



UNITED SPINAL
ASSOCIATION'S

Kissed by a Cheetah Resiliency Telehealth

NM
NEW MOBILITY

United Spinal CEO Vincenzo Piscopo: Leading from the Heart



TO
SUBSCRIBE,
CLICK HERE

newmobility.com

MAY 2021 \$4

A SPECIAL THANKS TO
THOSE WHO SUPPORT



**United Spinal
Association**



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.

If You Have Pressure Sores *You Need This Cushion*

Aquila cushions have healed thousands of sores worldwide.

Recommended by physicians and therapists for 20 years with more clinical data than any other cushion on the market.

Upgrade to the best.
Upgrade to Aquila.



- Automatic alternation simulating pressure lifts up to 60 times per hour
- Custom built to offload where needed while stimulating circulation

Call today to find a dealer near you
or visit www.aquilacorp.com
for more information.



Shown without cover

AQUILA CORPORATION
Seat Cushion Systems

HCPSC code E2609

AquilaCorp.com



866-782-9658



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

Our Mission

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

Our History

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

About VetsFirst

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

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

Timely Support

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

Valuable Resources

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

Our Core Beliefs

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

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

Timely Access to Quality VA Health Care and Benefits

We support improved access to VA health care and compensation and pension benefits that are the lifeline for many veterans with significant disabilities.

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



www.vetsfirst.org

Vincenzo "Enzo" Piscopo's resume raises the question, what do you get when you blend an impressive background in corporate America with a degree in creativity and a passion for disrupting the status quo? JOSIE BYZEK answers that question and more in her profile of United Spinal Association's new president and CEO.

COVER STORY

ENZO! MEET UNITED SPINAL'S NEW PRESIDENT 20

Cover and Contents Photos by Gabriela Isabel Photography

FEATURES

16 IS TELEMEDICINE FOR YOU?

Wheelchair users have fought for easier access to health-care for years. Could the pandemic-hastened arrival of telemedicine be the breakthrough we've been looking for? TIM GILMER reports.

26 ENCOUNTER WITH A CHEETAH

While on vacation in South Africa, DAVID LOWY's wheelchair caught the attention of a cheetah. Nobody was prepared for what happened next.

29 COPING WITH COVID-19 While the world worried about the physical threat of COVID-19, the virus did its best to undermine our mental health and stability. Wheelchair users tell BOB VOGEL how they are adapting.

DEPARTMENTS

- 4 BULLY PULPIT
- 5 BEHIND THE STORIES
- 6 SHARE
- 7 UNITED NEWS
- 8 NEWS ANALYSIS
- 10 REFRAMED
- 12 PRODUCTS
- 14 HOW WE ROLL
- 34 IN THE MEDIA
- 36 DAILY DILEMMAS
- 39 CLASSIFIEDS
- 40 LAST WORD





**NEW MOBILITY IS THE
MONTHLY MAGAZINE OF
UNITED SPINAL ASSOCIATION**

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

EDITORIAL

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

CUSTOMER SERVICE

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

ADVERTISING SALES

MANAGER, CORPORATE RELATIONS:
MEGAN LEE, 718/803-3782, EXT. 7253

ADVERTISING SALES ASSOCIATE:
BOB VOGEL, 916/768-4802

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 32, Issue 332, is published monthly by United Spinal Association, 120-34 Queens Blvd., #320, Kew Gardens NY 11415. Copyright 2021, 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

SLEEP QUEST PART TWO

Last March, I wrote about my abject failure as a sleeper and my quest for nighttime redemption. I ended the column on a cliff-hanger, as I received my sleep study results and found out I have extreme sleep apnea.

A few readers inquired to find out what happened next. In all honesty, I'd hoped to have an interesting (if not exciting) conclusion to share.

Sadly, 14 mostly-sleepless months later, and over 66 weeks since my initial sleep study, instead of anything resembling a satisfying result, all I have is another lengthy list of delays and frustrations and more uncertainty. In other words, the same old, same old.

It all started with my doctor confirming what a nurse had already told me: I have sleep apnea, it is extreme, and we needed to schedule another sleep study to get better data and come up with a solution. As unexcited as I was about another night sucking down the jet engine-like airflow of a CPAP machine, I signed up for the first appointment in hopes of finally getting some resolution.

Unfortunately, that appointment happened to be in the middle of March 2020. Two days before my night at the hospital, I received a call saying all non-essential appointments had been cancelled.

#ThanksCOVID

Over the next 10 months I experimented with every sleep variation I could think of: pills, supplements, Breathe Right strips, temperature regulation, different sleeping positions ... you name it, I tried it. Occasionally I thought I'd stumbled on the perfect blend, but after a couple of nights of semi-decent sleep, I inevitably found myself lying in bed awake wondering how I could be so naïve.

Last winter, the scheduling service for the sleep clinic called to inform me they were once again booking appointments.

With no vaccine in my body or in sight, the idea of wearing a communal mask in a hospital on an overnight stay wasn't on my COVID to-do list.

By the time I finally did get my first dose of vaccine (#TeamModerna), re-scheduling the sleep study had a place near the top of my Fun Medical Tasks Post-Vax list — right above “fix gross toenail.” Unfortunately, because so much time had passed, the study required another authorization and, of course, that required another doctor visit.

In one of the few serendipities of this saga, the option to see my doctor online saved me a trip to the hospital and made scheduling faster and easier than it had been the first time. After a predictable online chat, my doc apologized for the delays and assured me we'd end my sleep quest quickly. She told me to expect to hear from the scheduler in three to five days and said she'd see me again two weeks after the study.

That was over three months ago. I still haven't seen or talked to her again. I finally did the follow-up study a week prior to writing this, but only after a paperwork error and a problem with authorization from my insurance led to countless phone calls and two months of delays.

Still, last Wednesday night, as the sun was setting on the warmest day of the year, I rolled into the hospital with my pillow and blanket, hoping for progress. For eight hours I did my best to fall asleep while the sleep technician seemingly did his best to thwart me.

I don't have the results from the study yet, but based on the technician's disappointed face when I left, I'm not optimistic.

As for what's next, I'm not sure. The only thing I am sure of is that if history is any guide, I'll have plenty of time to figure things out.



BEHIND THE STORIES

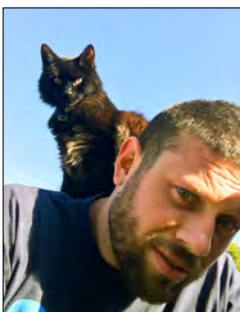
With Ian Ruder

David Lowy has been an elementary school teacher for 22 years, and it only takes one glance at his passport to tell he's made the most of his summer breaks. Lowy has visited over 30 countries in addition to making multiple trips to Europe and Southeast Asia. "I do love to travel," he says. "Italy is probably my favorite destination. It's also the most inaccessible, but I love the food, the people, the architecture and the art." In this issue he recounts a recent trip to Africa that resulted in a too-close-for-comfort encounter with a cheetah. Up next on the bucket list? The Darvaza gas crater in Turkmenistan, also known as The Gates of Hell.



Josie Byzek got her first glimpse of Vincenzo "Enzo" Piscopo when he spoke at the 2018 Roll on Capitol Hill. She came away impressed. "I wanted to profile him back then," she says. "I remember thinking it was cool that one of us got that high in corporate America, and I wanted to know more." We had him on a short list of people to feature before he became United Spinal's president and CEO, and once his new position was announced the assignment was a no-brainer. Byzek was all in. "I love getting to know somebody and figuring out how to tell their story," she says.

Adam Cooper is the nondisabled half of the power duo behind our Last Word comic stalwart, Please Remain Seated. He and his creative partner, Mat Barton, have been churning out media since the two met while attending Cal State Fullerton almost 20 years ago. As much as the two are good work partners, they are better friends. Sometimes work calls turn into something more. "It's an excuse to talk to each other," says Cooper, with a laugh. "If I can make Mat laugh, then I know I'm onto something. Those conversations are just the most fun to have."



COLUMNISTS

MAT BARTON • JOSH BASILE
SHERI DENKENSOHN-TROTT
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
LOREN WORTHINGTON

WEB PARTNERS

BACKBONES
CURB FREE WITH CORY LEE
PARTNERSHIP FOR INCLUSIVE
DISASTER STRATEGIES
ROLLIN' RNS
ROOTED IN RIGHTS
SPINALPEDIA
SPIN THE GLOBE
WHEELCHAIR TRAVELING

FEATURED WEB PARTNER:

The Partnership for Inclusive Disaster Strategies works for equal access to emergency programs and services and full inclusion of the whole community before, during and after disasters.
[Disasterstrategies.org](https://disasterstrategies.org)



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

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

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

MARCH 2021

The Fight for the Right Chair Great Customer Service Makes a Difference:

Serious changes need to happen so people can obtain durable medical equipment. This goes for private and government insurance. I submitted an insurance claim to obtain a TiLite ZRA back in 2012 and the process was ridiculous. My next chair, a TiLite ZR, I paid cash for in 2017. It set me back some serious cash but it was worth my mental health. I ordered my chair through dmehub.net and the owner took a huge amount of time to help guide me through finalizing these measurements. He was a huge help and I still use his online store for just about everything I need. He is all about customer service.

Many people cannot pay out-of-pocket. I feel like innovation will suffer if there is a broken system in place.

Mike

Newmobility.com

Terrible Customer Service Creates Misery:

I've had some pretty crappy experiences with the suppliers here in Hampton, Virginia. The guy who did my assessment with this one I've had since January pretty much took liberty with most of the options on my chair. I didn't get a chance to look at anything he ordered aside from the color when he came out for the assessment. It was so unlike the assessments I had in the past that I assumed he was coming back for a second visit to show me more options, and he lied and said he was. I was preoccupied with work and school and thinking this chair would take as long as

"The process was ridiculous."

the others so when they called to tell me my chair was ready, I was caught off guard. My other chair was giving me so many problems at work that I felt like I had to just deal with this one but it's already got pieces falling off after a few months. I pray the next company I work with does me right. With the way this chair is going, I'll end up having to find a way to get a new one on my own.

Amber Weddington

Facebook

We Can't 'Make Do': All those who say or decide we can "make do" with the cheapest, most barebones wheelchairs available should all have only one pair of ill-fitting shoes to wear for at least the next five years. Then when it finally comes time to get a new pair, they can only purchase the shoes that someone else tells them are allowed.

Zona Housh

Newmobility.com

Faster, Lighter, Smarter – M25 Power Assist Wheels

Not So Smart: I just got the SmartDrive, but I don't like it at all. I feel like I have no control over it. Would the power assist [wheels] be a better fit for me? What's the difference?

Christina Loffredo Passarella

Editor: For the answers to this question and a robust discussion on power assist, please visit our Facebook page.

Outdoor Tracks: Wild About Walleye

Wilder About Walleye: I love fishing as well and usually fish in northeast Minnesota in the smaller lakes, not Lake



Superior as it is too unpredictable. I enjoyed reading this article as my fish of choice is also walleye. This fish is absolutely delicious! I could relate to the anticipation, excitement once the line pulled, and then actually catching the fish. Last time we fished we caught our limit of walleye and had to stop. Thank you for this article. It made life a little easier today, as it was a pleasure to read where someone was having fun.

Karen McCulloh

Newmobility.com

Bully Pulpit: Do Life

Keep Doing Life: How best to "do life" is a question I ask myself every day. I loved this blog, Ian, and am so happy that you came through this latest tough patch very well, with renewed determination to helping everyone "do life" with as much clarity and purpose as possible.

Ann Mandelstamm

Newmobility.com

Web: newmobility.com
Facebook: [@newmobility](https://www.facebook.com/newmobility)
Twitter: [@newmobilitymag](https://twitter.com/newmobilitymag)
Instagram: [@newmobilitymag](https://www.instagram.com/newmobilitymag)
YouTube: bit.ly/3980Fu4

NEWS FROM UNITED SPINAL

A NEW SOURCE FOR SCI/D ANSWERS

United Spinal Association's Resource Center is pleased to introduce Resource Center Live, a free monthly Zoom roundtable, as a new way for members to get their SCI/D questions answered. "It's an opportunity for everybody to come join us in an informal way, meet the Resource Center team here at United Spinal and bring their questions about anything related to spinal cord injury or disorder," says Lindsey Elliott, United Spinal's director of member initiatives. "Any question is fair game."

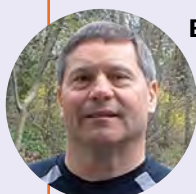
Every year the Resource Center team personally responds to hundreds of inquiries from people across the SCI/D community, resolving questions ranging from health, to employment, to legal resources and beyond. Until now, most inquiries came via phone or email. Resource Center Live provides a new means for people to pose questions and tap into the team's years of lived experience.

"We wanted to make our services more interactive, and this gives us the ability to do tours of what the Resource Center offers," says Elliott. She points out that many people who reach out to the Resource Center are unaware of the vast amount of knowledge the team has collected and archived on its website. "If you're looking for a specific resource, we can actually share our screens and take you through the online Resource Center and show you where to find the resources you need."

The casual setting also allows attendees to get to know the six team members and their unique expertise and perspective better (see box below). "Resource Center Live helps us build more of a rapport with the attendees," says Elliott. "Making the interactions more personable is a big step in helping people get comfortable to ask what are sometimes intimate questions."

Resource Center Live is held at 4 p.m. EST on Zoom on the fourth Wednesday of every month. The sessions are free, but pre-registration is required. To register, visit unitedspinal.org/events/resource-center-live.

Resource Center Team Specialties



Bill: Virginia-based team leader, living with paraplegia — home modification options, low-tech personal transportation options.

Jane: Massachusetts-based, SCI nurse information specialist — guidance to appropriate SCI-related medical resources, research survey process, Medical and Scientific Advisory Committee liaison.

Bill Lindsey: North Carolina-based, master of social work — peer support group development, training, organization and implementation.

Daniela: Washington D.C.-based, living with quadriplegia — resource development, travel by air/wheelchair accessible van, inquiries from Spanish and French speakers.

David: New York City-based, living with quadriplegia — membership coordination, New York City resources and high-tech adaptive driving.

Jose: New York City-based, living with quadriplegia — advocacy efforts, New York City resource specialist, high-tech adaptive driving and smart home tech.



Jose



Lindsey

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

Special offers and discounts from partnering organizations

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 75 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.



By Seth McBride

FAULTY BOOTSTRAPS IN TEXAS

It's the middle of the night in Texas, a state with an economy larger than Canada's, and Emily Wolinsky has to decide whether she wants to try surviving without her ventilator, or whether to let the ventilator continue blowing 40-degree air up her nostrils.

The ventilator is blowing 40-degree air because that's the temperature inside her house, the result of a massive winter storm that devastated Texas. In attempts to reduce stress on the state's power grid, utility providers shut off power to millions of Texans as temperatures dropped into the 20s, sometimes for multiple days.

Wolinsky, a student accessibility services associate advocate at Austin Community College and president of the nonprofit NMD United, was one of many disabled Texans who were left to fend for themselves without basic services. After three freezing days and nights, the power came back on and she recounted her harrowing experience in a story she published on The Disability Visibility Project. You can read her tale in its entirety at: disabilityvisibilityproject.com/2021/02/24/still-in-texas

In it, she goes into the details of surviving those three days, but also how the storm burst her "bubble of independence" — that Lonestar, pull yourself up by the bootstraps Texas ethos that she'd bought into when she moved to Austin after college. "I thought that if I paid my bills and my taxes that this would be enough to receive ongoing social ser-

vices and basic protections, like access to utilities, street upkeep, etc. Meeting my civic responsibilities as an adult would keep me an independent disabled Texan and that, I thought, kept up my end of the bargain," she writes.

Apparently that's not how everyone sees it. "Nobody owes you or your family anything; nor is it your local government's responsibility to support you during trying times like this!" wrote the (now former) mayor of Colorado City, Texas in a Facebook post during the

storm. "Sink or swim it's your choice!" That's about as extreme as a pull yourself up by the bootstraps mentality gets.

So, with climate change making formerly once-in-generation storms all the more frequent, I got in touch with Wolinsky to chat about what she learned about self-sufficiency, her state, how to

create more resilient communities and, of course, bootstraps.

NEW MOBILITY: In the story you talk about coming to Texas and buying into the ethos of independence. With this storm, do you think that it changed how people in Texas view this independence mindset?

EMILY WOLINSKY: Because it's Texas, I just think it made people more proudly believe that if they're going to survive, they need to depend on themselves. I don't think it helped.

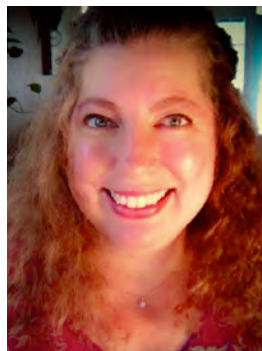
Overall, the experience made me want to get to know my neighbors better, and I want them to know that they can come



"The storm burst her 'bubble of independence' — that Lonestar, pull yourself up by the bootstraps Texas ethos that she'd bought into when she moved to Austin."

talk to me if they need help. I was pretty isolated before this. I know people who are friends with all their neighbors, and they have block parties. That doesn't really happen in my neighborhood, and that needs to change.

But I have no faith that anything Texas is going to do emergency-management-wise is going to work. I don't have much faith in our local politicians working toward helping people with disabilities.



Emily Wolinsky



Illustration by Mark Weber

Still, I'm going to try — like I'm speaking at the governor's committee on people with disabilities next week — but I know the governor [wheelchair user Greg Abbott] won't hear it.

NM: That's a terrible realization to come out of an experience like this with.

EW: It just confirmed my fears that I would be completely left for dead. I'd always assumed that before, but now I can actually say, 'Yeah, that's true. That's what happens.' Our government's leadership does not care about people with disabilities and it's shown. Our governor is the Texas king of giving no f—s, and he has a disability, which reflects his inability to empathize with his voters.

NM: What do you think it would take to create more resilient systems so that Texans in general and disabled Texans in particular never have to go through something like this again?

EW: It's going to take someone who's not an ableist to go into a leadership role and prioritize people with disabilities and other more vulnerable populations. Texans with disabilities need to get involved in their local politics. Like my friend Ali Ramos is running for city council of Amarillo. There are people out there like Val Vera who is very active in his small community of

Denton. Mutual aid programs are huge for people with disabilities. Going local is going to be really, really important, and that's how it'll change.

NM: You grew up in Upstate New York. With how bad this past experience was, did it ever shake your faith in staying in Texas?

EW: I would probably leave if it were just about what my services are. But there are so many wonderful people in Texas, like my personal care assistants. The people in my life, the relationships I've built and my job — everything about being here is good. It's just unfortunate that it can't be like that for everyone all of the time. I can't move because I just couldn't say goodbye to all the people I love.

NM: So if Texas is taking self-sufficiency to the extreme, are you investing in a more powerful pair of bootstraps?

EW: We bought a generator, and now we're nervous we didn't buy a powerful enough generator. We're turning into weird preppers. Technically, this kind of storm hasn't happened in 30 years, so you're basically buying peace of mind. I bought a \$1,200 generator — that's how much peace of mind I have, and I don't know if it'll hold out. Since Elon Musk is here, it'd be neat if I could get some solar-powered bootstraps.

Did You KNOW...



United Spinal Association produces more than 30 brochures and pamphlets on subjects like *Disability Etiquette*, *Fire Safety for Wheelchair Users at Work and Home* and *Understanding the ADA*. You can download them for FREE or order printed copies on our website at www.unitedspinal.org



REFRAMED

by Reveca Torres

FOOD, FEELINGS AND FUNCTION

“Have you eaten?” It’s the inevitable question from my mother, regardless of my age or the fact I’ve lived independently for over 10 years. It used to annoy me. Does she think I’m not capable of managing what I eat?

As a quadriplegic with an inaccessible kitchen, I never thought I’d be able to cook — dicing, chopping, picking up pots and pans. Turns out I can. Whether I’m following a recipe or I’m creating something with the food I have available in my home, my role is to give step-by-step instructions, assess if we’re on track, taste-test and approve the final product.

My personal attendant serves as my hands, following instructions and occasionally offering suggestions. With her hands and my directions, we have fun cooking up a tasty feast or sometimes barely edible experiments. She pre-cuts and assembles my meals in containers and places them in the fridge where I can reach. Retrieving my food requires control and precision. If I drop things and no one is around to pick it up, I can’t eat and there’s a mess on the floor that only the cat will enjoy.

I think about food a lot, mostly because it’s good, but more importantly it impacts my life as a person with a spinal cord injury. As I have gotten to know my body, it is fascinating to see that what I consume makes a difference in how I feel and function. Which foods provide the nutrition I need to help my skin stay intact, my bones strong, my gut healthy and my immune system ready for battle? To me, food is medicine when I am sick, and it is the life of a dinner party. Food is culture and a connection to the Earth and my family.

It doesn’t bother me when my mother asks anymore. Sometimes I hope she asks, “Have you eaten?” With a full stomach I reply, “Yes, but what’d you make? Yes, I want some!”





Discretion by design

Introducing a discreet catheter with design that is truly inspired.

The **Infyna Chic™** Hydrophilic Intermittent Catheter was designed with input from clinicians to help provide a high level of discretion for women who use catheters. It is beautiful and easy to use. The **Infyna Chic** catheter can help a woman feel better about having to use one.



Request a sample today!

Visit www.Hollister.com/InfynaChic or

Call **1.888.808.7456 (option 3)**



Infyna Chic™

Intermittent Catheter

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

The Hollister logo and Infyna Chic are trademarks of Hollister Incorporated. © 2021 Hollister Incorporated.



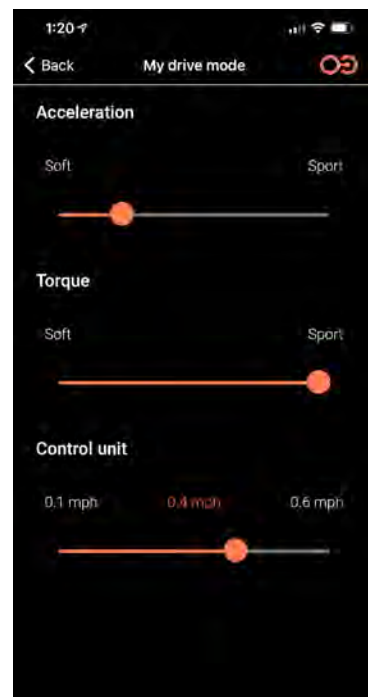
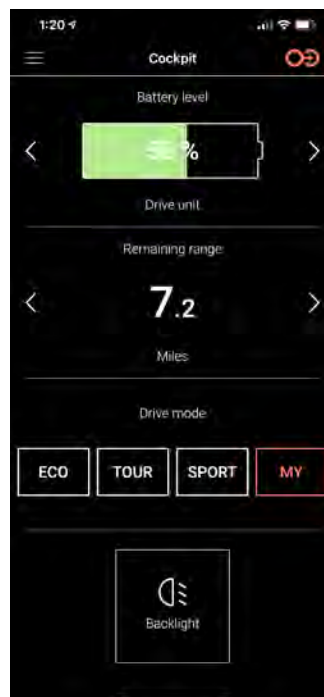
Continence Care



PRODUCTS

By Michael Franz

TESTING THE SMOOV ONE



The author tested the SMOOV One power assist unit on his rigid manual chair, left. Screenshots from the app, above, show information like battery level and remaining range, as well as acceleration and torque settings.

Finding a way to protect your shoulders is a priority for many manual wheelchair users. The human body is not built to push a wheelchair and our shoulders take most of the punishment. The SMOOV One by Alber is a new rear-mounted power assist wheel that can be attached to both rigid and folding wheelchairs. It aims to reduce stress on our shoulders and make it easier to push our wheelchairs. At the time of this review, I was dealing with cartilage damage in my left shoulder and knew I needed to find a way to protect my shoulders. I decided to put the SMOOV One to the test.

The Review

Typically, a technician from a DME provider would install the SMOOV One, but COVID restrictions prevented that. Nevertheless, my aide was able to install the 16-pound unit in about 20 minutes by attaching a mounting bracket to my wheelchair's camber tube. The only tricky part was getting

the bracket perfectly centered and making sure that the locking mechanism was at the proper height so the SMOOV One made contact with the ground.

For folding chairs, an adapter axle is available that attaches to the quick-release axles on the wheels. The drive unit locks on the adapter axle in the same way that it would lock onto the mounting bracket on a rigid chair. The final step in the installation process is attaching the mounting plate for the control unit, which can be installed anywhere convenient on the frame. Once everything is installed correctly and turned on, the drive unit and control unit link via Bluetooth, and the SMOOV One is ready to go.

The SMOOV One is easy to use. The speed is controlled by turning the dial on the control unit forward and back. The dial turns easily, so it is best to start slowly and work your way up to higher speeds. It is easy to accelerate too quickly, which can lead to dangerous situations. The SMOOV One has a maximum

speed of 6 mph. It feels very fast — much faster than what 6 mph feels like in my power chair. Once you find an appropriate speed for what you are doing, all you need to do is steer the chair like normal.

Slowing down and stopping the SMOOV One can be done in two ways. First, the user can turn the dial on the control unit backwards to slow it down. If the user turns the dial back far enough, the SMOOV One will shut off. Second, the user can tap the dial on the control unit to stop the SMOOV One faster. This will shut the drive unit off, and the chair will gently — but quickly — slow down. The SMOOV One responded as expected every time I tried to stop. The user will still need to hold on to the pushrims to bring the chair to a complete stop.

The biggest improvement the SMOOV One made for me was making it easier to get up hills. My neighborhood has a few long, gradual inclines that are manageable but still somewhat difficult. There is also a steep hill that I would not try to get up on my best day. The SMOOV One made both the gradual and steep inclines effortless. I was unsure if the SMOOV One could handle the steep hill, but I made it up in a few seconds without a single push.

One of the coolest features of the SMOOV One is the app that can be used to adjust its drive settings and monitor its status. The SMOOV One comes with three settings — Eco, Tour and Sport — that can be used in different situations. There is also the “My” setting that allows the user to completely customize the functionality of the SMOOV One. I found this to be especially useful to make getting up short steep ramps easier. The ramp on my van has always been difficult for me, but by turning the acceleration down and the torque up, I was able to get up it after a little bit of practice. I also found this setting to be useful when going over bumpy and grassy surfaces. The SMOOV One app is free for both iOS and Android devices.

The only major problem I encountered while demoing the SMOOV One was that the drive unit would pop off in some instances while I was going backwards. For example, the curb at the end of my driveway is steep and my footplate hits the ground first when going down toward the street, which could lead to disastrous consequences. Therefore, I go backwards down the curb. However, when going backwards, I hit the seam in the concrete between my driveway and the curb, and this little bump is enough to make the drive unit detach from the locking mechanism. Obviously, this would be a huge problem for someone who might be alone and would need assistance reattaching the drive unit. The engineers at Alber were made aware of the problem, and hopefully a fix will come soon.

The SMOOV One is a great option for anybody looking for a power assist device for their wheelchair. It is simple to install, reduces the demand on the user’s shoulders and arms and can help make it easier to navigate inclines and uneven surfaces. Even with the cartilage damage in my shoulder, I traveled distances that I would not have been able to without



The control unit attaches to the frame within easy reach.

the SMOOV One. Having a device like the SMOOV One would likely help to mitigate any future damage to my shoulders.

The customization for individual users through the app also provides many different levels of performance that may be suitable for different situations. There are many power assist devices available for wheelchair users nowadays, and the SMOOV One is certainly worth considering. The SMOOV One is the best rear-mounted power assist wheel that I have tried. I would consider getting one for myself and I would recommend it for those looking to protect their shoulders and arms, and for anyone who needs a boost getting up inclines or pushing

long distances.

That said, it does take some time to get used to, and I would not recommend it for a new wheelchair user who is not yet confident in their ability to safely get around in a wheelchair, especially a quad. For someone who does not push long distances or is looking for something to help get around the office or while shopping, I would recommend something like the E-Motion power assist wheels made by Alber instead. The SMOOV One can be ordered through a DME provider, an Alber or Invacare sales representative, or at shop.smoov.com. The SMOOV One is covered by many insurance plans and retails for \$6,895.00.

Follow us on INSTAGRAM
@NewMobilityMag



Join our amusing and informative Instagram community for images, videos and stories highlighting wheelchair users. And tag us in your posts.



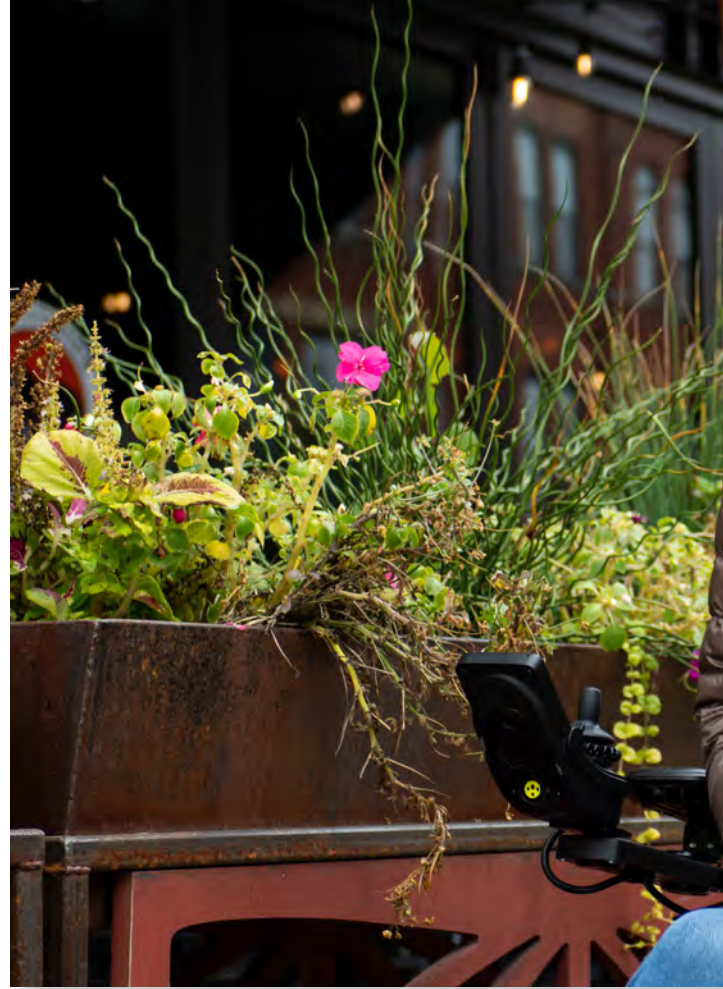
Repost from @worldsoflaurel

ADVOCATE ANALYST

Michele Lee



It took Michele Lee a few years to adjust to her injury, but she eventually directed her frustration into accessibility and representational activism, and now she can't be stopped.



The Will to Look in the Mirror and Then Hold

The first few years after a 2003 car accident that resulted in C5-6 complete quadriplegia, Michele Lee, 38, couldn't even look at herself in the mirror.

"I didn't recognize myself as that paralyzed person in the wheelchair. I couldn't accept the permanence of the situation," says Lee. "But after a while, I resigned myself to my fate. I thought, 'F— this. It is what is. I'm going to be in this wheelchair because what's the alternative? Eventually, I had to go shopping and find clothes, so mirrors were unavoidable, and slowly I started looking the mirror and seeing me and not just the chair. It was a gradual reconciliation and realization that the wheelchair doesn't define me. It wasn't like one day I just thought, 'OK, I have this disability, great.'"

When she reached that place, she was also dealing with the reality of her injury in other parts of her life. She'd returned home to Chicago after a few years in China exploring eastern medicinal therapies and was meeting other people with SCIs living their lives for the first time.

Once she met more people with disabilities, Lee found her

community and realized there were people out there that were just as frustrated and fired up to change things as she was. The experiences helped her come to terms with her injury and get more involved in issues. Instead of protesting, Lee chooses to speak to authorities from within their own boardrooms.

"I advocate for more accessibility because I'm angry that things are not accessible, and they should be by law," says Lee. "I live in the city, wheeling distance from my office, and still just getting around to live my life — meeting friends, trying new restaurants and hanging out with my boyfriend — is really difficult because of the accessibility issues with transportation, and so on."

Today, Lee works for international financial solutions provider Aon as a senior financial analyst for the corporate treasury. Her job gives her a venue to channel the frustration she has about her injury into fixing the inequities she sees disproportionately affecting the disability community. She created a disability resource group for her office. The group now has between 200 and 300 people with and without disabilities. Colleagues come to her for resources when onboarding new employees with

HOW ARE YOU KILLING TIME

DURING COVID? Besides stress eating junk food, I'm also taking a creative writing class because it's a way to flex a different muscle.



WHAT'S YOUR IDEAL OUTING?

I love a picnic in the park on a warm summer evening with music in the air and stars in the sky.





Photo © Lynn Renee Photography

Lost in Translation

Shortly after her injury, Michele Lee's aunt convinced her to travel to China to explore eastern medicine as a way to improve her function. However, being a person with a disability in China wasn't easy.

“China was a jarring experience. You don't see people with disabilities. I think it's because it is shameful to show weakness in Asian culture. Everyone would stare at me like, 'What are you doing out in public?' They wondered why I wasn't home. I didn't speak the language, so everything was through a translator. There was zero accessibility. There were no curb cuts on the sidewalk, so I would roll my wheelchair in the street. It was interesting to them that I was American because everything in America was cool, but they were also like, 'What the hell are you doing out here in a wheelchair?' Initially, I was angry, but I grew a thick skin and eventually didn't care. I would just say, 'Hey, I want to eat here,' and they would recruit a bunch of people to carry me in. They were confused, but they knew I had money to spend, so it didn't matter.”



Italy was less of a culture shock than China says Lee, pictured with her boyfriend, Daniel Kufer, in Rome.

It Up to Others

disabilities, and she was asked for input on how to make their Chicago office more accessible.

“I wanted to create a safe space to discuss disability issues, to make these conversations less awkward, more inclusive and more accessible,” says Lee. “Ultimately the goal is to get more people with disabilities hired.”

Beyond Aon, Lee serves as a member of the ADA Advisory Committee for the Chicago Transit Authority and the Chicago Department of Aviation's Airport Advisory Committee, which helps increase accessibility at both O'Hare and Midway airports. And most recently, she joined Chicago's COVID Recovery Task Force to make sure the vaccine rollout is accessible.

“Whether I serve on a committee or you chain yourself to a bus, the problem is we have no power. People with disabilities need people in power, but how do we get there? We need to support each other to rise up and have that power, and I think getting to know the people already in power is helpful in the meantime because it means they can put a face to our issues and think about them more.”



BEST ADVICE FOR HIRING AN ATTENDANT:

Gauge their ability to be flexible, and realize that nobody knows everything and no one can read your mind, so be specific.

WHY I JOINED UNITED SPINAL: It took me a while, but I'm finally ready to know more people with spinal cord injuries.



Is Telemedicine *for You?*

BY TIM GILMER

By now, as the age of Zoom seems here to stay, many of us have experienced at least one or two telemedicine visits with a doctor. The obvious advantages of talking with your doc on a screen at home are mostly related to convenience. It takes less time, less energy and even less cost when you figure in transportation, not to mention time away from work. This is especially true for those of us who have mobility challenges and already work from home. But there are potential downsides.

For me, in the last five years or so, I have had more doctor appointments than at any other time of life, no doubt due to my advancing age and more frequent complications. Zoom appointments have worked well for me, but not always. Of course, people of all ages can be busy and beset with complicated medical situations. United Spinal Association's Tech Access Group, which meets bimonthly to discuss access to technology for wheelchair users, is made up of mostly 30- to 50-year-olds. "A main topic we've been discussing lately is when telemedicine works best or not so well, for whom, and what the future looks like when remote medical appointments seem to be gain-

ing popularity and widespread usage,” says TAG Director Brook McCall.

The consensus of the group is that telemedicine definitely holds a lot of potential benefit for SCI survivors, but they don’t want to see it become the default, go-to-choice for regular medical care. And the danger of anything new

quintuple coronary artery bypass graft operation, I woke at 3 a.m. to find him sitting in the darkness next to my bed. “Is that you, Mel?” I asked. “What are you doing here?”

“I came in a little early to check on you and say a prayer,” he said.

When you find a doc who is this caring, they can be trusted in any situation — in-person, on the phone, on a screen or with email. Docs like this are worth their weight in extra years of good health and friendship. Trust them. Employ them. Use them however you will. They are the best of all health care providers.

Over the last four years, in my ongoing battle with recurring infections with UTIs and epididymitis (see NM, January 2021), my need for frequent doctor appointments has been more urgent than before. When my regular urologist suggested I needed surgery to fix a urethral fistula, I began a search for the right doc, one who had the right credentials and experience but also would be available for appointments whenever I needed one. My then-current urologist, also a busy surgeon, only kept office hours one or two days per week. I changed to another urologist who was always available, but he didn’t impress me with his SCI knowledge. So I changed again, to someone who met my needs.

Dr. N was friendly, detail-oriented and understanding of my history and my problem. At times it felt like, under different circumstances, we could have been personal friends. Then came the pandemic, and I no longer had access to him. After a few months of being in limbo, we had our first Zoom visit. It felt good to reconnect. We seemed to enjoy our virtual visits. We shared the same opinion of what needed to be done. On the third virtual visit, he explained to me his plan for operating. In

the meeting, he tried, unsuccessfully, to tell me the exact location of a tricky incision that would be needed, but words alone sometimes aren’t sufficient. In an awkward improvised moment, he took his laptop off his desk and aimed it at a specific area in his crotch. He was fully clothed, of course, but there I was looking at an extreme close-up of my doctor’s crotch on my laptop when my wife happened to walk by behind me. Talk about a weird, comical moment. The look on her face was priceless.

Of course, that’s one of many examples of what’s missing with virtual appointments. A detailed physical exam in the doctor’s office would have put the matter to rest. As it turned out, after all of our discussions, we both decided I needed a surgeon who specialized in fistula repair. So off I went in search of my next urologist/surgeon.

Is Seeing a New Doc Virtually Advisable or Not?

Unless it is absolutely necessary, I would not recommend it. That is why I opted to meet my new specialty surgeon in her office. It was the right choice. She was prepared, thorough and wanted to examine me. Too much can be missed in a virtual appointment, even when you are face-to-face on a screen. Better to have an initial consultation and physical exam, either complete or partial, before going to virtual visits. But sometimes that can’t happen.

Today, for instance. This morning I had a virtual appointment with an infectious disease doctor for the first

Telemedicine has emerged as an invaluable tool during the pandemic, but what will its role be going forward?

to mainstream culture is it rapidly becomes the preferred overall health care protocol — to the detriment of those of us with little-known or poorly-understood health situations. Sadly, many doctors and nurses are lacking in detailed specific knowledge of our everyday circumstances, which calls for more educating in the process of making new public healthcare policy. “And we need to be part of that process,” says McCall.

Searching for Doctor Right

My own experience with remote doctor appointments began with telephone appointments, which offer some, but not all, of the benefits of onscreen visits. For me, any kind of remote communication works best with someone you already know or have ample in-person experience with. My primary care physician, Dr. Mel, has been my doc for more than 20 years. When we talk, our shared history is extensive, so getting to the point in an efficient way is the norm, as is picking up on subtle clues on mood and tone of the conversation. I also trust him unconditionally. He is a truly dedicated doctor. In 2005, as I was struggling in the hospital with the pain of angina the night before my scheduled



Action Alert: Protecting Access to Post-COVID-19 Telehealth

United Spinal Association understands that telemedicine is not a replacement for in-person medical visits but during challenging times, it is a critical supplement to necessary care.

United Spinal supports expanded access to telehealth, and the COVID-19 pandemic has demonstrated just how valuable this service is not just to our community but to all Americans. United Spinal supports the Protecting Access to Post-COVID-19 Telehealth Act, H.R. 366, bipartisan legislation introduced by Reps. Mike Thompson (D-Calif.), Peter Welch (D-Vt.), David Schweikert (R-Ariz.), Bill Johnson (R-Ohio), and Doris Matsui (D-Calif.). This bill would do the following:

- Eliminate most Medicare restrictions on where a person can use telehealth services, while establishing that patients can use telehealth in their own homes and allow their health care provider to be reimbursed by Medicare.
- Prevent a sudden loss of telehealth availability at the end of the COVID-19 public health emergency by authorizing the Centers for Medicare and Medicaid Services to continue to reimburse health care providers for telehealth services for 90 days beyond the end of the public health emergency.
- Make permanent the current disaster waiver authority, allowing the Department of Health and Human Services to expand telehealth during all future emergencies and disasters.
- Require a study on the use of telehealth during the COVID-19 pandemic, including its costs, uptake rates, measurable health outcomes, and racial and geographic disparities. Please visit our Action Center, unitedspinal.org/action-center/ and contact your members of Congress and tell them to pass H.R. 366 today.

time. The visit began with a technical glitch that blocked my video — a virtual meeting killer — so we switched to our phones. Then I began having problems understanding her every word because she spoke in an accent that I wasn't used to. Thankfully, the glitch was fixed, and we returned to Zoom. "Well, look at you!" she said on first glance. Instantly we connected, personalities and all. The accent problem gradually disappeared as I watched her speak. The only problem with this visit was I got the impression that she, too, lacked extensive experience with spinal cord injury. But I could see on her face, and hear in her words, that she was aware of this and willing to learn. It went as well as any in-person visit could have — except for the initial glitch. I decided to trust her.

As a rule, especially when dealing with specialty care rather than your primary care physician, there is simply no substitute for face-to-face, hands-on, in-person visits, especially when you have a skin problem or some other complication that must be seen to be appreciated. For instance, McCall had difficulty convincing a doctor of the severity of a swelling problem in her leg in a remote visit until she was able to re-connect with her physiatrist in person, who examined the leg in her office and instantly saw the need for immediate action. No photo sent remotely could have adequately captured the full extent of the problem.

Potential Benefits of Telemedicine

Hugh Brady, 63, a T1 para living in New Hampshire, has also had experience with video appointments

during the pandemic. "That was the only way you could speak directly with your physician for the first six months of the pandemic," he says. He had two virtual visits with his dietitian and one with his regular doctor. His takeaway from his limited experience was similar to everyone I have talked with.

"It was similar to a visit in person, but if you had any type of problem that required it to be examined, you were told to go through the emergency department if it couldn't wait. I think they will continue to use it for

If you have multiple doctor appointments in a month, it saves quite a bit.

minor problems in the future regardless of the pandemic."

Also like others, he says his biggest benefit was cost savings on travel. "I have to take a 100-mile round trip, and if you have multiple doctor appointments in a month, it saves quite a bit." He finds that, in general, "new technology is always tough to get used to. But it's a sign of the times — you either adapt or get left behind."

Mike Collins, a stalwart NEW MOBILITY contributor and former columnist, has logged several decades as a C5 quad and has a lot of medical needs these days. He has had four telemedicine calls, mostly just in the last month. Before that, he used telephone as well as in-person visits. He had no camera available on his computer, so he bought a portable camera to open up that option. "It seems like the preferred option for a lot of providers," he says. "They're all offering it. It's worked well for me, but for

some reason the docs I've been talking to seem like they're in a dark cavern with one light that is too bright."

It seems a lot of us could use a mini-course in camera lighting and "set decoration" to maximize this new technology.

Collins, a Washington state resident who lives in a suburb of Seattle, had virtual visits with a physiatrist, a urologist and a stand-in for his PCP. He changed insurance plans recently and now gets his healthcare from UW Medicine, with its three hospitals, several clinics and much better SCI care. "But everything is 20 miles away, and I can't drive anymore, so just getting there takes a ton of effort and help."

He had one in-person appointment with a physiatrist who had become familiar with some spasm problems he

was having. "When she wanted to meet again in person, I declined due to the spike in coronavirus cases." Enter telemedicine, just at the right time. "In our virtual meeting we discussed the possibility of spinal stenosis surgery. It was mainly just talking and discussing, and it worked well for making plans for the future. I'd had an MRI done previously so she was able to pull those up when we talked. I did the same thing with a urologist later who was looking at an earlier ultrasound." No physical exam was needed in either case.

His PCP was a brand-new provider he had never met personally before. "I was new to their system. We've had phone conversations before, but nothing face to face. On the virtual visit we talked about options for changing

prescriptions and other types of health problems and also about future opportunities for in-person appointments, which I'd rather not do if not necessary. So for me, Zoom works best, especially given my circumstances now that I no longer drive."

All of his docs are now a 20-mile round trip both directions. Gas and parking are both problems. He likes the convenience and not risking his health and sums up his experience neatly: "Why not take advantage of the new tech as well as the traditional model when you need it, virtual or whatever? Better to see a face on screen than hearing them on a phone. They become real. It's more personal talking with a face than a disembodied voice." **MM**

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

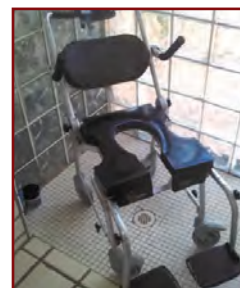
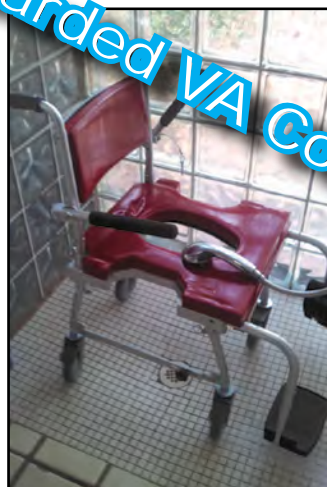
No more waiting out having accessible facilities.

- 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



LEADING FROM THE HEART: UNITED SPINAL'S NEW CEO, ENZO PISCOPO

BY JOSIE BYZEK

It is our first all-staff meeting with our new boss. Jim Weisman has retired as United Spinal's CEO and gracefully bowed out, and now Vincenzo "Enzo" Piscopo is in charge. What will the culture of our organization be like with him at the helm? He has a hardcore corporate background — 25 years of experience in various roles at The Coca-Cola Company — and we're a grassroots nonprofit. Those two types of entities seem to be polar opposites.

And, also, a year of COVID-19 has been wearing on many of us. New York City arguably has been hit by the pandemic harder than anywhere else in the U.S., and our home office is in Queens. A few of my coworkers have photos of that office as their Teams and Zoom background filter, they miss it so much. But we've all experienced some level of loss, no matter where in the nation we live. Could a change in leadership at the top of our organization and all the cascading, resulting changes that are sure to happen be too much?

As he talks, the mood in the Zoom room lightens up.

We start to see what type of leader he is. First, he's subtle. He pulled profile pics of coworkers from LinkedIn to highlight them in positive ways but did point out if the photos were casual, which prompted a few of us to tighten up our profiles within days. Second, he's jovial and funny and warm.

Some bilingual coworkers interject Spanish into our conversations, and Piscopo replies in kind since it's one of his mother tongues. His parents immigrated to Venezuela from Italy, and he's fluent in Italian and Spanish as well as English. Hearing my colleagues banter in their languages moves

me. Then he compares the LGBTQ+ community positively to the disability community. Suddenly I realize that I, a queer woman raising a multicultural family with my wife, fit in here better than I ever knew.

I feel my heart expanding as he demonstrates his inclusive, inviting leadership style.

BE BRAVE ENOUGH TO GO

Ever since he was a little boy, Piscopo wanted to experience living in another country, just like his parents and others in his family have. "One of my older sisters lived in England for six months, and I always looked up to her and had in my mind that after high school I would go somewhere," he says. He got his chance while still in high school when he stayed with the Warburton family in New Jersey as part of an exchange program. In the years since, although his host parents have passed, he stays in touch with their three kids, Peter, Bob and Lizzie. "They are like my brothers and sisters."

The experience was so positive that he wanted to come back to America and in 1994, after he had finished his under-



The Piscopo family (L-R): Gabriela, Arianna, Enzo, Rafael, Sabrina, Antonella

grad degree in economics, he and his future wife, Gabriela, did just that. “The initial plan for us was to come to the states, get our master’s degrees, work here for a few years, get some experience on American corporations and go back to Venezuela,” he says. “But when we began our studies, things in Venezuela started to go bad and we postponed going back. Then we started having kids and it was like, you know what, forget it. The Venezuela I left was a nice Venezuela, but unfortunately it doesn’t exist anymore.” Plummeting oil prices in the late ’80s and the rise of Hugo Chavez had a lot to do with this.

At first Piscopo studied economics at the State University of New York at Albany. He tells a story from that time period to show the influence Gabriela has on him. “It was the middle of winter, I was doing a master’s I hated, and living in a house I hated. It was awful,” he says. He and Gabriela weren’t married yet. “One day she told me something like, ‘Wake up, you need to get out of this.’ It was something that showed me her admiration for me was weakening.” He says she was subtle, “but it was enough for me to say, ‘I’m leaving Albany, I’m getting out of this, this doesn’t make any sense.’” He enrolled at Carnegie Mellon University in Pittsburgh instead, where he received his MBA. He and Gabriela married, and he calls his years at Pittsburgh an extended honeymoon.

Not long after he earned his MBA, Piscopo began obtaining the experience he sought with a big corporation at The Coca-Cola Company in Atlanta. “It’s such a huge organization that you can move around and experience different roles,” he says. During the 25 years he spent there, he worked in finance, IT, marketing and innovation. While in innovation, his supervisor was Keith Wilmot, a man who believes that un-

leashing creativity can positively impact every part of a person’s life. “He created an environment within Coke that spoke to that, to challenging the status quo.”

Wilmot’s penchant for breaking boundaries provides insight into Piscopo’s own approach to management. Once, to illustrate a story he liked to



Photo by Matt Odom

Gabriela and Enzo married in 1994, but she has been a voice of reason and an invaluable support for him even longer.

tell about a man who brought a tiger to a board meeting to reinforce his pitch, Wilmot brought an actual Bengal tiger to Coca-Cola headquarters. “He uncovered a cage with a tiger, in the middle of downtown Atlanta, in an office room,” says Piscopo. “Don’t let the status quo stop you and tell you what is possible and not possible.”

Piscopo appreciated Wilmot’s energy and passion, so he decided to pursue a Master of Science in creativity and leadership from SUNY Buffalo State College. “Wilmot had a loose, emotional understanding of creativity and this degree gave me more the brain side of creating, the process that backed it up,” says Piscopo. Where Wilmot’s perspec-

tive was gut driven and even spiritual, the program at Buffalo focused on science. “It’s powerful and gave me specific tools to unleash creativity. What the culture of it is, what an organization needs to do to really motivate people, to let people be creative and all that.” A pet peeve of his is when people are too comfortable with the status quo. “That makes me itch because I always think there is a better way to do things even if what you’re doing is perfect. If you don’t have that curiosity to look for the betterment of things that are perfect, you are really missing out.”

THE POWER OF RECOVERY STORIES

One morning in 2010, while Piscopo was working in innovation and studying for his creativity degree, he was getting ready for work when he felt an awful pain that knocked him down. “And that was it,” he says. “I had a herniated disc that ruptured, and it pressed on my spinal cord and created the damage. So I am a T6-9 complete paraplegic.” He was flown by helicopter from North Fulton Hospital to Shepherd Center in Atlanta.

“I was going through the big depression, the big sadness that we all go through when we experience those traumatic experiences, and I remember I was in my bed crying and then my wife said, ‘Hey, Enzo, stop it. The things that make us happy are still intact.’ And that sentence marked the inflection point in my recovery.”

Gabriela says she didn’t realize at the time how powerful those words would be for him. “As soon as it happens, you feel that your life is over. The first few days, both of us were thinking that we would never have fun again, we’d never travel, he was not going to be able to work,” she says. “At that moment you are completely overwhelmed, and he was depressed, of course, and then I see him

PISCOPO'S VISION: MAXIMIZING THE DISABILITY ADVANTAGE

Seventy-five years after United Spinal Association was born, Piscopo is looking to leverage his background in creativity and innovation to make sure the organization remains the go-to organization for the SCI/D community for the next 75 years. "I want to create a culture of innovation in United Spinal," he says. "We have to be brave — not be afraid to fail, learn from it and go on. We have to be an organization that is great at building on ideas and making them better and not an organization that kills ideas. We have to hate the status quo and constantly look to improve, even when we think we are perfect."

Fortunately, creativity is one place he thinks the disability community already has an advantage. "People with disabilities are very creative because we live in a world that was not created for us — we are in problem solving mode 24/7 and that makes our creative muscles very fit," he says. "I want to empower our community to better flex those muscles and make real change."

Piscopo expanded on his hopes and vision for the organization in a Q&A with our staff.

NEW MOBILITY: As you settle into your new role as CEO of United Spinal Association, what do you envision for our community?

Enzo Piscopo: I envision a world where wheelchair users can compete on the same playing field as our nondisabled counterparts without having to worry about accessibility, stigma and the rules and regulations that limit employment opportunities.

I envision a time when the world realizes the power and brilliance of our community and embraces us for the betterment of our society.

I envision United Spinal to be the organization that brings together and

empowers the community of people with SCI/D to proudly show the world our brilliance and our ability to make in an impact in the world!

NM: What keeps you up at night?

EP: We're still not treated equally in our society. There's still stigma, and it's still difficult for many of us wheelchair users to find jobs. We've done a lot to get laws like the Americans with Disabilities Act, and that's allowed us to be more visible, but there's much more work to do. We

we ever thought possible. As we speak, United Spinal's accessibility services team is consulting with businesses on how they can better serve us, and our advocacy and our policy team is working to improve or pass laws and policies that benefit us. Together we will continue to take greater strides to improve opportunities and the quality of life of our community.

NM: Are there any particular areas where you see an opportunity for United Spinal to expand or to add services?

EP: I think we have an opportunity to expand our services in employment. When I say services, I mean 360-degree services — facilitating job search, getting people more qualified for their dream job, guiding them



Photo by Gabriela Isabel Photography

have to fight with our insurance companies to get the right wheelchairs and health care that we need to be on the same playing field as our nondisabled counterparts, for example. There is still a lot to do for our community, but I am super energized by the possibilities.

NM: What energizes you specifically?

EP: I'm energized by the fact that we've accomplished a lot as an organization in the past 75 years. If we think big, we will accomplish more in the next 75 than

through the legal and benefits maze, and advocating to ensure that laws make it possible for people to work. Other big areas are in diversity and inclusion in our membership base — developing programs for the underserved communities that live with SCI — and transportation and technology. The broad focus is in changing the narrative to show that our community does not need charity, but opportunities — and when we are given opportunities, we shine and everybody wins.

and I say, he stills loves the children, we still have our family, our love and I know we can conquer everything. He said, 'Do you want to leave me?' and I said, 'What? The things that make us happy are still intact.' It came from my heart. Both of us realized that we can still do it."

Their four children rallied around their parents. "My oldest son was more

of a little man" says Piscopo. "He was only 12 or 13 and he took ownership, saying, 'Don't worry, I have it, Dad.'" His older daughter, around 10 or 11 at the time, cut him no slack. "She said, 'Dad, I still need you to drive me to dance, to help me with homework.' That was very important for me. Yes, I have a huge responsibility to Gabriela and my four kids. I don't have time for 'oh my God.' I have to act."

His wife and his older sister took turns staying with him at night, his nephews and nieces stepped up as well, and the family, like so many others in similar situations, began their recovery process.

"Our life is fine with his disability," says Gabriela. "I recognize the impact that it has had in our life, both positive and negative of course, but the positive side has opened a different world for us. And we do so many things together, conquer so many things. I just don't feel we are different from any other couple in that we face challenges and conquer them."

Everyone in his life pulled together to assist Piscopo. "If you think about it, I had everything, and I'm so thankful ... an amazing family, wife, supportive friends who never doubted me and gave me everything to be successful. I got to



Piscopo left a long legacy of boosting diversity and creativity at Coke, including founding the company's THIS-Ability group.

go to Shepherd, a dream come true for people who have to go through those experiences. My coworkers at Coca-Cola were just incredible. I had so much."

While still at Shepherd, Piscopo met Father Thomas, a priest from Uganda who was there the same time he was. Although both men were there for spi-

"I thought God was saying, 'Hey dude, don't you want to leave the world better than you found it? I'm giving you this opportunity.'"

nal cord injuries, their circumstances and support systems couldn't have been more different.

"While I was transported in helicopters, he was thrown in the back of a pickup truck and after three days sent home," says Piscopo. The priest spent a year in his bed, no bowel or bladder program, and once he made it to Shepherd, it took a month and a half for him to become strong enough to go back to his community. Back home in Uganda he wouldn't have access to the basic medical supplies he needed, not to mention quality DME.

Piscopo was shocked by his new friend's situation. "I realized there's so much I need to do here. They are not living in dignity and that is a human right, and they just need a push."

That push came in the form of a foundation Piscopo started called Wheels of Happiness. It provides assistance ranging from equipment to scholarships for people with mo-

tor disabilities from disadvantaged communities in eight countries spanning four continents so far. He built it by creatively sharing powerful stories of recovery, including his own and Father Thomas'. "I leveraged a lot of my network and I shared my story with my friends, and they got engaged. Then

I shared my story with my coworkers, and they got engaged. That's the way it has been growing, very organically," he says. "It was just my wife and my sister, asking friends for money for Father Thomas, and people loved it and gave us more money than we needed for him."

Father Thomas introduced them to another man who needed assistance, and then the Piscopos decided to help people in their home nation of Venezuela, and then someone in Mexico learned about what they were doing. Then they met with the consul of Peru in Atlanta, "so we grew in Peru. Now we are starting in Vietnam and Nigeria."

HAVE A COKE AND A SMILE

When Piscopo was ready to rejoin his coworkers at Coke, he gave his manager, Stan Sthanunathan, a call. After their conversation, Sthanunathan sent him a long email with everything he wanted

Piscopo to focus on when he got back to the office. “When I read that email, it was like nothing had changed,” says Piscopo. “He was a wonderful manager, but he had a lot of demands.”

As he absorbed the email, Piscopo wondered if his boss recognized he had just come back from a traumatic experience. Then he stopped himself mid-thought as he realized that the email meant Sthanunathan trusted him to get the work done. “And I owe it to him to deliver and to show that I can do it. And that for me was, ‘OK, bring it on. I’m ready.’” He decided if his boss didn’t doubt him that he had no reason to doubt himself. “He empowered me with his trust, which I think was very instrumental for my success.”

Soon Piscopo moved into a new role at Coca-Cola as the director of community and stakeholder relations. He focused on managing the philanthropic relationships between the company and Hispanic, veterans and disability organizations.

In his new role, he answered to Coke’s VP of Community and Stakeholder Relations Lori George Billingsley, now the Chief Diversity and Inclusion Officer. “I love Enzo! First of all, he is an amazing ambassador for whatever he represented at Coke, just a picture-perfect ambassador of our brand,” she says. “He started Coke’s THIS-Ability business resource group for people who have and don’t have disabilities. It became a top group in a short period of time, and he brought in a blind pianist, wheelchair dancers, and just opened up perspectives about people with disabilities being just as abled as anyone else. He demystified the stigma that sometimes people may have.”

Piscopo’s sharing his own experiences and stories helped Billingsley and others enable people with disabilities to have the full employee experience at Coke and also to ensure a disability presence in programs that the company supports. “He’d share stories about the things he would have

to do that I just take for granted, and then when I travelled with him, I saw the extraordinary tenacity and perseverance that he had in dealing with some of the challenges.”

Billingsley’s experience is a reminder that no matter how well someone may understand their own group’s challenges, they can’t always understand what someone else deals with unless they see it for themselves. Many of the leaders at Coke similarly changed how they understand disability because Piscopo showed them what it’s actually like for him and others with disabilities.

“He is a tremendous leader,” she says. “And worthy of following.”

LEAVE THE WORLD A BETTER PLACE

During Piscopo’s three years in his role as the director of community and stakeholder relations, he attended United Spinal’s signature advocacy event, Roll on Capitol Hill. “I met Jim and Abby, and I love Jim and Abby,” he says, referring to recently retired James Weisman and current Chief Operating Officer Abby Ross. “I loved what the organization was doing, and as a Coke person I helped United more and more.”

He thought he’d enjoy working for an organization like United Spinal, but

Coca-Cola was so comfortable. After all, he’d been there 25 years. Then came a big opportunity as two events happened almost simultaneously.

First, Coke went through a reorganization process and offered Piscopo a generous voluntary leave package. “I thought God was saying, ‘Hey dude, don’t you want to leave the world better than you found it? I’m giving you this opportunity. I’m giving some financial help,’” says Piscopo.

Second, Piscopo called up Weisman to ask about opportunities and Weisman responded, “You know my position is open? If you apply you need to do it quick, though, because they’re in the middle of interviewing.”

“Give me the weekend,” Piscopo told Weisman. He worked on his resume, talked to his wife and kids and then applied. A few days later United’s board of directors sent a message that they wanted to interview him. But here was the problem: Piscopo had to let Coke know by Tuesday if he would take the leave package, and the interview with United wasn’t scheduled until Thursday.

“One of my kids said, ‘Dad, we don’t know what life is without you at Coke.’ But another said, ‘Go and do it, that’s what you are, what you need to do. Go for it.’ So I signed the separation package. For 15 seconds I thought, ‘Oh my God what did I just do?’ Everything in my life is because of Coke, all the things I have. I looked around my house and thought, ‘I have this house thanks to Coke. I send my kids to college thanks to Coke, my sister moved to the states here in Atlanta thanks to Coke.’ However, after that 15 seconds, I felt it was the right thing. I felt energized. It was the opportunity of my life — I gave it my all. I prepared so much for my interview. You have no idea all the research I did around United Spinal and disability,” he says.

As we know, he was offered the job. “I accepted and couldn’t be happier.”

MM



Piscopo and Martina bask in some late afternoon sun.

Photo by Gabriela Isabel Photography



BY DAVID LOWY

STALKED BY A CHEETAH

As we bounced around in the van, down a dirt road with rainwater-filled ruts, we were excited about the big cats we were going to see. My family and I were vacationing on the east coast of South Africa and arranged a week of safaris. This was an excursion from our lodge, Zulu Nyala in Hluhluwe, to a cat rehab center an hour away.

Unlike many zoos and parks that breed big cats for profit in the U.S., this facility's sole purpose is to care for sick or injured animals. Some of the cats will eventually be released back into the wild, and others will spend the remainder of their lives here. I visited with my wife, three kids, sister, brother-in-law and a couple we became friends with at our lodge. We anxiously anticipated going into a cage with a tame female cheetah that the center had raised since birth.

We gathered outside the fenced-in cages along with another group. There was a large sign listing *do's* and *don'ts*. The guide proceeded to tell us all the rules to follow at the facility including not to put our fingers in the cages ... if we wanted them back. These pens were quite large and only had cats in them that were unable to live in the wild for one reason or another. The guide mentioned that one of the cheetahs had an

underbite and since "they don't have braces for cheetahs" he wouldn't be able to leave the center.

Careful to follow all the safety rules, we entered into a high fenced-in area and the caracal was one of the first cats we saw. This beautiful, 40-pound cat was rescued from a family that lost control over it — and it was destroying their house. The cat wouldn't survive in the wild because it had back issues, so they gave it to the rehab facility. This is a fierce cat that can take down an animal three times its size, so we didn't go in this cage. We just admired from afar. We strolled past another cage with a beautiful serval. He hissed at us, showing a lot of teeth and not much warmth. Our guide threw him a raw chicken leg that he caught in mid-air while perched on a tree branch. His agility was amazing.

Next we went into a cage of a tame serval that was very curious about my wheelchair. It didn't want anything to do with the other 20 people in the group, just me and my wheels. This little, 25-pound cat put its paw up on my legs and sniffed around my wheelchair while circling around me.

My Too-Close Encounter with a Cheetah

Our guide led us around the big

half-acre cheetah pen. One male followed us as my brother-in-law pushed me. When we stopped, the cheetah stopped. The hair on the back of his neck was raised and he was drooling. He was stalking me! The guide said that he was interested in my wheelchair, which was a bit unnerving, but we weren't going into his cage.

As my brother-in-law pushed me on the hard, compacted grass, my wife and my sister tried to talk me out of entering the tame female cheetah's huge pen for fear that something bad might happen. I told them I'd be OK since we weren't entering the cheetah's pen that was stalking me. In retrospect, perhaps I should have listened to them.

The guide opened the gate to a path that ran between the two pens. On the left was the male cheetah that stalked me, and on the right was the docile female cheetah that was hand-raised from a kitten.

I made it just inside the gate when the male cheetah reached his paw through the wire. Then he swiped my leg and pulled me closer to the fence. Suddenly he pushed his head through the wire fence and bit me. I looked over my shoulder at him and my eyes met the eyes of a creature that wanted to eat me. I didn't know what was going on for a few seconds. My wife screamed

“I wanted to see the big cats. The big cats wanted to see my wheelchair.”



Photo by Zocha_K/Getty Images

and the group gasped. Thinking quickly, my brother-in-law tipped my wheelchair sideways to prevent further mauling from the cheetah, dumping me onto the hard ground.

The trainer who was in the pen with the tame, female cheetah yelled at the cat that had just attacked me. It immediately retreated away from the fence. I was helped off the ground and settled back into my wheelchair. I felt no pain where I was bitten on my shoulder because of all the adrenaline. The trainer came running over and was as angry as I have ever seen a South African. He threw open the gate to the cheetah that mauled me and yelled as the cat ran from him as fast as it could. The trainer left the gate open and I was worried that I, or others, could be attacked again.

At the Doctor's Office

My wife grabbed my chair and quickly pushed me back to the lodge reception area, and a bunch of people came from all over to meet us there. There had to be eight to 10 people from the lodge, plus many concerned witnesses to what had just happened. I was calm throughout all of this. The lodge manager asked if I wanted to see a doctor for the wounds on the front and back of my left shoulder. I didn't

want to inconvenience others in the group, and as the rehab staff were cleaning me up, they reassured me that all their animals had rabies shots. My wife and sister finally convinced me to go to the doctor. By the time we left the rehabilitation center it was dark outside, and we were all feeling bleak about what had just happened.

The doctor's office had bars on the windows and was located in a strip mall with no street lights. My family had to turn their phone lights on because it was so dark in the parking lot.

The office was closed, but they came to see me. My wife helped me out of my bloody, ripped T-shirt. As the doctor cleaned my wound, he explained that since cats have filthy mouths, he was concerned about the wound becoming septic. He applied a topical antibiotic, gave me oral antibiotics and then bandaged up the wound. He told us how to clean and bandage it for the next few days. He wanted to see us back in a few days so he could stitch up the back of my arm if necessary. He didn't want to stitch it up right away because he wanted the germs to bleed out. I followed his advice since the last thing I wanted to do on my vacation was to be admitted to a hospital and receive IV antibiotics,

especially in a developing nation.

We left the lodge in the early morning to see the doctor again before our flight to Cape Town, on the other side of the country. The receptionist showed us into an exam room that looked like it was right out of the 1970s. The doctor was late, and when he came into the office, he put his briefcase down on the desk, opened it, took out a gun and put it into his desk drawer. Shocked, I asked him if it was because of the drugs he had in the clinic. He told us absolutely not. It was because he lived in South Africa. He gave us a short lesson on the civil unrest in his country as he examined my wound. He decided that my cut had healed enough to not need stitches, but just Steri-Strips.

Even with the cheetah attack, or maybe because of it, our trip was an incredible experience. We met people and learned more about South Africa than the average tourist gets when they visit. The rest of the trip was great, and no other animals bit me or anyone else in our group. **MM**

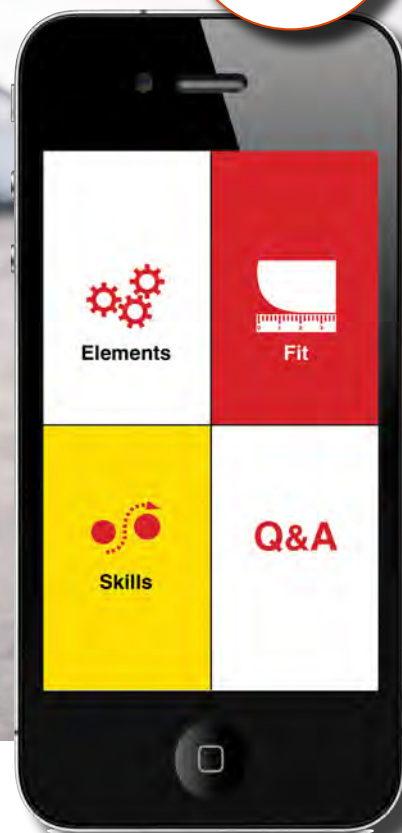
MAXIMIZE YOUR INDEPENDENCE

with the 'My Wheelchair Guide' Mobile App



When choosing the right manual wheelchair, one size does not fit all.

POWER
WHEELCHAIR
INFO
COMING
SOON!



Finding the right manual wheelchair is hard, we make it easy!
My Wheelchair Guide makes choosing the right manual wheelchair easier and more efficient. (*Search 'MWG Manual' in Google and Apple app stores to download.)

Now, all the necessary tools and resources to guide you through manual wheelchair selection, delivery and maintenance are at your fingertips. This comprehensive app covers the entire process of getting a wheelchair, providing practical information to evaluate your needs, wants, and concerns from beginning to end.

THE MY WHEELCHAIR GUIDE FEATURES:

- Self-assessment & maintenance checklists
- Customizable to-do lists
- Wheelchair skills videos
- Illustrations on wheelchair types, parts, & accessories
- Critical health considerations
- Organized hub that integrates the contacts essential to getting a wheelchair
- Ability to take notes within the app using text, pictures, or voice recording
- Q&A section

Whether you're a beginner or advanced wheelchair user, My Wheelchair Guide will help you discover greater health, mobility and independence.

"The app will be a handy reference providing credible and practical information about usage, maintenance, and health issues that wheelchair users face daily."

— Tanya L., Physical Therapist/
Assistive Technology Provider



Our Partners:



Co-developed by:



[HTTPS://UNITEDSPINAL.ORG/MY-WHEELCHAIR-GUIDE/](https://unitedspinal.org/my-wheelchair-guide/)

COPING *During* COVID:

How Our Community Stays Sane in Crazy Times

BY BOB VOGEL

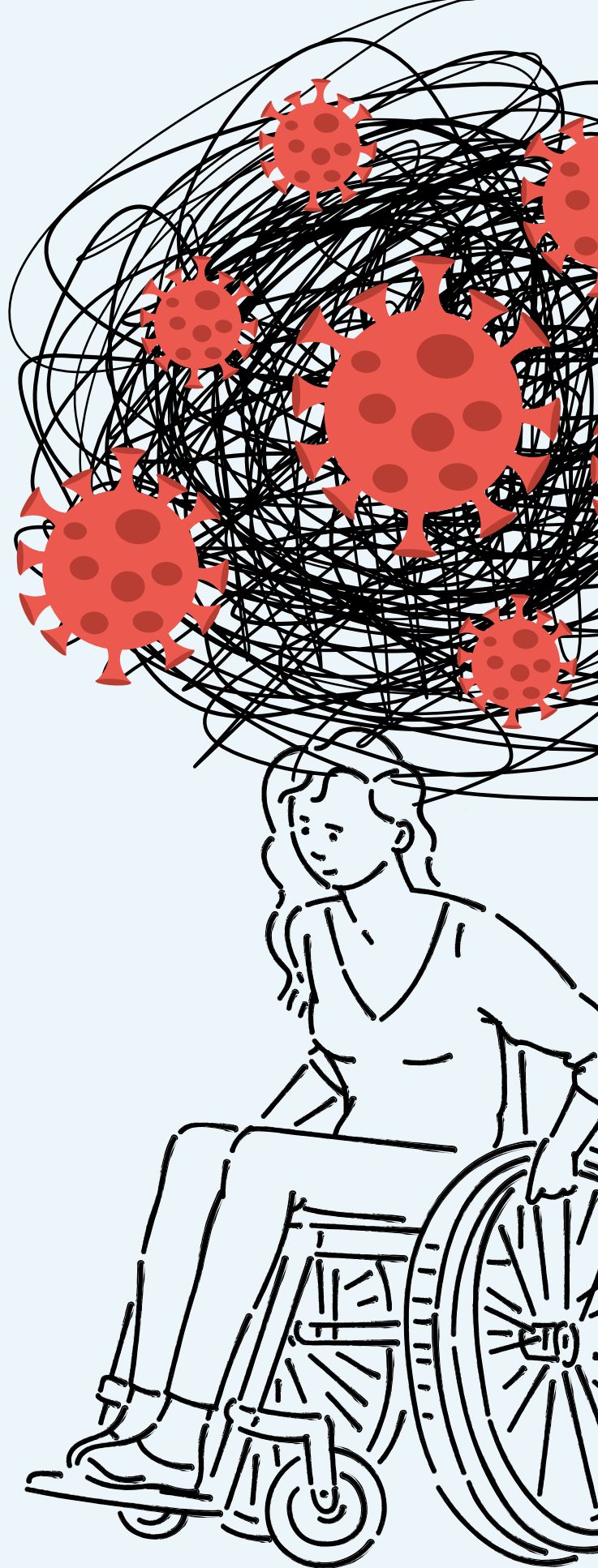
Nancy Hanson felt like she was being held hostage. Alan Moonsammy battled depression. Nadine Boyce struggled with anxiousness and isolation. Claudia Grubler was terrified. For each of these wheelchair users, and for the majority of the world's population, the onset of the COVID-19 pandemic last year triggered a range of potentially harmful emotions along with challenging new logistical obstacles and a maddening uncertainty that combined to threaten our sanity. Over a year later, we're still figuring out how to adjust and cope, but in navigating our way through the last 14 months, we've learned a great deal.

Creative Peer Support

When COVID-19 started ramping up in the United States, Hanson, 64 and an incomplete C5 quadriplegic, was still struggling with her husband's death in a 2019 plane crash. Her siblings and adult children had been taking turns staying in her Queens, New York, home to provide solace and assistance, but the visits quickly ended. "The initial information was, if you caught it you were basically going to the hospital and you were going to die, so my family stopped coming for fear they might be asymptomatic or pre-symptomatic carriers," says Hanson. "This was especially scary for my adult children because they had just lost their dad, and now they couldn't visit me. ... It was like I was being held hostage."

Hanson's situation was far from unique, according to Angela Riccobono, the senior clinical psychologist at Mount Sinai Rehab Hospital in New York City. "We were right in the thick of things when COVID hit last year. We were hit hard and fast," says Riccobono. Inpatients received expedited discharges to make room for COVID cases, and in April the hospital was forced to temporarily close its SCI unit.

Riccobono recognized the importance of peer support and connecting with other people with disabilities, and the potential damage that could be done to the community by losing both. When COVID restrictions led to the cancella-



tion of Transitions, a long-running SCI support group, she wasted no time getting in touch with the New York City chapter of United Spinal along with other local advocates and coordinators to create an online version of the group using Zoom.

“When Transitions came online, people were thrilled to see each other in those little boxes on the computer screen and know they are there and safe. They were so happy that they were almost crying,” she says. “These days they refer to the group as their lifeline.”

Certain themes quickly emerged in the online Transitions meetings — feelings of confinement, loneliness, frustration, anxiety, agitation and facing an uncertain future with no control. “These are all feelings that people often experience when they are first injured and going through rehab. People’s memories of their injury and rehab were being re-triggered, which was like a double whammy on top of COVID,” says Riccobono. In addition, members shared that in lockdown their lives had no structure or routine, and they were having trouble sleeping and losing track of dates and time beyond the noon meeting of Transitions every Wednesday.

Moonsammy, a T8 paraplegic, was one of the many Transitions family members trying to find a new equilibrium. “The first month of lockdown was really depressing, and looking at the news was getting me down,” says Moonsammy, 47, from Queens, New York. “When Covid hit, the main thing affected for me was not being able to attend the Transitions SCI meetings at Mount Sinai and not being able work on outpatient physical therapy.” Additionally, he was concerned about remembering all the things he learned three and a half years earlier in inpatient therapy — things he needed to do to stay healthy.

Hanson was wrestling with the same issues. Before Covid, she had focused her time and energy on attending physical, occupational and massage



Zoom groups and meetings provided an unexpected lifeline for Nancy Hanson when the isolation of COVID-19 threatened her mental health.

therapy. “COVID shut down my ability to be around my family, and it shut down my physical ability to work to regain function and rehabilitate my body, something I’d done every day since my accident. By March, my body was imploding on itself,” she says.

Riccobono saw the problem. “Transitions was helpful, but they needed more,” she says. “The primary difficulty that kept coming up was stress and loss of control, so I reached out and found some fantastic meditation instructors who volunteered to teach and lead online meditation classes every Monday.” The next issue she addressed was that people in the group were saying they weren’t getting any exercise. “I reached out and another person created an online exercise group called ‘Sitness,’ and elite trainer Alex Bundt — Olympic skier Lindsey Vonn’s trainer — volunteered his time to lead group. That’s a thing about New York: This crazy, scary time really brought out the best in people. They were pulling together and tried to help in any way.”

Hanson and Moonsammy both signed up for the new offerings and enjoyed immediate returns. “The

meditation and breathing class was a brand new healing possibility. I learned through breathing that my diaphragm is part of my core, which was extremely powerful in my emotional well-being and my physical recovery,” says Hanson. “The fitness class has helped me build muscle and endurance.”

Moonsammy incorporated all of Mount Sinai’s Zoom classes into his weekly routine. “The online classes are very important,” he says. “They help me mentally and keep me stable and focused on things in a positive light with a daily structure that make me feel good about myself because every day I know I’m accomplishing things. Every day is a challenge, and the challenge for me the last year has been to stay as healthy as possible.”

He credits the online classes with helping him make it through the past year with a positive outlook. “The Zoom classes are a blessing in disguise, as being able to attend the classes and meetings online brings everybody together,” he says. Hanson concurs, “Interestingly, COVID sort of forced certain classes on me, like meditation. I’ve learned things that I never would have done or perhaps heard about if COVID hadn’t led to the Zoom classes. The people who are leading these classes are the greatest and have made a very positive impact on my physical and mental health.”

From Stress to Self-Improvement

Thousands of miles away in San Francisco, Grubler, 45, found similar relief via locally-hosted Zoom classes. A C5-6 quadriplegic for 30 years, Grubler was terrified about the prospect of ending up on a ventilator because of COVID. “Two years ago, I caught pneumonia and ended up on a ventilator,” she recalls. “I vividly remember my panic as I gasped for air in the ER. I lost consciousness and while I was being intubated, the noise of the machine woke me up. It was a horrible experience that I don’t want to go through again.”

To avoid that possibility, she stayed

FIGHTING COVID-19:

A First-Person Report

"If I was forced to choose between breaking my back and going through SCI rehab or my fight with COVID, I would choose 'broken back and SCI,' because the pain and helplessness of COVID was much worse," says Barb Zablutney, 35.

Zablutney, who is in her 13th year as an active T10 incomplete paraplegic, took COVID seriously. Besides her SCI, she has no other health conditions, so she continued working and doing her own grocery shopping while diligently wearing a mask and sanitizing her hands.

In early December, her 75-year-old father, a pharmacist with whom she shares a house, developed what he called "his usual winter cough." Six days later, Zablutney woke up with severe back pain centered at her injury site. By mid-day her voice went hoarse. Within hours she spiked a 99.8 temperature, became extremely nauseous and felt like she had

been hit by a truck. "By evening I felt like somebody was sitting on my chest," she recalls. "I thought, 'I have frigging COVID.' That night I struggled to breathe, and my chest felt extremely tight, similar to having a panic or anxiety attack, and I was having drenching hot and cold sweats and horrible 'fever dreams' that continued for about seven days." A COVID test the following day confirmed she was positive.

By day three, her fatigue became so bad she couldn't sit up in bed or transfer.

Around mid-day, her dad passed out at work due to low oxygen saturation and was rushed to the hospital. A test confirmed he had COVID. "So here I am, three days into COVID, my dad is in the hospital, and I'm alone and so sick I can barely breathe or move. On day three I also lost my sense of taste and smell, which is scary because you can't tell if food is bad, or smell if you may be starting a UTI."

By day five, COVID was attacking and causing searing pain any place she had ever been injured, her shoulders, wrist, and neck muscles. Severe neuropathic pain manifested over her entire body. "It felt like my whole body was a giant bruise, on fire, with thousands of ants crawling on it," she says. "It was pure torture and so bad that at night I'd be crying."

Although she never developed a cough, on day 10 she was fighting for each breath and her pulse oxygen monitor read 89. Her brother rushed her to the ER. "After three hours of being treated like crap in a really ableist way, I was in so much pain and wasn't getting anywhere, I checked myself out against medical orders," she says.

By day 14, Zablutney's symptoms started to wane. A second COVID test confirmed she was no longer contagious. It took another week to regain the strength to transfer in and out of her car.

Three months have passed since Zablutney came down with COVID, and she is still fighting symptoms including brain fog. "It is like somebody went into my brain and scrambled up my words — it's difficult to find the word I want to say, and I will mix up my words and say 'can' when I mean 'can't,'" she says.

Her neuropathic pain hasn't gone away but has decreased in intensity. She also still has a hoarse voice and lung issues that require steroids, an inhaler and six nebulizer treatments a day. "I still have a tight chest and shortness of breath and get winded really easily, even doing transfers," she says. "And I've been out of work since December and am not cleared to return until the middle of April. The hardest part of getting through this has been the continuous pain as well as the fatigue and continued difficulty breathing."



Barb Zablutney was out of work for over three months as she battled the long-term effects of COVID-19.





Wayne Bennett and his pandemic puppy, Arya, have used the downtime to get to know each other.

in her house and backyard, except for an occasional visit to her 84-year-old neighbor. “COVID isolation stole the little glimpses of happiness I had, like going to the gym and the farmer’s market, being around people, smelling fresh baked bread,” she says. “The isolation became really stressful, and I went into a horrible depression.” Online seated exercise classes through NorCal SCI and Bay Area Outreach and Recreation Program helped pull Grubler out of the spiral of stress and depression. “Prior to COVID I was going to a seated exercise classes at the local YMCA. The online exercise classes produce feel-good chemicals in my brain that calms my stress, makes me feel better and enables me to sleep soundly at night,” she says. “In addition to the exercise, it motivates me to do something on a schedule, and I see and interact with other people on my computer screen, which is very important to me.”

Grubler also found a way other than group meetings to use video chat to boost her pandemic productivity. “About six months ago, my friend called and asked what I’ve been up to,” she recalls. “And I said, ‘Oh not much, just binge-watching on Netflix.’” When her friend asked about some watercolor paint she had sent three years earlier, Grubler decided to give them a try. “We

set up a video chat every Saturday for her to teach me,” she says. “I’m learning, and I’m really enjoying having my mind focused on something positive and creative.”

Staying positive became increasingly difficult for Boyce, 57, as the pandemic wore on. “I live alone, intentionally, and I’m happy by myself, but COVID was starting to make me feel isolated and anxious,” says Boyce, who’s in her 14th year as a hemiplegic stroke survivor. “Watching the constant barrage of COVID coverage was really getting to me. I made the decision to cut back on my news intake and also switch to a Japanese news station, NHK, that to me has more science-based information, versus politics or opinion.”

Like Grubler, Boyce also chose to use the downtime of the pandemic as an opportunity for self-improvement and reflection. “For the past 30 years, I’d been a mother and a wife but hadn’t taken the time to figure out who I was,” she recalls. “I decided to take the time to improve myself and took the time to develop a sense of self. I did this through meditation, journaling and doing lots of reading books on leadership and development.”

Boyce also started attending Spinal Network meetings online and an online group called Young Enthusiastic Stroke Survivors. “I’d been attending both groups prior to COVID, however they became even more important in Zoom form,” she says. “I got involved with Spinal Network’s outreach program and volunteered to be an advocate for people with new injuries. Nothing makes you feel better and takes your mind off of difficult times like volunteering and helping others.”

For Denver resident Wayne Bennett, 44, wheelchair sports had always been key to staying positive and happy. The pandemic forced Bennett, a T6 paraplegic, to adjust his usual schedule of flying to compete in tennis tournaments and working out regularly at the gym. “I stopped going to my local gym and even stopped using the gym at the com-

plex where I live,” he says. “Instead, I got work out equipment for my place; medicine balls, dumbbells and TRX bands so I can work out at home.”

He took advantage of the fact that COVID didn’t impact his ability to handcycle. “Last year I rode 2,000 road miles on local bike trails,” he says. He also started riding the E-power assist mountain handcycles available through the Open Space and Mountain Parks adaptive program in Boulder, Colorado.

All that fitness still left Bennett with plenty of time to kill, and he found two very different but equally satisfying



The pandemic provided a perfect time for Nadine Boyce to reflect and work on self improvement.

hobbies: dogs and books. What better time than quaran-time could there be to realize his goal of training a service dog? “I got an eight-week-old German Shepherd/Malamute mix puppy named Arya, and she is now 12 weeks old,” he says. “All my time and energy goes into training her, which keeps me in a really good mood. I hope to have her carrying my water around and towing me in my wheelchair.”

Well, not *all* of his time. When he’s not working out or playing with Arya, Bennett is likely buried in a book. “I’ve always been a reader and a writer, but my reading has really taken off during COVID,” he says. “I’ve read 76 books, includ-

ing *War and Peace*, *The Count of Monte Cristo*, novels, detective books, spy books, political books and the King James Version of the Bible, which took me 32 days.”

No matter what happens with COVID, the positive changes and coping methods developed since its arrival aren’t going anywhere. “Even when COVID is over, I’m keeping the Zoom groups,” says Riccobono. “It opens these resources up to people that don’t have transportation, or access to top rehab facilities, or their power chair broke, or it’s snowing, or they are at home and bed-bound with a pressure sore, or they live in rural areas where there aren’t support groups. It’s a total game changer.”

Just as game changing, the skills and tactics we’ve used to survive the pandemic — whether that’s picking up a new hobby or adapting an old pastime to changing conditions — will be just as viable in a post-pandemic world. **M**

Resources

- BORP Online fitness studio, borp.org/borp-online-fitness-studio
- Mount Sinai Spinal Cord Injury Virtual Groups Schedule, labs.icaahn.mssm.edu/brycelab/weekly-virtual-events/
- For an invite to Transitions, email Woody Wood, richard.wood1@mountsinai.org
- NorCal SCI Adaptive Fitness for Quadriplegics, norcalsci.org/news/2020/10/18/adaptive-fitness-class
- Spinal Network, spinal-network.org
- Young Enthusiastic Stroke Survivors San Diego, stroke.org/en/stroke-groups/young-enthusiastic-stroke-survivors-san-diego



Paralyzed Veterans
of America

Healthcare Summit+Expo

August 29–September 1, 2021 • Dallas, TX

REGISTER NOW!

Lodging Scholarship Closes by June 30, 2021



summitpva.org • [f ParalyzedVeterans](https://www.facebook.com/ParalyzedVeterans) • [t](https://twitter.com/summitpva) [i](https://www.instagram.com/summitpva) [y](https://www.youtube.com/summitpva) #summitpva

Give your savings a tax-free advantage



ABLEnow®

Tax-advantaged savings accounts
that won't impact certain disability benefits

able-now.com

Call 1-844-NOW-ABLE or visit able-now.com to obtain information on the program. Seek the advice of a professional concerning any financial, tax, legal or federal or state benefit implications related to opening and maintaining an ABLEnow account. Participating in ABLEnow involves investment risk including the possible loss of principal. For non-Virginia residents: other states may sponsor an ABLE plan that offers state tax or other benefits not available through ABLEnow. © 2021 Virginia College Savings Plan. All Rights Reserved.



IN THE MEDIA

By Teal Sherer

ROLLING IN CLUBHOUSE

After a long day at work, Maayan Ziv logs on to the audio-only social media app Clubhouse to unwind with Lullaby Club. Beginning at 9 p.m. Pacific Standard Time, artists play popular hits and tranquil renditions of their music to help listeners fall asleep. "It's a magical space," says Ziv, who has muscular dystrophy. "Last night, John Mayer was there playing a song."

Ziv is the founder and CEO of AccessNow, a mobile crowdsourcing platform that allows people to search for, rate and discover places based on their level of accessibility. She joined Clubhouse, which at press time was invite-only and available only on iOS. "I was immediately hooked," says Ziv, who lives in Toronto, Canada. "I work with accessibility and disability issues every day and all of a sudden there was a platform that allows me to use my voice in a new, intimate and organic way."

Clubhouse users select areas of interest, like entertainment, tech,



Maayan Ziv

"It allows you to get a sense of who someone is in a very different way than the beautifully crafted, sometimes superficial versions of ourselves on other platforms."

How Do I Get on Clubhouse?

Clubhouse is in the beta testing phase. It is currently invite-only and exclusively available for Apple users. There are plans to launch an Android version.

The easiest way to join is to be invited by a friend who is already on the app. You can also sign up and join the waitlist and, since users have the option to connect their profile to their Twitter and Instagram accounts, there is a chance someone you know will get an alert and wave you through. Once on Clubhouse, Mallozzi recommends following people and clubs with intent: "There is a search feature where you can put in key words of topics that you are interested in. Room notifications will show up based on the people and clubs you follow."

identity ("disabled" is an option) or wellness. Based on those, the app recommends people and rooms, where live conversations take place, to follow or join. Ziv connected with Adriana Mallozzi, a fellow disabled entrepreneur, who had just created the 15% Club. Like a Facebook group, clubs allow users to host more intimate conversations with a specific community. "Adriana invited me in, and I have really taken to it," says Ziv.

With over 5,000 members and followers, the 15% Club is evolving into the largest disability-led club on the platform, connecting people with disabilities and allies around the world. Conversations are being held on love, relationships, sexual well-being, body confidence, accessible travel, representation in media, digital accessibility and more. "Some topics are more serious in nature about injustices and barriers that people face in the world," says Ziv, "but we have silly conversations too. We had a room called 'Disabled people can be assholes too.'"

Mallozzi, who has cerebral palsy and is a quadriplegic, wants the 15% Club to be a space where people feel comfortable to share their experiences. "The disability community has exploded on this platform because it's really easy to connect with others on here," she says. "I have met people that I never would have otherwise, and you don't have to worry about texts and how you look. There is unlimited content, and you can pop in an out of rooms."

Like a conference panel, each room

has a virtual stage made up of speakers that have a microphone icon that can be muted. You can tell who is talking by a subtle gray halo around their photo. If an audience member wants to participate, they click the raise hand button and the speakers can choose to bring them up.

Ziv appreciates the ability to engage with others in real time. "It allows you to get a sense of who someone is in a very different way than the beautifully crafted, sometimes superficial versions of ourselves on other platforms," she says.

Ziv and Mallozzi make it clear though that Clubhouse is not perfect. "It's not fully accessible, particularly to the deaf and hard of hearing community," says Ziv. "There are no live captions." The 15% Club holds conver-

users know what they are.

Clubhouse launched in April 2020, early in the pandemic. It now has over 10 million users and is growing. "It's obvious to me that the success associated with Clubhouse is 100% tied to the times that we live in," says Ziv. So, what will happen to the social media app in a post COVID-19 world? "There have been rooms where I literally feel

like I am at a party, and I think that is what we have been craving this past year," says Mallozzi. "But typically, on Friday and Saturday nights, people are not going to be on Clubhouse, they are going to be out."

Media writer Teal Sherer is also the host of *New Mobility Live*, NM's online video series. Check it out on Instagram, Facebook or bit.ly/3980Fu4.



Adriana Mallozzi is the founder and CEO of Puffin Innovations, a technology startup focused on creating solutions for people with disabilities. She invented the Puffin, a mouth operated wireless input device that connects to mobile devices and computers.

sations about these issues that have caught the attention of Clubhouse's founders and developers. "One of the developers joined our discussion and we now have a Google Doc that we share with him," says Mallozzi. "On it, is a laundry list of issues they need to tackle." One of those issues, which Clubhouse has since fixed, was labeling the buttons on the screen so blind

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



DAILY DILEMMAS

By Sheri Denkensohn-Trott

AVOIDING THE PITFALLS OF CAREGIVER COMPARISON

Q. I am a low-level quadriplegic and I require assistance from attendants for my morning and evening care. Gina has worked as my sole attendant for two years and is intimately familiar with my routine. She talked to me about the importance of having a backup attendant and suggested her friend Susan, who recently received her certified nursing assistant certificate and wants extra work. Finding reliable and capable attendants is challenging and having a recommendation from Gina made the task easier. I interviewed Susan and outlined my care needs and the related light housekeeping associated with the position. Susan accepted the job and started working for me the following week. But I soon found out that having multiple attendants presents tricky personal dynamics.

I work from home, so my morning routine is set, except when I have an early meeting or a medical appointment. On those days, I wake up earlier, but the sheer volume and nature of my morning care routine requires a quick pace. The days when Susan was working and I had an early appointment, I was often late. On each occasion, I asked Susan to move faster, but she didn't speed up enough. I was frustrated and stressed.

One such morning, while Susan was making my bed, I went to the other room and dictated a text to Gina stating that Susan was not responding to my requests that she move quickly to accommodate changes in my schedule.

In the following weeks, it was clear that Susan was upset. While normally chatty and happy, she did her work quietly and seemed to avoid conversation with me. After many days of this, I asked Gina if there was anything wrong with Susan. Gina reluctantly told me that Susan had heard my text and was upset that I did not talk to her directly. I realize my mistake and want to correct it. Should I talk to Susan directly, even though Gina was the one that told me why she was upset? How do I apologize to Susan and work with her productively to find a solution to the problem of her not picking up the pace when needed?

Any good employer must recognize that employees' skill sets differ. Each attendant has strengths and weaknesses, and you will want to assign duties accordingly, whenever possible. But you, as the individual receiving care, also play a critical role here. You must communicate a clear, consistent understanding of your expectations to your assistants so they can effectively meet your needs. Where problems do arise, it may be tempting to talk to your long-term attendant about another caregiver, but it is not a wise practice.

In this instance, texting Gina about Susan's tardiness was unfair and put Gina in an awkward position. Even though attendants may know each other and interact regarding your

care, it is important to deal with each person directly. Here, you could speak with Susan individually and apologize for talking to Gina about your frustration. Explain in detail why your timeliness is important and that there are mornings when you need to expedite your routine. Use this conversation with Susan to make clear that you were not trying to embarrass her. This is also an opportunity to hear from Susan. Maybe there is a reason that she didn't rush, such as fearing she might compromise an aspect of your care. This dialogue provides an opportunity to brainstorm with Susan about possible solutions. She may have valuable input on how best to meet a morning deadline. Also, this is an opportune time to promise her that there will be an open dialogue with her alone about any future issues.

If Susan understands that you are sorry for making her uncomfortable and that you value her as an attendant, the two of you will have a basis to move forward. It is also important to impart the same message to Gina — that you will not be talking to one attendant about the other. This will ensure that each attendant feels worthy, respected and not subject to comparison with her colleagues. These elements are key to an effective caregiver relationship and can go a long way toward avoiding the pitfalls of caregiver comparison.



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.

Work with an Advisor Who Understands



Disability Focused Wealth Management

Being disabled is challenging enough; we strive to simplify your life, assisting with financial management and life advocacy services. To us, there is no greater honor. You are the center of everything we do.

• Income Generation • Settlement Analysis • Partnership Services



COLDSTREAM
WEALTH MANAGEMENT

Roger Reynolds
Founder & DAS Team Lead
(425) 283 - 1602

Celebrating 25 Years of Service

Learn more at www.coldstream.com/DAS



 **United Spinal
Association**

**Resource Center
Live Zoom**

**DO YOU HAVE QUESTIONS
RELATED TO SCI/D?**

**Come join our resource center team to have
your questions answered live!**

*Our team of information specialists are ready
to share their knowledge and experience with you.*

**EVERY 4TH
WEDNESDAY
AT
4:00PM EST**

*Come join and bring your
own questions! We
look forward to sharing
our resources with you.*

We can answer questions about:

- Health and Wellness Resources
- New Spinal Cord Injury
- Financial Assistance
- Transportation
- Employment
- Rehabilitation
- Sports and Recreation
- Traveling with a Disability
- Peer Support
- And much more!

EXPERIENCE FREEDOM
WITH **Wheel**  **MOBILITY**
EEZ



Wheel
EEZ

SANDCRUISER™

wheeleez.com



A Little Birdie told me...

Follow us on Twitter @UnitedSpinal to get the scoop on the latest updates, news and event information! Come see what all the tweeters are saying.

www.twitter.com/unitedspinal



United Spinal
Association



Social Hour

**CRAVING CONNECTION
THESE DAYS?
YEAH, US TOO!**

**EVERY THURSDAY
AT 1:00 PM & 8:00 PM EST**

**Join us for connection, general chit chat
and to get a break from the daily grind!**

*Connection these days is more important
than ever, come learn more about ways
to connect with your local United Spinal
chapter, support groups and peer
mentoring networks.*

GREAT STUFF



**ACCESSORIES
MADE IN THE USA
for 29 years!**

Available at your local
mobility dealer or VAMC.



1.800.795.2392
DIESTCO.COM

YouTube f /diestcomfg

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



**Like Us
on Facebook!**

Join our growing Facebook
community to share SCI/D
resources, tips and
encouragement. You'll
also learn about upcoming
stories and how you
can contribute your
experience to the publication!

www.facebook.com/newmobility

FOR SALE

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

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

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.

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

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 mchintalla@unitedspinal.org

JUMP START YOUR SEX LIFE



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
- FDA & VA approved
- Inexpensive alternative to fertility clinics
- Help with incontinence thru Kegel Exercise

(Not FDA approved for sale inside the USA for incontinence)



a program of United Spinal Association

If you have questions regarding your Veterans Benefits or benefits that your family members may be entitled to, VetsFirst can help you.



www.vetsfirst.org/ask-vetsfirst



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 Maria Vega

Age 29, from Avondale, Arizona
T12 incomplete spinal cord injury
Seeking a position as a receptionist at a medical facility
Instagram: @marytevga



Why I joined United Spinal: I joined to get more involved and get to know more people.

What is the one product you couldn't live without?
I'm a T12 Incomplete so the most important disability items are my KAFOs (Knee Ankle Foot Orthoses) and my Ethos wheelchair.

If you could change one thing in the world to improve quality of life for wheelchair users, what would it be?
I love to travel, but it's hard to find accessible places. I would love it if accessibility were universal so that people with disabilities could experience all the great places and not just be stuck at home.

Meet other members or join United Spinal at unitedspinal.org

NM LIVE *with Teal Sherer*

MAY'S GUEST: NEW MOBILITY EDITOR IAN RUDER

Being the editor of *NEW MOBILITY* is no small task, and Ian Ruder embraces the role. He plans each issue, mentors writers (like me), advocates for our readers and so much more.

In our interview, Ruder takes us behind the scenes of the magazine and shares how he got to where he is. He also talks about his love of cookies, his favorite hobby and gives advice to aspiring writers.

Here are five quick Q's for Ruder

Who is one person dead or alive that you would love to interview for *NEW MOBILITY*? I would love to get FDR's take on modern day disability.

How do you unwind after a busy work week? I am a sucker for terrible action movies.

Favorite piece of adaptive equipment? Either my typing aids or the glovebox compartment I designed for my wheelchair.

Funniest story pitch you have received? Someone who should have known better pitched me a cover feature on the person who was currently on the cover of the magazine.

Best advice you've received from a fellow chair user? Never trust a quad with worn out soles on their shoes.

Instagram: @newmobilitymag Facebook: @newmobility YouTube: bit.ly/3980Fu4



PLEASE REMAIN SEATED





Your life gets better with Abilities Expo!



**FREE
ADMISSION**



Expand your abilities with...

- Products that meet your challenges
- Resources you didn't know were there
- Workshops to access experts
- Connections with peers
- Service animals that make the difference
- Adaptive activities like sports, dance & more!

Abilities.com • Register online today.



@AbilitiesExpo



@AbilitiesExpo



@abilities_expo

Chicago
June 25-27, 2021

Houston
August 6-8, 2021

Phoenix
Sept. 10-12, 2021

New York Metro
October 1-3, 2021

Los Angeles
October 29-31, 2021

Toronto
Nov. 12-13, 2021

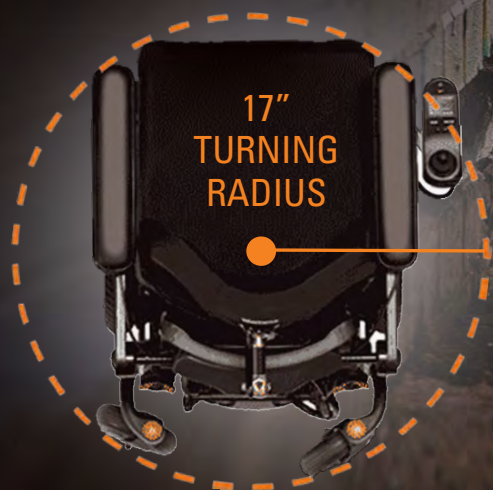
Dallas
Dec. 3-5, 2021

Miami
TBD 2022

Q300M Mini

Compact in size, BIG on performance

The Q300® M Mini's **ultra-narrow base**, allows it to go where other powerchairs can't. Thanks to its **TRUE mid wheel drive** it turns **on the spot**, for an ultra-small **17" turning radius**. Whether it's a complicated living room, a tight kitchen or a narrow doorway, the Q300 M Mini fits into your life.



QUICKIE

ADVANCED ENGINEERING.
PERSONALIZED FOR YOU.
[SUNRISEMEDICAL.COM/Q300M](https://sunrisemedical.com/q300m)