenance-free.
- Cushions are available in (3) colors and remove easily for cleaning.
- Optional accessories include: wheeled custom travel bag, positioning belts, slide-out commode tray, 2-way adjustable headrest, and upgraded cushions!



Mobility Solutions

"GO-ANYWHERE" Chairs



30-Day Risk-Free Trial

For Home AND On-The-Road;
When Ya Gotta Go, We Go With Ya!"

www.GoesAnywhere.com | Sales@GoesAnywhere.com | 800-359-4021

LIFE IN



BY SETH MCBRIDE

It's been eight months since the COVID-19 pandemic took hold in the United States, and as we've moved through 2020, what began as a public health emergency has morphed into a force that has infiltrated every aspect of our lives. Even as COVID has dominated 2020, other crises have popped up to demand our attention. We talked with wheelchair users across the country and were immediately struck by how varied and dramatic this year's challenges have been, and by the strength and resilience of our community.

BATTERED BY THE STORM

CEDAR RAPIDS, IOWA

Garret Frey was outside soaking up some August sun when he saw the clouds — dark and moving fast. When the wind picked up and the tornado sirens started blaring, he rushed inside. Frey crammed his power chair into the bathroom, the only room in the house without windows, alongside his mother and brother. Outside, there was a sudden downpour and winds ripped through the trees around their house. “We didn’t know what was going on because we lost power within seconds,” he says.

They huddled together as the storm raged for 40 minutes. A loud humming noise like a car going through a tunnel was punctuated with the smack of branches and debris hitting the house. When the wind finally calmed, they left the bathroom to survey the damage. “Every house either had damage to windows, their whole roof, part of their roof, the garages, or all of their fencing. There was nothing but trees down everywhere,” Frey says.

The Freys had survived August’s derecho, the deadly windstorm that ripped across the Midwest and damaged or destroyed an estimated 8,000 houses in Iowa alone, with losses especially catastrophic in Cedar Rapids. For Frey, who uses a ventilator, the sudden disaster wasn’t an isolated event, but the

After a night with his vent plugged into a gas-powered generator, the Freys decided to risk staying with family in a COVID hotspot.



Garret Frey survived close brushes with COVID and climate disaster this year.

latest in a year that had already been challenging enough.

Back in April, one of Frey’s PCAs developed COVID symptoms a day after she had worked for him. She immediately got tested but it took nearly a week for the results. “It’s a waiting game,” says Frey. “All you do is live in fear.” The test came back positive.

The waiting and the fear continued,

but luckily, neither Frey nor anyone else in the household contracted the virus. It was a frightening experience nonetheless, one he didn’t want to risk again.

Now, after a night with his vent plugged into a gasoline-powered generator and an August day without air-conditioning, the Freys decided that the risk of staying with family in Missouri — a COVID hotspot at the time — was less of a gamble than staying put. A few days after arriving in Missouri, his brother got sick with fever and chills.

Frey says his brother “doesn’t believe in COVID, thinks it’s a hoax,” but he agreed to go and get tested. Again, they dodged a bullet — his brother tested negative and no one else got sick. Still, it was like reliving a nightmare, except this time with the guilt that they could have exposed others.

They returned home after eight days, when the power was restored to their house. Frey, who serves on the city’s ADA Advisory Committee, went to work helping to coordinate relief efforts for elderly and disabled residents. He says that up to two weeks after the storms hit, there were still individuals with disabilities who were stuck, unable to leave their upper floor apartments. “It was a mess,” he says.

INTO THE FIRE

REVA, VIRGINIA

Daniela Izzie, a C6 quad who works for Spinergey, was pregnant with twins when the pandemic hit. At the time, there was a ton of uncertainty — about whether her husband, Rudy, would be allowed into the hospital, about her risk of infection and the possibility of passing it to her twins — but Izzie was confident in her doctors and care team [for more, see “Life in the Time of COVID,” NM, May 2020].

As a quad, Izzie had a high likelihood of preterm birth, and true to predictions, the babies came six weeks early. The realities of life during COVID, the fragile health of the premature twins and Izzie’s own complications resulting from giving birth only heightened the emotional rollercoaster of becoming new parents.

Izzie was discharged from the hospital after a few days, but the twins, Lavinia and Georgiana, remained in the neonatal ICU for two weeks. Izzie



Daniela Izzie gave birth to twins during the pandemic.

“I was just doing what needed to be done.”

took time off from her job but, with no paid paternity leave, Rudy had to keep working. “It was really tough because if there hadn’t been the pandemic, I could have asked my mother-in-law to take me down [to the hospital],” says Izzie. But with Izzie and the twins’ weakened immune systems, they had decided to completely self-isolate. “I had to stay home, away from the babies, all day, until Rudy got off work at five. And then we drove down there, 45 minutes, and we would stay there until 11 p.m.”

They were isolated from family, cut off from their community by the pandemic. The church meal train they had planned

on didn’t happen. They wound up eating ramen and other basics, or, on some nights not eating at all at the NICU. Izzie was recovering, immunologically compromised and further stressed by the fact that she and Rudy

could be bringing germs to their still fragile infant daughters. Furthermore, cut off from her babies for most of the day, Izzie developed milk supply problems she wasn’t able to recover from. Not being able to provide breastmilk “was emotionally devastating,” she says.

Looking back at those first weeks, she says, “It was a nightmare.” But at the time she didn’t think of it that way — she couldn’t. “I was just doing what needed to be done. I wasn’t allowing myself to be introspective about the whole thing because that would have been too hard.”

The emotional load eased a little when the girls came home. But Izzie only was able to take six weeks off work, making for another tough transition. When she was first pregnant, Izzie had planned to hire a “mother’s helper” as she called it, basically a PCA that could help her with all the mom tasks — from buttoning clothes, to bottle preparation, cleanup and countless others. But in the height of the pandemic, she didn’t feel comfortable with the exposure of bringing a stranger in their home. “We just don’t know if we can find someone that we can trust,” she says.

The babies are now five and a half months old, healthy and active. Even with family coming to help, between working full-time, raising twins, and managing life as a quad during a pandemic, there’s a lot to juggle. For Izzie though, there wasn’t a choice. She’s figured it out because she had to. That’s what moms do. Being a mom brings her real joy. “We’re over the moon ... just so happy that there’s something good happening in our lives,” she says.

DANI’S TWINS FILM

If Daniela Izzie’s year wasn’t wild enough already, she’s also been filming *Dani’s Twins*, a documentary that chronicles her journey to motherhood. Izzie says the filmmakers have steered clear of the typical inspiration porn, instead bringing a “commitment to learning about disability and motherhood, and telling an unfamiliar story in a way that is truly authentic.”

The film is scheduled for release in 2021. For updates and to see a preview, visit danistwinsfilm.com.



Follow Daniela Izzie

Insta: @daniizzie

Website: danniizzie.com

DADDY/DAUGHTER TIME

FORT WORTH, TEXAS

When Anthony Sanchez talks about his daughter Mya, you can hear the smile in his voice. “She’s amazing. She’s outgoing. She’s funny,” he says. I don’t know if she grew up faster because of my injury ... but she’s very mature. She’s sassy. She’s everything.”

Mya was born seven months after Sanchez started using a wheelchair due to a motorcycle accident that left him with a spinal cord injury at T4. She was about 8 months old when Sanchez and her mother split. Sanchez was battling depression after the accident, but he says, “I always wanted to make sure that I was going to be a great father, regardless. I didn’t plan on splitting up with her mother. I wanted to have this perfect family.”

Reality had interrupted his plans, but Sanchez, who shares custody of Mya every other weekend and whatever weekdays he can, was confident he could figure it out. And he did — from using a reacher to put Mya’s bottle in the microwave; to learning how to roll with her on his lap, one arm holding Mya, one arm pushing a wheel and back again; to, as she’s gotten older, dancing with her at daddy/daughter dances. “Anything they have that I can participate in. I’m doing it. Even if I suck at it, I’m going to do it,” he says.

An unexpected benefit of the world

“Anything they have that I can participate in, I’m doing it. Even if I suck at it, I’m going to do it.”



Anthony Sanchez and his daughter, Mya, have become even closer by trying new, COVID-safe things to do together.

Photo by Jacklynn Lomeli

shutting down was that it brought Sanchez and his daughter even closer. He used to take her out everywhere, to the salon to get her nails done, to the movie theater or to Chuck E. Cheese. With everything closed, he’s been finding new ways to keep her occupied. “Kids get bored really easily,” he says, laughing.

He tries to bring their favorite activities home. They’ll bake cookies together, make popcorn and watch movies — they even set up a living room nail salon. “She would say, ‘Dad, I’m going to paint your toes.’ I’m like, ‘All right, cool. You paint my fingers too.’”

Of course, it’s not all easy. Mya just started kindergarten. When local schools reopened, the first three weeks were all online. Sanchez’s schedule freed up after he quit his job at an engineering firm to focus on building his brand as a content creator, so Mya has been spending more time with him during the school week. With online schooling at such a young age, Sanchez says, “You have to be the teacher.” The school provided a laptop and a dry erase board, but he’s having to translate the online instruction into real world lessons, something he has no experience with. It can be frustrating. Like Mya, he’s having to learn as he goes.

School has since returned to in-person learning, and Sanchez says Mya is making the transition well. Both of them already have plenty of practice dealing with life’s unexpected forks. Whatever comes next, they’ll figure it out, together.

School has since returned to in-person learning, and Sanchez says Mya is making the transition well. Both of them already have plenty of practice dealing with life’s unexpected forks. Whatever comes next, they’ll figure it out, together.

Follow Anthony Sanchez

- TikTok: wheelchairpapii
- Youtube: Behind The Chair A Sanchez
- Insta: @wheelchairpapi

IT WAS GOING TO BE A GREAT YEAR

NEW YORK CITY

Yannick Benjamin and George Gallego had big plans for 2020. The longtime friends and collaborators on the Axis Project, an adaptive fitness and community center in New York City, were finally in the home stretch of launching their dream restaurant, *Contento*. The opening was set for late April and everything was going smoothly.

Then COVID hit. In early March, Benjamin (“2017 People of the Year,” *NM*, January 2018) started to feel lethargic, but didn’t think much of it at first. Then he began to feel worse, similar to how he would when a UTI was brewing. A day or two later, he woke up nauseous and shivering like he’d slept outside in the middle of winter. “It definitely no longer felt like a UTI, he says. “It was something completely different.”

His fever rose to 101, 102, and he spent five days going from bed to couch and back again. He got a telehealth appointment with his doctor, who confirmed that he likely had COVID, but told him to stay put for the time being. Then his wife got sick too, and within two days, she lost her sense of taste and smell; Benjamin’s went soon after. Fortunately, Benjamin, a fit 42-year-old with an SCI at T6, says he never developed a bad cough, shortness of breath or any other respiratory symptoms. He felt terrible for about two and a half weeks, followed by another week or more

of slowly improving symptoms. By the end of the first week of April, he and his wife were finally able to get in for a COVID test, which confirmed that they no longer had the virus, as well as an antibody test, which confirmed that it had indeed been in their systems.

A week later, Benjamin fractured his femur while doing his morning stretches. He went to the emergency room and underwent surgery the next day. It was a spring from hell, yet Benjamin, a sommelier, still considers himself lucky. He works for a private club that has weathered the pandemic better than the vast majority of New York’s dining and drinking establishments. “Every day, there’s a great restaurant

Ultimately, the project will provide training opportunities for wheelchair users to gain experience in the restaurant industry.



Yannick Benjamin and George Gallego planned for a spring opening of their full-service, wheelchair-friendly restaurant. Eight months into the pandemic, it looks like they will soon be able to open for takeout and delivery.

that we’re all familiar with, that we all respect, and they’re closing,” he says. “I don’t know what the future for the hospitality industry is.”

Uncertainty also clouded the future of *Contento* and the Axis Project. The dream behind *Contento* was multi-fold:

to open a quality restaurant, but also to cater fresh, healthy meals for the Axis Project members and provide workshops and other training opportunities for wheelchair users to gain experience in the restaurant industry. “It made sense for one to feed off the other, literally,” says Gallego.

The pandemic hit both establishments hard, but they’ve managed to survive. Gallego and Benjamin hope to open *Contento* in November for a trial run of takeout and delivery.

Despite shutting down their physical space entirely, Axis has managed to find opportunities in the chaos. The organization needed to reduce overhead anyway, and the pandemic significantly reduced commercial real estate values, allowing them to secure a new space with cheaper rent that’s also closer to *Contento*. Their

clients’ insurance companies have allowed them to switch to virtual programming, letting the organization keep its head above water. Members can tune in to accessible workouts, cooking classes, mental health workshops and even follow a physical therapist as he goes for daily walks around the city. “We have been able to engage more people virtually than we did in our space,” Gallego says.

As they work on building out their new location for whenever Axis is allowed to bring members back, they’re installing cameras so that they can

live-stream classes. They hope this type of hybrid approach can reach more of their community than ever.

Follow Yannick Benjamin and Axis Project

 Insta: @yannickbenjamin

 Facebook: TheAxisProject

PEOPLE HELPING PEOPLE

HOUSTON, TEXAS

Early in the pandemic, the phones started ringing at United Spinal Association of Houston. “It immediately became clear to me how unsafe people were feeling,” says Rafferty Laredo, the chapter’s executive director. Members had lots of questions, but he had few concrete answers. One thing was clear: No one had enough personal protective equipment.

So Laredo got to work. He had a random contact at Baker Hughes, a multi-billion-dollar energy services company based out of Houston, and cold-called them. Baker Hughes had access to vast quantities of masks and hand sanitizer that it had been sending to hospitals, but, Laredo says, what was happening

in the disability community “was very much, out of sight, out of mind.” Laredo asked for PPE, and Baker Hughes delivered some 30,000 masks and dozens of gallons of hand sanitizer. After more searching and calling, Laredo was able to find an organization that could donate large amounts of disposable gloves.

With these supplies, Laredo and the staff at United Spinal Houston were able to put together over 500 boxes of masks, gloves and hand sanitizer. The next problem was figuring out how to deliver it all. With staff and volunteers stretched thin, they started slowly, delivering maybe 20 boxes a week. A breakthrough came when Laredo connected with the Houston Mayor’s Office for People with Disabilities, which leveraged the Metro public transit system. “Their drivers were mobilized with as many kits as they could possibly put into their vehicles, and they drove for eight hours straight,” he says. Metro was able to get the remaining 400-plus boxes out into the community in a single day.

Angie Square, a member of the Houston Chapter, had a kit delivered to her home, even though she lives about 20 miles outside public transport’s normal area. “They’re just so giving and genuine,” she says of Laredo and Wes Holloway, the program manager for the Houston chapter. “Anything you need, they’re right there.” Square had been running low on gloves, the result of her DME supplier running out of stock, plus she didn’t have any masks for her caregivers. “The kit was so helpful,” she says. The PPE kit had more masks than she needed, so she ended up sharing with a friend of hers, a polio survivor, who lives in the area.



United Spinal Houston delivered PPE supplies to 500 wheelchair users in its service area.

A LITTLE GOES A LONG WAY

Helen Whitcraft, a 71-year-old retired school teacher and part-time wheelchair user due to a spinal stroke, had recently moved into “a nice little house” that she’d built in Fredericksburg, Texas. She’d made the move to be closer to her daughter and grandkids, and had planned to supplement her meager retirement income with substitute teaching. When the pandemic shut schools down, she applied for and received a \$500 relief grant from United Spinal Association. “It was wonderful,” she says. “I appreciated it so much because it helped a great deal.” Her house was new, but she still had a few access needs — like concrete ramps in the garage and out onto the patio and making a few doorways wider — that the grant allowed her to pay for. It’s the first time since her 2014 injury that she’s lived in a fully accessible home.

“They’re just so giving and genuine. Anything you need, they’re right there.”

That kind of networking helped bolster the chapter’s efforts to expand its reach and visibility. In all, the chapter added about 500 members through its PPE efforts. “I’m hoping that our expanded membership becomes a very quick lifeline whenever the next disaster hits,” says Laredo. **MI**

THE ATHLETE'S QUANDARY: HOW PARALYMPIANS ARE DEALING WITH THE PANDEMIC

BY JESSICA FARTHING



Photo by Yasuyoshi Chiba/AFP via Getty Images

USA's Matt Scott celebrates with fans after receiving a gold medal in men's wheelchair basketball at the Rio 2016 Paralympic Games in Rio de Janeiro on September 17, 2016.

This year, the Olympic and Paralympic Games, scheduled for July, joined a long list of canceled events due to the global novel coronavirus pandemic. The International Olympic Committee rescheduled the games for summer of 2021 and ordered that the Olympic torch remain lit in Tokyo as a “light at the end of the tunnel” for the world. Now, Paralympic athletes poised at the brink of international competition have readjusted their training regimen and mental preparation to qualify in another year. Here are some of their stories.

ELLEN GEDDES: KEEPING THAT COMPETITIVE EDGE

Wheelchair fencer Ellen Geddes got her start in the sport when she was approached by the captain of the Shepherd Swords while still rehabbing at the Shepherd Center in Atlanta, Georgia. “He asked if I thought it would be fun to stab people, and I said yes,” she says.

Since that introduction, Geddes, a T10 SCI, has quickly

moved up the ranks in international competition. She currently ranks first in the U.S. for both foil and epee in her division, and has competed at many World Cup events. She was moving toward her first Paralympic performance in Tokyo this year when the pandemic shut down the competitions required to qualify for the games. To reach her goal in 2021, “we have to qualify again,” she says. “They are going to add two competitions to our previous competitions.”

To qualify for the Paralympics, fencing athletes have to compete in three zones — the Americas, Europe and Asia — within a certain period. Minimally, that is six World Cup events, and points are compiled to create a world ranking list. Since the 2020 schedule was never finished, athletes still have to vie for the top spots. Geddes has her sights set on a World Cup and regional championship already scheduled for February and March of next year to earn her points. Naturally competitive and athletic, she is fine adding more to her fencing schedule.

All these events depend on the global pandemic situation.



Steve Serio in action in the men's final between Great Britain and the United States during the Wheelchair Basketball World Championships at the Edel-optics.de Arena on August 26, 2018 in Hamburg, Germany.

Travel is required, and there are ongoing restrictions in place for athletes to move about freely. COVID-19 is still circulating, and the risk of infection in any large grouping creates a huge challenge for the Paralympic organizers. Also, training regimens have changed, and opportunities for high-level coaching are limited in the United States due to the virus.

Normally, Geddes would fence with the Shepherd Swords and her home team, the Augusta Fencers Club. Plus, she would participate in national team practice at the Olympic and Paralympic Training Center in Colorado, and meeting the team's coach for more practice in Philadelphia. None of these opportunities are available, but luckily, she's been able to continue training. She lives with a fencer, and they spar five to six days a week so she can keep her competitive edge. She also works on strength and conditioning for her shoulders and the small muscles of her back in an effort to prevent injury.

Geddes remains optimistic that the games will continue on the 2021 schedule. "You have to keep moving forward," she says. "You have to trust that things are going to get better and that progress is going to be made."

STEVE SERIO: MISSING THE COURT

Gold medalist Steve Serio began playing wheelchair basketball at the age of 14, when he discovered a team about 10 minutes from where he grew up. "My only regret is that I didn't seek out adaptive athletics earlier in my life because it's literally given me everything that I have," says Serio, a T3-4 paraplegic since he was 11 months old.

By the end of his sophomore year, Serio made an under-19 team that gave him a first taste of traveling out of the country for competition. He was recruited to play on an athletic scholarship at the University of Illinois and after graduating, he signed a five-year professional contract for the German team RSV Lahn-Dill. He played for Team USA in the last three

Paralympic Games and led the men's team to winning the gold in 2016, the first time they'd done so since 1988. For that achievement, he won an ESPY for Best Male Athlete with a Disability in 2017.

He was competing in Wichita, Kansas, at the National Championship when COVID-19 hit in March 2020. By the first day of the event, cancellations were already rippling across the world in reaction to the virus's spread and Serio, an athletic representative on the board of directors of the National Wheelchair Basketball Association, had a hard decision to make. "There was not a lot of information and a lot of uncertainty," he says. "We canceled the junior's tournament and decided to accelerate the timeline for the adults, finishing the next day."

That was the last time he was on a court.

"It's been an interesting transition for me. Not to be on the court, a place where I feel the most comfortable, has been a challenge," he says. "I've grown in other aspects, though, training-wise."

Serio dusted off his handcycle over the summer and implemented cross-training to get exercise. Also, the U.S. Olympic and Paralympic Committee and the NWBA provided their athletes with some home equipment like weights and kettlebells for at-home workouts.

Serio lives in Brooklyn, New York, and recalls there were times during the pandemic when people were afraid to walk outside. But dealing with a disability may have helped him cope with the changes brought by COVID-19. "Living with a disability, you are pretty much programmed to live in a world that wasn't built for you," he says. "There are no excuses, no one is going to feel sorry for you. So, in a strange way, I was a little prepared."

Though his competitive schedule could potentially resume this year, witnessing the pandemic in New York makes Serio tentative about starting too soon. "My parents live on Long Island. My grandfather is living with them right now," he says. "The last thing I would want is to bring



Ellen Geddes hopes to qualify for the Paralympics.

MURDER BALLERS READY TO ROLL OVER THE COMPETITION

Just like with wheelchair basketball, the USA Wheelchair Rugby team is finding it challenging to bring players together to practice and ready themselves for the Paralympics. The 16 -player roster would normally have been culled down to 12 in preparation for the games, but the athletes never reached that point.

Josh Wheeler fell in love with rugby as a way to have the same contact and hits he enjoyed from football before his SCI at both the cervical and thoracic levels. He was looking forward to his second Paralympic experience, having participated in the Rio games in 2016. The USA team was in the United Kingdom for a tournament when everything stopped for the pandemic.

Wheeler had mixed emotions about the season's abrupt ending. "It was hard at first to hear that play and practice was over, that everything you could do was on your own basically," he says. "I actually hadn't taken a break from when I started playing in 2008. I took that and it was nice."

He watches videos and trains on his own, focusing on maintaining his physical readiness for the next possibility to get together as a group. He isn't worried about the team's performance from the break in training. "Our chemistry on the court will come back quickly. Seven or eight of us have had eight-plus years together. Some of the newer athletes might have a challenge, but there is still time. As an athlete, there is nothing I can do about it except train my hardest so that if the games do happen, I'll be ready myself."

Teammate Joe Jackson had a similar set of emotions when the season ended abruptly, "I felt like I was in a really good place endurance-wise, mentally," says the C6 quad. "When COVID struck, I thought it would still be fine. I thought they wouldn't postpone it. Then we got the news, and it was like a kick in the face."

Jackson took the break as a chance to build strength and mental toughness. He studied the game, analyzing it rather than just participating in the physical work. He found keeping motivated by working out at home a real obstacle, so when a former football teammate opened an outdoor workout facility, he jumped at a chance to train in a gym again. He wakes up as early as 4 a.m. to beat the Arizona heat three times a week.

Jackson does feel that the team will eventually have to get back to business. "If there isn't a camp by November or December, we have to look at risk over reward," he says. "If we want that gold medal, we are going to have to train."

Athletes aspiring to the USA team are feeling the pinch from pandemic restrictions. Talbot Kennedy, a C5-6 quad, was a member of the USA Wheelchair Rugby team in 2017. He was working hard toward a Paralympic goal, eventually making a traveling squad in 2018, "Every training camp is a tryout to make the 12-person travel team," he says. "It keeps you on your game. You don't get complacent."

He didn't fit into the lineup for the team in 2019, but planned to get an edge at the tryouts in December after the Tokyo Games. "Sometimes the Paralympic athletes take off after the games, opening spots for others to get on the team to develop and hopefully keep a spot," he says. Once a player gets that spot, they have access to a sports and strength conditioning coach, a nutritionist, a counselor. "There is professional coaching. You have equipment, a medical staff and healthy meals provided for you."

Now, with training stopped, it's hard to get to a higher level of performance. Kennedy feels ready for recreational league play but that extra nudge to get him back on a Paralympic path is missing. He's respectful of the pandemic, despite personal goals, "I'm ready to play, but I take COVID seriously," he says. "I can wait a year out of my life to play rugby."

home COVID-19. I'll continue to train individually and stay Tokyo-ready."

Serio does think that plans developed for the Tokyo Games will be appropriate and reasonable. "I know people are working behind the scenes to create a safe and effective games. The world needs a little unity, and I think the Olympic and Paralympic message highlights that."

BRANDON LYONS: SPINNING HIS WHEELS

A 2014 accident left Brandon Lyons, T5-6, looking for way to stay active. His friends and family hosted a fundraiser while he was in rehab and used the funds to buy him a handcycle. He looked at the equipment as a fun way to recover, not knowing how far it would push him athletically.

When Lyons moved to San Diego in 2016 for a stem cell clinical trial, he became passionate about cycling. He started training full time, and the U.S. Paralympic and the Olympic Training Center in Colorado extended him an offer to live and train at the facility. He was the first handcyclist to be accepted into the residency program. His move-in day was especially sweet, as May 24, 2017 was exactly three years from his injury date.

Tokyo's 2020 Games were Lyons' first opportunity to qualify for the Paralympics. Now, because of the pandemic, the sport had to change its approach to qualifying. The time trial events that grade and rank athletes take place at the end of June. Since COVID-19 closed competition in March,



Joe Jackson is shown on the court in happier, pre-pandemic times.



The 2020 Tokyo Games would have been Brandon Lyon's first chance to qualify for the Paralympics.

there were no real opportunities to earn points. "We were just getting ready," says Lyon. "Our selection event to be named to the world championship team was going to take place in April in Indiana, so we were about a month out. That's what made it difficult. I could feel my body starting to peak at the right time. I was ready to perform. It was tough."

Uncertainty is now his biggest challenge, especially mentally. "I look at it like there's a strong possibility that the games might not happen," he says. "I've already put that into my mindset."

He didn't want to change his training regimen this close

to the games, but it was obvious that the training center wasn't the best place to stay during the pandemic. There were just 13 athletes in residence when he left, and dining options were limited. His work schedule made it hard to meet the food schedule.

He decided to move to take back control of his training and lifestyle, heading to Florida to get closer to family. "I turned a whole room into a training facility. I can ride my bike indoors on a trainer and I have a Tonal Gym, a cable-type machine for training at home," he says. "It works really well for someone with a disability. I can touch the screen to adjust the weight."

Lyon also has access to trails outside around his new home and is thankful for the space. "There's a 12.5 mile stretch out and back, almost the exact same distance as the time trial," he says. "They are building neighborhoods around me so there's not a lot of traffic."

He was invited by a neighbor to take part in group rides organized by a local bike shop. The cyclists in the area were curious about his equipment and the level of athleticism of a man who can outrace their legs with his arms.

His goal is still Tokyo in 2021, even if there's a possibility that the games won't happen. "There is more than just what the United States can control. It's a global event," he says. "Countries can't fly to certain other countries right now. I think it's about a 50/50 chance." M

MULTICHAIR Slider Systems

ALL NEW! MULTICHAIR 6000RS



DON'T REMODEL YOUR BATHROOM, "NUPRODX IT!"

Is the threshold of your stall shower preventing you from rolling in? Is access limited by a narrow shower door? With the new MULTICHAIR 6000RS, you'll be able to get into your existing stall shower without spending \$1,000s on bathroom remodeling costs. NuprodX' exclusive compact modular design allows the system to fit showers of nearly any size. Log on to www.nuprodX.com to see the entire range of shower and commode systems that will improve the quality of life for users *and* caregivers alike. NuprodX, the one system that can last a lifetime. Proudly made in the USA!

Features Include:

- Eliminates bathroom transfers and is an effective alternative when installing a roll-in shower isn't possible or affordable
- Under 22" wide with a rotating base, it easily gets into small, hard-to-access bathrooms and showers
- Available with Tilt-in-Space seating
- Fold-back padded locking arm rests and adjustable swing-away/removeable footrests ease transfers and improve comfort
- 5" casters with Total-Lock brakes prevent swiveling *and* rolling
- High-quality soft and comfortable padded seat and back cushions
- Seat height adjusts over the highest toilets required by the ADA
- Removable locking bridge section available in optional lengths
- Won't rust or corrode: Aluminum, brass, stainless steel and plastic construction—it's going to last!



Tub, Toilet and Shower Access Systems

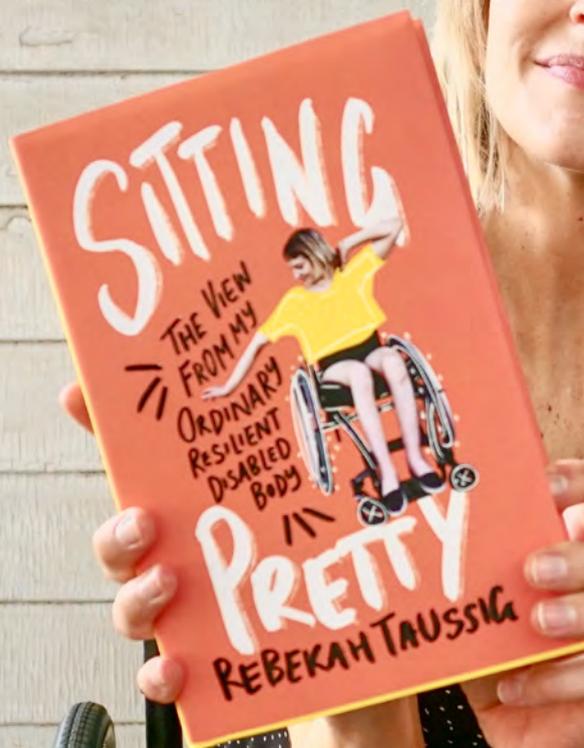
www.nuprodX.com (855) 220-5171

Visit our web site for complete information about our products. *"light, strong, and portable"*

Sitting Pretty:

An Excerpt

Adapted from
*SITTING PRETTY: The
View From My Ordinary
Resilient Disabled Body*
by Rebekah Taussig
with permission from
HarperOne, an imprint of
HarperCollins Publishers.
Copyright 2020.



Rebekah Taussig's engaging, thoughtful book, "Sitting Pretty," is about growing up a paralyzed girl in the '90s and early '00s. Taussig is funny and smart and just sarcastic enough to be interesting and delightfully feminist and charmingly academic — and so is her book. In this excerpt, Taussig explores what it means to be lovable. And more importantly, what it means to love. Published by Harper Collins, "Sitting Pretty" is available from all the usual places. Learn more about Taussig at her site, rebehtaussig.com.

An Ordinary Unimaginable Love Story

Sam Wagner was my one chance — at a love story, at being loved, at living the life of a wife. We went to church with the Wagners, and when Sam and I were 8 years old, he spent all of his allowance money to buy me a \$3.95 Magic Eye book I'd picked out of my school's Scholastic catalogue. His generous gift set off a tiny spark that maybe, if I wished it into the universe with all of my whole earnest heart, Sam would love me enough to marry me one day.

I still don't know what did the trick but slowly, slowly, as the years stretched out and we turned into adolescents, Sam really did start to pay attention to me. He'd sit near me on the bus during youth group trips, and we'd sing along loudly to Relient K. He'd ask me and a handful of other church kids over to his house "to sing praise and worship songs," then ask to braid my hair as we sat around the fire pit in his backyard.

I believed myself so rigidly stuck in my disabled role that it was very difficult for me to believe Sam saw me as anything other than his nonthreatening gal pal. I didn't truly believe he felt anything special toward me until one 2 a.m. phone call, me sitting on the kitchen floor and Sam hiding in his basement, when he said the words, "I'm really into you." "Really?" I said. I could hardly wrap my head around it.

I could never forget how lucky I was to be loved by Sam. Which made the experience of dating him very confusing. Because, it turns out, I didn't actually like him the way I thought I did. I mean, yes, I liked him. Especially at first. But very quickly my crush turned into a begrudging affection, like the way you care for a little brother who grates on your every nerve, but he's been through a lot of life with you and also, he's pretty cute when he falls asleep on a road trip, so you can't just throw him out on big trash day.

The idea of breaking up with Sam never really felt possible, because I knew what it meant. If I ended things with this harmless man-child, I would be alone for the rest of my life. I would never have a family of my own. Never feel loved again. Never feel wanted. And choosing to give all that up felt foolish. I could put up with almost anything to avoid being alone and unwanted.

At the wise age of 22, we decided to get married.

* * *

As you probably have guessed, the marriage didn't go well. Out of desperation to get out, I found myself boldly unafraid of solitude, independence, or even being undesirable to potential love interests. What I found in this fearlessness was delicious: Nights alone drinking red wine and chomping down whole bowls of popcorn with Angela Lansbury on *Murder, She Wrote*. Sleeping in late with purring orange cats circling the top of my head. Reading every Jane Austen novel with hot drinks clumsily concocted from my sputtering, thrifted espresso maker. I leaned heavily into this sacred solitude for years.

I finally started an online dating account because 1. my roommate got a serious boyfriend, and the pair of them seemed very invested in getting me a boyfriend of my own, and 2. I was curious. At the empowering age of 28, I wanted to see: Would a wheelchair really be a giant obstacle for people? Would I put all this thought into my online profile and hear crickets in response? Or worse, would men be cruel? Would they laugh at me? Would they fetishize me? I was prepared for some uncomfortable dates that would make for great stories I could later recount for the entertainment of my best pals. I was even prepared for getting hurt. I wouldn't let myself hope for much more than that.

I'm pretty sure I put more time and energy into curating my profile than any other online dating citizen. I agonized over which pictures to use, trying to find just the right number that included my disability, but to just the right proportion. What handful of images could convey that disability was a part of me without eclipsing all of me? How could I emphasize that I loved my nieces and nephews and eating take-out on porches and my

own funky style without pretending that my paralyzed body wasn't a part of all of it? How could I invite people to really see me without scaring them off?

At first I was pretty bored with the whole dance. There was the older guy with kids who only ever sent me long, quippy messages about how ordinary his life was. I found myself wondering what it might be like to be someone's stepmom, but the messages slowed, and I hardly noticed. There was the sweetie pie in the blue baseball cap who met me for ice cream on a Saturday afternoon and clearly didn't know what to do with a first date who asked follow-up questions after every little life detail he shared.

One notable interaction from online dating was with the scientist — a problem-solver, finding his great riddle in the disabled woman he'd met online! Soon I discovered he had a plan for curing my paralysis. It turns out, he had transformed his experience of Type 1 diabetes through a very specific diet

and was convinced that my ailments could also be solved, at least partially, through a similar regimen. We'd probably have to add some exercises to the routine, but, as he assured me, he'd figure it out.

After a month of these fun times, I was amused, but little more. I had not felt a single spark of connection — in fact, nothing that even approximated a sizzle. I felt like an odd duck. Not necessarily because of the wheelchair in my dating profile pictures, but because something about the way I saw the world didn't match these people I'd met.

Was it the wheelchair that had shaped that lens? Surely in part, right? Mixed with being the youngest of six in a family fueled by feelings and storytelling and the understanding that we had no money all with a backdrop of chemotherapy and surgeries and braces on my legs under the glow of the Midwest in the 1980s and 1990s. All of it, forces at work shaping me into the person who just couldn't brush by life's painful or complicated bits. None of it was traumatic. It just didn't make my eyes dance.

And then, one measly month into the online dating, there was Micah. I found his face while scrolling through pages of profile pictures with my mom, giggling at all the shirtless, bathroom-mirror selfies. We both paused over his charming half grin. He wasn't in a bathroom, no mirrors were in sight, and he was wearing a shirt!

"Send him a smiley face!" my mom demanded. She was giddy over his half-smile.

"Hold on," I said, grinning back at his photo. "Let's just see about this Micah, 28." As I scrolled through his profile, I felt tiny

“
I found myself
boldly unafraid of
solitude, indepen-
dence, or even
being undesirable
to potential love
interests.
”

A Q&A With the Author of *Sitting Pretty*

NM Editor Ian Ruder: The postscript to *Sitting Pretty* has to be one of the more drama-filled postscripts I can remember. You reveal that the day after turning in your manuscript, you and your husband, Micah, found out you were pregnant. Then, seven days later Micah was diagnosed with colon cancer. Add in the COVID-19 pandemic, and you've had a 2020 to rival anyone. How is Micah? How is the baby, and how are you holding up?

Rebekah Taussig: Thanks for asking. It totally depends on what day you ask. We have good days and rough days, but I think the thing that outweighs all of it is that Micah is doing really well. His treatment went really well. The cancer hasn't come back, and he just went in for some tests and there weren't any big red flags. I was really, really relieved about that.

It's such a weird space because it is so hard, but there are also so many things we have to be grateful for, like this baby with his massive cheeks and his two teeth that are sprouting in. And when he grins up at us, it's like, are you kidding me?

He can't really see any of his family besides us, so he lives in this tiny little house with us and we don't have a lot of help because of COVID-19. And so we're kind of like all a little bit raw all the time. It's a lot of everything. It's just so much at once. I feel like a lot of people are in that space though,

even if cancer isn't involved, it's just so much at once.

IR: Throughout the book, and online in your Instagram posts, you talk about the importance of getting your narrative out there and telling your story. What would you say to someone who wants to do that, but doesn't think they have any writing skill or background and doesn't know where to start?

RT: I don't know that it's a matter of having writing skill. If you don't have the writing skill, you probably still won't have the writing skill if you never start writing. I found my voice on Instagram and writing in that space more than I did in graduate school. Wow, that was a bold statement. I've never said that one out loud.

IR: I won't tell your professors.

RT: Thank you. I'm scrambling to retract that one. I would say the two went very much hand-in-hand. I learned a lot in that online space in terms of craft, in part because it's a limited space. And so I would write something that was three times longer than it could be, and I would have to go through and polish and polish and polish until it was short enough.

If you are interested in sharing your

Micah,
Rebekah
and baby



story and having people receive and connect with it, I don't know that that your skill level as a writer is as important as the process of identifying for yourself what your story is and finding those memories or those thoughts. I think we're pretty hungry for true, real life experience in storytelling.

IR: What's next for your writing career? Have you started any new projects?

RT: I'm not sure what I'm allowed to talk about, so I would just say there's a couple of things in the baby stages of coming to life. I'm stepping into some different genres, which is exciting. I can barely chip away at the iceberg in terms of how much more is waiting to be written and read and shared. There's a lot of work to be done. I say work like it's drudgery, but there's a lot of exciting work to be done.

little lovebirds flapping around my head. The more I read, the more I marveled. Was this a real person? Had the internet created him out of a lifetime collection of my Google searches and online shopping? This guy valued storytelling, curiosity, and artistic expression. He liked one-on-one conversations and was looking for someone who would be easy to talk to (Ding! Ding! Ding!). And, the real clencher, he made a joke reference to *Dr. Quinn, Medicine Woman*. Hello, you may have my heart right here and now, really, here it is, it's yours.

I sent him a smiley face.

By the time I'd gotten in my car for the drive home, Micah had sent one back. It wasn't until two weeks in that Micah asked me about my wheelchair. Gracefully, with care and curiosity in the middle of a back-and-forth thread about pain and empathy, he wrote: "You mention in your profile that you've used a walker and a chair since you were young. Is that something that has taught you empathy? How has it shaped your life? Maybe it's a

ridiculous request, asking you to fit such a large matter into a typed message, and maybe there's a more polite way to be curious about such a situation, but curious I am, and so I ask."

His question, his tone, his word choice delighted me. I treasured his genuine curiosity. Not a greedy grab for gory details, but humble interest. An acknowledgment that he didn't know what it meant to me, and he wasn't about to step in and try to fix anything. He simply extended an invitation to me to share my stories. I couldn't have crafted the inquiry better myself.

We spent our first date eating giant cookies dipped in big mugs of coffee on a Wednesday night. When I coasted up the ramp to meet him, I don't remember thinking about how he saw me — what the image of my paralyzed body sitting in a wheelchair might mean to him. Why is that? Maybe, in that moment when I saw him sitting alone on the patio of the coffee shop, I trusted that I was already so much more complicated to him than just one wheelchair or one turquoise dress with a lace col-

lar (which is what I'd chosen to wear after three hours of deliberation). I rolled my hands into a pretend telescope (like I was a pirate sighting him across the ocean?) and said, "It's you! You're a real person!" We sat under a red umbrella, and I started talking too much, too fast, and he smiled and bobbed his head and chuckled sweetly.

Hours passed, I calmed down, and we hadn't even begun to run out of things to tell and ask each other. Even when it started pouring rain, we huddled closer under our red umbrella and giggled at just how wild the storm was getting — were those actual rivers of water rushing down the street behind us?

On one of those early dates, we went thrift store shopping, and Micah confessed he didn't know how to walk with me. "Do I walk behind you? Do I rest my hand on your handlebar?" I didn't know what to tell him, but I liked that he let me in on his uncertainty. "I don't know, how does this feel?" I asked, grabbing his hand and dragging him up the aisle. At first he didn't want to push me anywhere. To him, it felt aggressive, controlling — the opposite of his driving force. "To me, it sort of feels like we're holding hands," I said. He considered. He hadn't thought of it that way before. And bit by bit, we created our own currency, our own intimacies, our personalized displays of affection. From scratch, we imagined our love to life.

I was sure Micah was worried about sex, but he didn't bring it up. In my head, fears about sex was the number one reason non-disabled people didn't ask out disabled people. I felt an urgency to soothe any fears he might be keeping close to his chest, so one afternoon, sitting on my orange couch under the frosty window, I asked, "Do you have any questions about sex?"

Micah was casual and calm. "I actually read a few blogs and a really helpful article about sex and paralysis."

"Did you?" I asked, amused and delighted. How simple, how helpful, how smart!

"Yeah, I mean, I felt a little silly, because they all basically said, 'Of course disabled people can have sex.'"

I beamed at this curious, intelligent person I'd picked to sit with me on my orange couch, to introduce to my cranky cats, to spend all of my Saturdays with. He made the unimaginable love story feel so ordinary.

I was much quicker to know that I wanted Micah in my life for the long haul. He took a little longer, and that stung. It also felt true to his careful approach to life, and probably a bit more reasonable than my flash, bang, boom approach. But even after we both felt comfortable using the word "forever" with each other, we weren't settled on the choice to get married. For me, marriage was wrapped up in the default route to life. I'd been there and had jumped out as quickly as the law allowed.

At the same time, I felt myself longing for a ritual, a day to mark, a ceremony with witnesses, a pocket in time and space to set down intentions with this miraculous, ordinary person I liked the most. Was there a way to build our own structure? To reimagine what two people can be to each other? To wipe the

slate clean and create something from scratch? Did we have to do this thing like anyone we'd seen before, or could we use our unique quirks and rhythms as the guide?

In some ways, I think my disability is the force that disassembled the template to begin with. Then I found a person who already wanted something different, too. From the way our bodies reach for each other to the expectations we have for the future, we are open and curious. Together, we used our blank slate as an invitation for play and imagination.

I didn't want a flashy ring or a one-way proposal. We chose a day to mutually recognize what the other person meant to us and declare our intention to commit to a very large building project together. We made collage wedding invitation zines using magazine clippings and thread. We invited only our families.

There was no aisle at our ceremony, and I definitely didn't walk anywhere. My chair was a part of all the photos, an extension of me, a part of our romance. My dress was short, form-fitting, and all lace. (I also bought it for \$7 at a thrift store three days before the ceremony.) Micah wore a pink floral short-sleeve button-up with a lavender tie, and we rented the rooftop of a building on the edge of downtown. We asked two of our favorite friends, Alyssa and Maren, to officiate, my sister to speak good words around us, and Micah's sister to say a blessing. We all sat in a circle as the sun went down. Micah and I wrote a song together that we sang at the ceremony. It's kind of like a vow song, but mostly a reminder of why we chose each other. A song to get in our heads, to sing in the shower or while we're cooking or when we've forgotten why we're together. A song to come back to us year after year.

Yesterday morning I slept in later than Micah. I'm always sleeper than he is, and on weekends, he gets up first and feeds the crying cats or washes the dishes that have inevitably piled up throughout the week. I rolled out of our bedroom in a giant sweatshirt with my big wooly socks and my bangs sticking straight up like an '80s rocker. I found him working on the computer in our study. Our cranky orange cats were snuggling on the couch behind him, and the rain was making padding noises on our windows. I reached my arms out for him. He moved over to me and climbed onto my lap, straddling me. I nestled into his chest, breathed in his scent, and felt the muscle ropes along his back. This was our space, our story, our love. I rested there for a good moment and savored us.

“
Bit by bit, we
created our own
currency, our own
intimacies, our
personalized
displays of
affection.”

MI



JOSH ON JOBS

By Josh Basile

GOVERNMENT WORK INCENTIVE PROGRAMS ARE HARDER THAN ROCKET SCIENCE

When I chose to become a lawyer after my spinal cord injury, I experienced firsthand how complicated Medicaid, Medicare, Social Security and government work incentive programs truly are. Because of this experience, I strongly recommend that you should not pursue employment alone if you have a significant disability, especially if you receive Social Security benefits or use Medicaid long-term care supports like personal assistance. There is a laundry list of complicated rules and regulations that must be followed or you will get kicked out of the government programs you depend upon.

Navigating Social Security and Medicaid rules by yourself is, in many ways, more complicated than learning rocket science because at least rocket science follows logical rules. Many government programs, on the other hand, have thousands of rules with numerous gray areas. Because of this, so often when I am mentoring someone interested in working, I hear the same questions over and over again:

- If I work, will I lose Medicaid?
- If I work, will I lose my caregiving?
- If I work, will I owe an overpayment to Social Security?

These three questions consistently come up because of the unfortunate horror stories that we've all heard about people with significant disabilities who were not able to follow the rules. Too many of them lost their Medicaid and personal assistance, or owe Social Security lots of money for overpayments.

I have known a handful of people

with significant disabilities who owed Social Security between \$30,000 and \$70,000 in overpayments. For years they failed to properly report their wages to the Social Security Administration and continued to collect their monthly Social Security checks. They thought that when they filed their taxes SSA would know they were working and would either stop sending or adjust their monthly Social Security benefits. In reality, it can take years before SSA realizes there are overpayments and that someone is double-collecting both SSA benefits and a salary.

But there are more positive stories of successful returns to employment than negative ones. The best outcomes for maintaining employment occur for people who navigate all of the rules with help. There are great work incentive programs in place that provide well-trained benefits counselors for free to help individuals with disabilities receiving Social Security benefits. Here's what the two main work incentive benefits programs do:

- The Work Incentives Planning and Assistance program provides benefits planning to individuals receiving SSI or SSDI, and provides priority enrollment to those who are currently working, seeking work or have a job offer pending, as well as transition-age youth (14 to 25 years old) and veterans.
- The Ticket to Work program provides benefits planning and comprehensive employment supports to individuals receiving SSI or SSDI who are looking to return to work, about to be employed or recently started employment.

Strategic benefits planning can help workers with disabilities maintain Medicaid and personal assistance. As a lawyer living in Maryland, I am enrolled in the Medicaid buy-in program and continue to receive government-funded community-based caregiving.

Currently 45 out of 50 states have a Medicaid buy-in program that allows workers with disabilities in a particular state to maintain Medicaid while employed. Like Social Security, there are many rules that must be followed, and navigating a state's Medicaid buy-in program by yourself is not easy. However, when you work with a well-trained benefits counselor, it becomes very doable and can lead to you learning about your many disability employment options and the existence of available Medicaid programs in your state, including community-based personal assistance.

Learning from others' mistakes and pursuing employment with the help of a skilled benefits counselor and disability mentor leads to the best results. This year alone I have mentored hundreds of families about all things related to disability employment. I personally provide free one-on-one job mentoring and match interested people with a WIPA or Ticket to Work benefits counselor. Please message me at josh.basile@gmail.com or fill out this survey: tinyurl.com/JoshOnJobs. Also, as a board member of United Spinal Association, I highly recommend visiting United Spinal's Pathways to Employment program at unitedspinal.org/pathways-to-employment.



DAILY DILEMMAS

By Sheri Denkensohn-Trott

NAVIGATING DURING COVID-19

Q. *Now that COVID-19 restrictions are loosened and restaurants are open again, I invited a friend to a neighborhood restaurant where we could eat outside. The restaurant is only three blocks away from where I live, but we were only able to go one block because another restaurant had extended its outdoor seating so far into the sidewalk that I could not get past it in my power wheelchair. I had to backtrack and then ride in the street for a block.*

I want to easily navigate my neighborhood like I used to before the pandemic. I support the reopening of businesses – especially outdoor dining. I worry, however, that continued expansion onto the sidewalks will further impede my path of travel. Is it legal for restaurants to block my access route? Should I report the offending restaurant to anyone? I am reluctant to talk to the restaurant manager because I'm not clear about the requirements.

– Hungry Quad

Many localities have waived policies in order to allow restaurants to expand their outside seating, with the goal of helping these businesses offset limitations on indoor capacity while offering customers safer dining options. However, as outdoor dining increases, some businesses are expanding seating into legally-required accessible paths of travel, even unlawfully converting their accessible parking spaces into patio seating or curbside-pickup areas. In some

cases, newly incorporated spacing to increase distances between tables is preventing people with disabilities from being able to navigate public sidewalks. Even if restaurants expand their sidewalk seating, the Americans with Disabilities Act, as a general rule, requires them to maintain a 3-foot-wide clear pathway.

It is not permissible for restaurants to impede your path on the sidewalk and thus prevent you from getting through. However, many business owners are unaware of this requirement.

You have a variety of options:

1. You can arrange to talk to the manager and calmly make them aware that while you support local businesses and increased outdoor seating, the restaurant is required to follow the ADA. Because of the blocked sidewalk, you had to risk your safety by riding out in the street to get to your destination.

2. If the manager is defensive or says you are wrong, you can report the incident to your local county or town and file a complaint. You can go so far as to file a complaint for an ADA violation with the U.S. Department of Justice, but that will likely take a long time to process and therefore not resolve your immediate problem.

3. Another option is to research online resources of disability organizations such as United Spinal Association, which produced an informative guide called, "Reopening Your Business in a COVID World:

“Many businesses and other establishments are not aware of how to adapt for COVID in a way that is accessible and ADA compliant.”

Safeguarding Accessibility/ADA Compliance.” You can take the initiative and share this guide (unitedspinal.org/reopening-business-in-a-covid-world/), which is available as a PDF download, with the restaurant, local business groups like the Chamber of Commerce and even appropriate policymakers in your town or county. You might also consider contacting United Spinal or other such organizations directly.

Because COVID-19 is such a new issue, many businesses and other establishments are not aware of how to adapt in a way that is accessible and ADA compliant. In a best-case scenario, you can resolve the problem with the restaurant directly. The restaurant owner may be relieved that you have made them aware of this requirement and change the outside seating so you can get by. Maybe the restaurant will even gain you as a customer if it promptly fixes the problem. But please remember that it is not mandatory that you take this on. Advocacy is an individual choice, although it is usually the right one.



IN THE MEDIA

By Teal Sherer Alsaleh

MAKING SURE DISABILITY STAYS IN THE CONVERSATION AFTER COVID

In January, Danielle Perez seductively maneuvered her wheelchair around a stripper pole in a parody of the film *Hustlers* for the CBS Diversity Showcase at the El Portal Theatre in North Hollywood. The audience was full of casting directors, agents, managers and showrunners.

"It was a sketch I really fought for," Perez, who is a stand-up comedian, told the *Los Angeles Times*. "I'm disabled. I don't have feet. I have a manual wheelchair. I'm fat. I'm Afro-Latina. You don't get to see women like me in roles that are sexy, fun and powerful."

The CBS event was designed to boost the chances of minorities seeking opportunities in Hollywood, and for Perez, a bilateral below-the-knee amputee, it succeeded. She was cast in two projects, including a recurring role in a Netflix series. Then, the coronavirus outbreak struck. "Obviously there are people dying, there are bigger things in the world, but it was devastating to shoot one show and to be getting ready to shoot another, and have both of them pause indefinitely," says the 36-year-old.

Perez is not the only disabled actor to lose out on work because of the pandemic. Robert Romani, who has spina bifida, had just booked a guest star role on NBC's *Law and Order: Special Victims Unit* when filming shut down. "I have been acting for 20 years. It was my first big break," says the 55-year-old.

With their momentum derailed, many performers with disabilities are using the time to reflect, work on their craft and find new ways to be creative — all while pondering the future of disability representation in media.

"Since we don't know what the future of theater, TV and film is going to be, we are now having conversations about how we can make sure that disability gets centered when we do eventually go back to work," says Christine Bruno, an actor and sought-after disability inclusion consultant who facilitates accessibility and inclusion workshops. "[We need to ensure] that all of the gains that we made in the past two, three years don't get siloed and backburnered again."

Some of the gains Bruno refers to are the increase in disability representation and the industry's acknowledgment that it is important and needed. For example, last year CBS signed the Ruderman Family Foundation's pledge to audition more performers with disabilities. The Black List — an annual survey of Hollywood executives' favorite unproduced screenplays — partnered with the Media Access



Danielle Perez



Christine Bruno and Chris Henry Coffey in *Public Servant* by Bekah Brunstetter.

Awards, Easterseals, and the Writers Guild of America Writers with Disabilities Committee, to create The Disability List, a curated list of the most promising unproduced scripts featuring at least one lead character with a disability.

“At first everyone was asking, ‘When are we going to get back to normal?’ And I think people have begun to realize that we are never going to be where we were in February and nor should we,” says Bruno, who has cerebral palsy. “We want to look at this an opportunity to do better, to be better. Now in this time of reimagining rather than resetting ... who do we want to be when we come back?”

A positive takeaway of the shutdown is that acting classes are being offered online, which in many cases, makes them more accessible. “I have wanted to take a character transformation workshop for the past couple of years, but the practitioner is based in London, and when he comes to New York, the places he teaches aren’t accessible. Now it is being offered online, so I was able to do that,” says Bruno.

What Perez, who performs at comedy clubs and festivals across the country, misses most is doing stand-up. “There are not a lot of spaces where I can be a disabled woman of color who is in charge and being heard,” she says. “When I am on stage, I am the show. I am running the room. I am in charge, and I am going to tell these jokes. I am going to entertain people. I am the one orchestrating the energy in the room. There is a lot of power in that, and it is really gratifying.”

Though productions are slowly starting to ramp up with stringent COVID-19 precautions in place, it is uncertain when Perez and other actors with disabilities will be back on stage or on set. In the meantime, Perez is performing in online comedy shows via Zoom and Instagram Live, filming sketches with her roommates, and developing *Wow Rude*, a podcast about pop culture, friendship and being too much. “Now more than

ever I want to create and share what I find funny, and I want to have a good time doing it,” she says.

Update: The series that Perez was cast in earlier this year has resumed production. Prior to filming, Perez had a COVID-19 test and attended a Zoom workshop that laid out the protocols on set. “It feels so good to be working, and I feel very safe,

which I am thankful for as I do have asthma and a history of pneumonia,” says Perez. To see her hilarious take on disability, dating and sex, check out her videos at thedanielleperez.com.

Follow on Instagram

- 📷 Danielle Perez: @divadelux
- 📷 Christine Bruno: @christinebrunonyc
- 📷 Robert Romani: @rjromani

Do you Believe in Magic?

Bowel & Bladder Basics are our Business!

Urological Supplements

Cran Magic +™
bladder, kidney & urinary health.

Mannose Magic™
maintain a healthy urinary tract- flush away E.coli.

Suppositories

The Magic Bullet™
safe & sure! Faster acting, water soluble suppositories.

Bowel Supplements

Magic Cleanse™
promotes fuller movements with greater ease (and less time).

Enzyme Magic™
better digestion= better elimination.



www.conceptsinconfidence.com

2500 Quantum Lakes Dr. #214
Boynton Beach, FL 33426
(800) 822-4050

*one time discount per customer

A SPECIAL THANKS TO
THOSE WHO SUPPORT



PLATINUM



GOLD



SILVER



BRONZE



EXECUTIVE



PREMIER



For more information on how you can support United Spinal and become a corporate member, please contact Megan Lee at mlee@unitedspinal.org or 718/803-3782, ext. 7253.

Acknowledgements on our website, in NEW MOBILITY, in United Spinal e-news or any other United Spinal publication should not be considered as endorsements of any product or service.



ERVIN

By Mike Ervin

OUR NEW ROBOT OVERLORDS

When I was a much younger man, lord knows that the state of Illinois tried its level best to rehabilitate me, in the vocational sense. The Division of Vocational Rehabilitation paid to put me through college and purchased my first motorized wheelchair.

But did it work? Was I rehabilitated, vocationally? Here I am more than 40 years later and I still don't know the answer to that probing question. But maybe rehabilitation isn't the right word for the process of helping cripples get jobs, because when you rehabilitate something, like an old house, you restore it to its previous grandeur. So if I apply that definition, I can say for sure that I wasn't rehabilitated because there was no previous grandeur to restore me to. I was just a teenaged crippled kid.

And when you rehabilitate a person, like a prisoner or a political dissident, you correct them. You show them the folly of the path they were pursuing. You get them to repent and change course and go straight. So according to that definition, I guess I wasn't vocationally rehabilitated, either, because I didn't become a social worker. That was about the only career DVR would pay for a cripple like me to embark upon in those days because we had to play it safe and major in something that would make us employable.

The idea was that if we became social workers, we could go to work for DVR and then push the next generation of cripples to become social workers so that they could go to work

for DVR and push the next generation of cripples to become social workers so that they could go to work for DVR, and so on into perpetuity. It was a drag, but if you said screw it and didn't go to college, your job prospects were even more dismal. Being a store greeter at Walmart wasn't even an option because that was before there were any Walmarts.

But DVR still covered me even though my only career goal ever was to get paid to write. And since that's what I'm doing as we speak, could it be that I actually was vocationally rehabilitated? Maybe this is a cripple success story with a happy ending after all! But I don't know. If the state of Illinois could read this, would it feel satisfied that it got its money's worth on me? Probably not. So I'll just have to say I'm sorry, state of Illinois. You gave it your best shot, and so did I. It just wasn't meant to be. No hard feelings.

I wonder if it's easier for the cripples of today to get themselves vocationally rehabilitated. It might be, in a way, because I imagine that there could be a career option or two besides social work that DVR would deem acceptable. They may say it's OK to study computer sciences. Back when I was in college, computers were the size of a Buick and only NASA had them.

But nevertheless, I fear that future generations of cripples will have a harder time than any of us getting themselves vocationally rehabilitated. Future cripples won't just be compet-

“Even the cripples who play it safe and become social workers and go to work for DVR and push the next generation of cripples to become social workers and go to work for DVR will probably be laid off and replaced by robots.”

ing for jobs with verts. They'll also be competing with robots for jobs. Even the cripples who play it safe and become social workers and go to work for DVR and push the next generation of cripples to become social workers and go to work for DVR will probably be laid off and replaced by robots. And then what will they do? They'll have to make an appointment with DVR to help them find another job. And when they get to the DVR office they'll meet with a robot social worker that speaks with a cyborg voice like Stephen Hawking. And if they don't like it when the robot social worker tells them there are no jobs, they can go over the robot social worker's head and appeal to the supervisor, which will also be a robot.

So all the future cripples who become social workers and go to work for DVR and get replaced by robots will be trying to get jobs as store greeters at Walmart. But those jobs will probably also be done by robots.



The Miami Project to Cure Paralysis

Our Research Center of Excellence, housed at the University of Miami Miller School of Medicine is dedicated to finding effective treatments, Improving the quality of life of individuals with spinal cord injuries, and ultimately, finding a cure for paralysis.

To be considered for current and future research studies, please visit our website:

<http://www.themiamiproject.org>
to fill out a digital intake form
or
call our offices and request a copy of the form by mail.

For more information, call 305-243-7108.



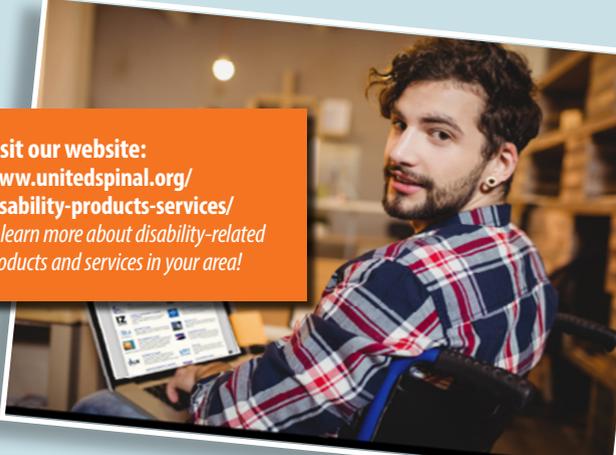
Disability Products & Services
It's All About Choices!

Search the United Spinal Association Disability Products & Services Directory to discover providers and organizations that specialize in optimizing the health, independence and quality of life of people with a spinal cord injury or disease.

Quickly connect with top providers specializing in:

- vehicle & hand controls • therapeutic & bathroom equipment
- urological supplies • scooters • wheelchairs
- ramps • assistive devices

and many other disability-related products and services.



Visit our website:
www.unitedspinal.org/disability-products-services/
to learn more about disability-related products and services in your area!

Don't Become ANTIBIOTIC RESISTANT



Fight and Prevent UTI's

Flush Away E-Coli

Concepts in Confidence
120 capsules for only \$25.95

www.conceptsinconfidence.com
2500 Quantum Lakes Dr. #214
Boynton Beach, FL 33426
(800) 822-4050

ACCESSORIES MADE IN USA!

Added **VIRUS SHIELD**



Available at your local mobility dealer or VAMC.

WeatherBreaker®
Canopy Max Protection

DIESTCO
MANUFACTURING CORPORATION

1.800.795.2392
DIESTCO.COM

YouTube /diestcomfg

Did Your Address Change



If so, please provide **NEW MOBILITY** with your updated information so you will not miss a single issue.

Full Name, Street Address, City, State & Zip Code are needed for **both** the old & the new address. Please allow 6-8 weeks for this change to be processed.

Please mail to:
120-34 Queens Boulevard, Suite 320
Kew Gardens, NY 11415
Or submit your request electronically to:
mkurtz@unitedspinal.org or at
www.newmobility.com

Or call: 800-404-2898 x7203

FOR SALE

2000 Dodge Caravan Sport for sale. Visit www.finalbreak.com/van

2012 Chevy Silverado three quarter on. Converted for a passenger. 41,000 miles. Asking \$32,000. Call 970-620-6480

JSJ Jeans: Specializing in wheelchair jeans. Made in Oklahoma. Call for free catalog. 918-379-5052

New Product, Electric and Manual Wheelchair seat pouch, \$14.99 visit www.cushpocket.com"

Nationwide Wheelchair Van Rentals. For the next time you want to get out, vacation, doctors appointment, or try before you buy. Learn more at www.BLVD.com

Over 1500 wheelchair Accessible Vehicles for sale at one website. A complete selection of New, Used and Pre-Owned wheelchair vehicles from dealers and private parties nationwide. Check it out today. www.blvd.com

New LEVO standing electric wheelchair. \$19,950. Call 530-906-5553

LEGAL

Do you or your loved one need legal assistance for injuries resulting from an accident or medical malpractice? We are here to assist you in finding the best lawyer for your specific case. Call us 1-888-888-6470. www.findinjurylaw.com

VACATIONS

Florida Keys! Accessible 2 /bed-room Waterfront Home, Large Bathroom with Roll-In Shower. Spectacular View, Resort Amenities included. 561-627-1941. www.placidaccess.com

Cape May farmhouse near beach. First floor entirely wheelchair accessible. Sleeps eight. Visit www.beautifullyaccessible.com for more info and reservations.

VACATIONS

St. Augustine Beach 3 bedroom condo. Great location across from ocean in historic Florida North East. Recent renovation for para owner. Excellent local accessible activities. For accessibility questions please contact: dbrucesinclair@gmail.com. For availability, pictures and pricing please visit our VRBO listing: <https://www.vrbo.com/1984785>

New Zealand Accessible Vehicle Hire. New Zealand disability vehicles, hand control cars, left foot accelerator cars for hire. Explore New Zealand – we make it easy! We are happy to pass on our former clients' recommendations of accessible activities and accommodation. See www.freedom-mobility.co.nz

Ocean-front condo, wheelchair friendly, sleeps six, pool, boardwalk to beach. Rents daily, weekly, monthly. St. Simons Is., GA. bmmk4@frontier.com 419-569-6114.

ADVERTISE WITH NEW MOBILITY!

To place your classified ad or to get information on advertising rates, call: 800-404-2898, ext. 7253 or email your request to mlee@unitedspinal.org

WHY THE MIRACLE OF LIFE NO LONGER NEEDS A MIRACLE



*while supplies last

With any Ferticare, Viberec or purchase over 250.00 receive a **FREE 2oz SANITIZER!***

Orion Medical Group, Inc.

(Full D.M.E. Pharmacy Specializing S.C.I.)

Tel. 714-649-9284 / 1-888-64-ORION (67466) / Fax. 714-594-4038

info@medicalvibrator.com

www.medicalvibrator.com

FERTI CARE® PERSONAL

- Treats men and women
 - VA approved
- Inexpensive alternative to fertility clinics
- Help with incontinence thru Kegel Exercise
 - Ferti Care 2.0

New Female Version of the Ferti Care Available Now



Challenge Circuit
7000

QUANTUM
Q100 Bathchair



WWW.APEXEQ.COM • 800-851-1122



United Spinal Association PATHWAYS TO EMPLOYMENT

United Spinal Association's Pathways to Employment (PTE) program supports the pursuit of new job opportunities and a successful career for people with spinal cord injuries (SCI) by providing the tools and support necessary to successfully overcome barriers to gainful employment.

www.unitedspinal.org/pathways-to-employment/

Meet New Member Jason Sims

Age 33, from Houston, Texas
Transverse Myelitis

Accessibility Chair for Pride Houston

Why I joined United Spinal: I joined when I decided that it was time to embrace my disability. I wanted to connect with others who understood what I go through on a daily basis.



What is the one disability-related product you couldn't live without? My wheelchair is my lifeline — it allows me to be a part of the world. It's made life as normal as possible.

If you could change one thing in the world to improve quality of life for wheelchair users, what would it be? I like to see accessibility in all forms. I have been very vocal about it most of my life, even before I became paralyzed. Not being able to get in places that my friends can enter is very disheartening.

Meet other members or join United Spinal at unitedspinal.org

WHEELCHAIR CONFIDENTIAL



LOVE HURTS

I woke up one morning with a red, swollen knee that alarmed me enough to go to my doctor. During the exam, he got stressed and asked, "Are you having chest pains or trouble breathing?"

Confused, I shrugged, and told him, "No, I just thought I might've hurt my leg."

"We need you to go to the hospital right now, this looks like a blood clot," he exclaimed. "We will call you an ambulance!"

An ambulance? A blood clot? I felt fine, so I opted to drive the block to the hospital. Once inside, the reality that it was 5 p.m. on a Friday during flu season set in. I ended up waiting seven hours surrounded by coughing fits and growing increasingly freaked about having a ticking time bomb of a blood clot inside me.

Finally, I got a bed and around 3 a.m. the doc had an answer. "No blood clot," she said. "But you broke a bone behind your knee, a rare one. I wonder how, since it's not a common break." Hearing that, I knew. A couple of nights earlier, exploring new sexual positions, my partner twisted my knee in a weird way and I heard a pop.

Embarrassed about my injury, I told her that it likely happened during a weight-bearing exercise requiring kneeling. The most painful thing was breaking the news about my broken bone to my boyfriend. He felt absolutely terrible.

Maida Glass

Instagram Follow



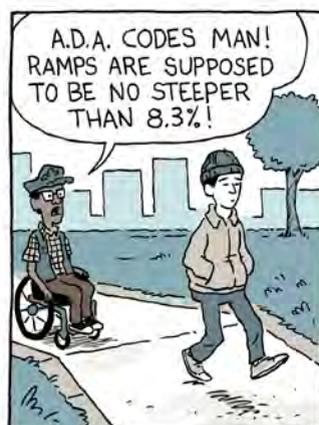
Liked by tealsherer and 205 others

newmobilitymag Paralympic dual athlete @birgitskarstein is currently competing in the 16th season of Skal Vi Danse, Norway's Dancing With the Stars.

"I like the show because it's so demanding," shared Skarstein in an interview for Paralympic.org.

Follow New Mobility on Instagram at @newmobilitymag

PLEASE REMAIN SEATED



www.matbarton.com

You got this!

Abilities EXPO

Serving the Community
Since 1979

At Abilities Expo, you can...

- Build independence with the latest products
- Learn tips and life hacks at workshops
- Improve fitness with adaptive sports
- Open doors with service animals
- Change the game with new tech
- Get answers from the experts
- Embrace your abilities through dance
- Access facts on therapeutic cannabis
- And so much more!

**FREE
ADMISSION**



Follow Us!
#AbilitiesExpo

www.AbilitiesExpo.com
Register online today. It's free!

Precautionary health procedures will be in place at the Expo. Stay safe, everybody!

Los Angeles
March 12-14, 2021

Toronto
Spring 2021

New York Metro
April 30 - May 2, 2021

Chicago
June 25-27, 2021

Houston
August 6-8, 2021

Phoenix
Sept. 10-12, 2021

Miami
Nov. 5-7, 2021

Dallas
Dec. 3-5, 2021



**NOTHING'S HELD
YOU BACK BEFORE.
YOUR PHONE
SHOULDN'T EITHER.**



From our website to our phones, we offer a wireless experience that keeps everyone in mind. You can get Unlimited Talk & Text plans starting at \$20 a month. Plus keep all the data you don't use with **Unlimited Carryover® Data.***



*Actual availability, coverage and speed may vary. *Unused data will not expire if service is active and in use with the Unlimited Talk & Text Smartphone Plan. A month equals 30 days.