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José
NYC Advocacy Coordinator
President of the New York City chapter
COVER STORY
RETURN TO TRAVEL  33

What does travel look like in a COVID-19 world for people with disabilities? CAROLE ZOOM talks with wheelchair users and travel experts to make some sense out of the new hurdles and realities of traveling. LILLY LONGSHORE and SETH MCBRIDE write about the precautions they took before traveling and what their experiences on the road taught them.

FEATURES

16  STUDY ABROAD  Studying abroad is an exciting option that is more viable than ever for wheelchair users, thanks to an array of scholarships and programs. By JUSTIN HARFORD.

42  EMBRACING POWER  Switching from a manual to a power wheelchair is a nonstarter for many wheelers, but as GARY KARP finds, it can be the best — or the only — move.

45  A YEAR TO EMPLOYMENT  Tired of sitting around all day, one wheeler connected with a nonprofit that helps underserved communities find meaningful employment. A year later he graduated at the top of his class with a good job waiting. By AARON BROVERMAN.
Since joining the New Mobility team almost 10 years ago, I’ve written, edited and assigned numerous stories about emergency preparedness and dealing with disasters. But none of that prepared me for rolling around my street and seeing the valley to the southwest of my house glowing with flame.

I’ve looked out over that same western Oregon horizon thousands of times on my daily rolls around my neighborhood. I’ve seen stunning sunsets, meteor showers, smog, snow and even countless small fires, but this was different. This wasn’t a wisp of smoke or a house fire burning in the distance; it was a massive fire — the kind of glowing hot spot you see on the news or CGI-ed into Hollywood blockbusters.

I’d been following the news all day, tracking fires as a historic east wind pushed them closer and closer to metropolitan areas. Those fires remained far from my home, and I didn’t freak out about the thickening smoke because I knew its origin. But I hadn’t read anything about a fire to the west. That told me it was new, and a new fire that big and that close affected me in a way I hadn’t expected.

My mind immediately started racing. How far away is the fire? How much is burning? And then a question I had never asked myself in almost a quarter-century of living in the same house implanted itself in my head: Could my house be in jeopardy?

It would take a once-in-a-generation blaze to burn across the miles of city still separating me from the flames, but wasn’t that exactly what was happening? Entire towns were being evacuated and hundreds of square miles were burning out of control. Anything seemed possible.

Suddenly, the threat of COVID-19, a summer of social unrest and the prospect of a turbulent fall election all temporarily disappeared.

I realized that despite writing about go bags and evacuations, I’d never even really considered what I’d take or where I’d go if the flames somehow reached me. I quickly went from nervous to depressed to scared and overwhelmed.

I watched the red “go now” zone on the evacuation map slowly creep toward me. I wondered about the thousands of people for whom it was already too late.

As of writing this, over 1 million acres and 1,100 homes have burned in the last nine days. And that’s just in Oregon. Up and down the west coast, unprecedented fires have destroyed lives, communities and some of our most treasured natural habitats.

I wish I had some big takeaway or brilliant insight that would make coping with these harsh realities easier, but I don’t. I’m not sure there is one.

We cope because we have no other choice. It’s not unlike how we respond after sustaining a life-altering spinal cord injury.”
I was thrilled to recruit Carole Zoom to dig into the post-pandemic future of accessible travel for this month’s cover feature. A passionate traveler with good connections in the industry and an insightful mind, Zoom embodies the New Mobility active wheelchair life. In fact, the week before COVID-19 hit in March, she moved from Hawaii to the mainland, in large part to facilitate a more adventurous travel agenda. But as we’ve all experienced, the best laid plans are no match for the novel coronavirus. Instead of traveling more, Zoom has been quarantined in her home. After reporting this story and much deep thought, she has decided to return to Hawaii. “I’m predicting it’s going to be a couple of years before it’s viable for me to travel again,” she says. “I’d rather spend that time somewhere safe and warm.”

Back in the early days of the pandemic when flying seemed like the travel equivalent of Russian roulette, Lilly Longshore found herself in an unenviable position: Her son needed surgery, and the specialist who could do it was thousands of miles away. She approached me with the idea of blogging about all of her preparations for the trip, but she did such a good job — and COVID-19 hung around for so long — that I asked her to expand the article to include what worked and what didn’t. Most importantly, her son’s surgery was a success. “It was definitely worth the risk because we came back unharmed and my son is doing really, really well,” she says.

As for future travel plans, Longshore would love to take her family to the United Kingdom or New Zealand, but not any time soon. “Personally, I would not fly anywhere right now.”

Gary Karp pitched investigating the big decision of whether and when to use a power chair instead of a manual, with an eye toward what people can do to avoid switching if they don’t want to. He was surprised by the complexity and range of responses he found from people who had made the switch. “It’s really a conversation about what control you have,” he says. “There are things you can do to take care of yourself so when you do decide to switch, you do it for the right reasons.” As for Karp’s future wheels? “I’m 65 now,” he says. “Who is to say power assist is not in my future?”

Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org
Never Comfortable, Always Important

Every single person [who commented] was eloquent, and I thank you (“Black Lives Matter: Voices,” August 2020). I’m a white wheeler married to a black engineer who dropped out of university for a year because of the hazing from white professors, but somehow I never get used to the gross unfairness of life. Even though I’ve heard scores of stories, often more violent [than my own], I don’t “get used to it” because it’s not my story. My reactions remind me of those of my dad, who in 1957 was astonished and furious that a Jewish colleague, Phil, felt that he had to ask my dad if a Jewish neighbor would be a problem to him before he bought the house next door to us. My emotionally-naive dad was furious that, on the heels of World War II and all we had learned about Nazi exterminations, Phil still felt he had to ask this question before he decided where to live.

It cannot be helped. No matter how much white people learn as children, then as adults, about racism, it is always removed from (most of our) life experiences. We rarely worry about racism affecting us, so it is not deeply ingrained. I don’t think it is ever comfortable for a black person, AB or wheeler, to explain their personal experiences of racism. It is forever an open wound. For this reason, I thank each of you for having the courage to share your stories.

Patty Lee
Newmobility.com

Protesting in Place

What a great section (“Marching for Change and Justice,” August 2020). I really learned from Mr. Ross and Ms. Rush. I am a white wheelchair user and I have been afraid to go to the protests here in Portland, Oregon, [like Ms. Rush!] because I was afraid I would get trampled and because of the pandemic. Kudos to both of you for figuring out a way to participate.

Barbara Fields
Newmobility.com

Needed Suggestions

Thank you, James, for this well written commentary on Black Lives Matter, disabilities and law enforcement (“BLM and the Disability Community: A Societal Mirror,” August 2020). We are all vulnerable and would do well to heed your suggestions.

Amener Williams
Newmobility.com

Looking for Support

I also would be interested in an online group as I reside in California (“The Power of Peer Support,” August 2020). I do believe that the benefits are so great by gathering together or these days via Zoom meetings to be able to have a safe place to listen, share as you are comfortable and gain valuable resources.

Joy Mangan
Newmobility.com

Editor: United Spinal has a great listing of peer support options around the country: unitedspinal.org/peer-groups

Travel Inspiration


Sue Terrion Burdicko
Newmobility.com

Masked Messaging

There are many of us who can’t wear masks (“Daily Dilemmas: Speaking Up About Pandemic Mask Rules,” August 2020). We aren’t trying to be insensitive or uncaring. Yes, I am at risk because of my lung injury when I became a paraplegic. I spent six weeks in ICU on ventilator with a tracheotomy. I can’t breathe. It sends me into a massive anxiety attack. I know the danger to myself, and I wouldn’t [purposefully] risk others. People without a mask aren’t [necessarily] trying to put you at risk.

Tammy Snowden
Newmobility.com
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AMYLIOR
**Disability Goes Partisan**

Whatever your political leanings, the recent Republican and Democratic National Conventions had a wheelchair user for you.

At the virtual Democratic convention, high-profile advocate Ady Barkan, who has ALS, issued a passionate call for politicians to start treating healthcare as a human right. “In the midst of a pandemic, nearly 100 million Americans do not have sufficient health insurance,” said Barkan, who speaks using a communication device. “And even good insurance does not cover essential needs like long-term care. Our loved ones are dying in unsafe nursing homes, our nurses are overwhelmed and unprotected, and our essential workers are treated as dispensable.”

A few days later, at the Republican convention, the messaging was decidedly more upbeat. Madison Cawthorn, 25, who uses a wheelchair due to paraplegia and has a real chance to become the youngest member of the House of Representatives, presented a lofty message about the power of young people to change history, while casting conservatives as America’s change makers. At the end of the speech, Cawthorn stood up out of his wheelchair with the help of leg braces and a walker. “You can kneel before God, but stand for our flag,” he said.

How you view Barkan’s healthcare assessment and Cawthorn’s theatrical use of his disability may be something of a Rorschach test for your political leanings. The New York Post gushed after Cawthorn’s speech that, “He truly is a rising GOP star,” while Karin Willison, writing for The Mighty, dug into the ways that Cawthorn’s performance played into harmful disability tropes. Add those to a recent controversy over a ranking House Republican who posted a doctored video of Barkan on his Twitter account, and it looks like disability in America has become a partisan cudgel, just like everything else.

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**One Million Dollars!**

In September, the Craig H. Neilsen Foundation announced Reveca Torres, Andrea Dalzell and Dr. Brian Kwon as the winners of its inaugural Visionary Prize, with a jaw-dropping award of $1 million each.

Torres, the 2016 New Mobility Person of the Year, is the founder of Backbones, a nonprofit that connects and serves the spinal cord injury community, as well as a board member of United Spinal Association. Dalzell, also a United Spinal member, is a wheelchair-using nurse who has worked the frontlines during the COVID-19 crisis and an advocate for more inclusion in the medical field. Kwon is a spinal cord injury researcher.

Dalzell discovered she was a prize winner on Good Morning America. When asked what she would do with her prize, she immediately responded, “I want to start a whole program for people with disabilities to get into health care. They should be given a chance.”

Torres plans to use the money to expand Backbones programs and services. “It’s exciting to have the opportunity to dream a little bigger,” she says.

Disability-Friendly Colleges

College Magazine recently released its list of top universities for students with disabilities — ranging from huge state schools like Ohio State to elite private schools like Harvard. Check the list at: collegemagazine.com/top-10-universities-for-students-with-disabilities-2020. And for a more in-depth guide to which colleges across the country are best for wheelchair users, stay tuned this fall for the release of New Mobility’s own college guide, Wheels on Campus.

The Cyborgs Are All in Your Head

Brain computer interface is a fancy term for a fancy technology: electrodes that let you control a computer or other electronic device using only your thoughts. The origins of BCI date back to the early 2000s, and in recent years researchers have made significant strides, allowing study participants to control everything from video games to robotic arms. (Read Kate Willette’s July Research column, “Mind Over Machine” at newmobility.com/2020/07/mind-over-machine.) The field obviously has potential implications for the spinal cord injury world, and it now has a high-profile new entrant: Elon Musk and his BCI company, Neuralink.

At the end of August, Musk held a press conference for Neuralink and claimed the device may one day be used for everything from recording and retrieving memories to streaming music directly to your brain. Tucked behind Musk’s transhumanist vision were a couple of concrete announcements. First, the Neuralink recently received breakthrough therapy designation from the FDA, expediting its path to regulatory approval. Second, the inaugural clinical trials for the device will feature users with spinal cord injuries.

Musk has made clear that BCI is a technology he thinks everyone, disabled or not, should use someday, and he’s investing like he believes it. That alone gives BCI an advantage over every other spinal cord injury research field. It looks like the future is here — if you’re willing to give a robot surgeon and a real-life version of Tony Stark access to your cerebral cortex. Who’s in?
MEMBER BENEFITS
unitedspinal.org

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

BENEFITS INCLUDE:
Personalized Advice and Guidance
Peer Support
Advocacy and Public Policy
Veterans Benefits Counseling
Accessibility Advocacy
Local Chapters
New Mobility magazine
Informative and Educational Publications
Ongoing Educational Webinars

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

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

PATHWAYS TO EMPLOYMENT

United Spinal Association’s Pathways to Employment program works with members who are interested in obtaining a job, whether they have been out of the market for a long time or are just exploring if they can work. Toward this goal, the program also provides potential employers with trainings and information they can use to find qualified employees with disabilities.

“If you’re thinking of returning to work, no matter where you are, even 30 years post-injury, we can help,” says United Spinal Chief Operating Officer Abby Ross. Pathways to Employment is designed around the individual job seeker, providing a range of services from peer support to advice on how to keep benefits packages intact. The program has also helped people to save their jobs or remain in their vocation.

“There are a lot of people in interesting situations who contact us,” says Ross. “One guy was a bonsai master looking for work. He moved from one state to another and was able to find employment as a bonsai master in his new town.”

There are an amazing number of resources for both job seekers and potential employers available at unitedspinal.org/pathways-to-employment, including podcasts and videos as well as links to job sources that give preference to people with disabilities. One webinar provides a step-by-step guide through the interview process, including how to deal with interviewers who aren’t sure how to handle the applicant’s wheelchair. Other resources include guides to going back to work, requesting accommodations and writing résumés.

The Pathways to Employment web page also has a section of resources for potential employers that showcases some attributes people who’ve lived through life-changing events, such as acquiring an SCI/D, bring with them. These include the persistence to overcome obstacles, ingenuity and trouble-shooting skills to navigate challenges. Also, there are interviewer tips for employers and contact information for them to learn about the Pathways to Employment training program.

“One companies hear about these options and opportunities, hiring a person with a disability doesn’t seem so difficult,” says Ross. “I’m so thrilled people are interested and reaching out for help.”

Join Pathways to Employment on October 29 at 2 p.m. ET for the first “Future of Work” webinar. This workplace inclusion event will focus on highlighting workplace solutions submitted by community members that solve barriers to work, workplace complications or the opportunity to advance into leadership positions. Email united-jobs@unitedspinal.org to register to attend or submit your idea.
NOTHING’S HELD YOU BACK BEFORE. YOUR PHONE SHOULDN’T EITHER.

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

†Actual availability, coverage and speed may vary. *Unused data will not expire if service is active and in use with the Unlimited Talk & Text Smartphone Plan. A month equals 30 days.
The good news is that in the fight against the machine — those forces that too often work to drag us down — we have more technology options than ever to help us win the battles. Today, accessibility tools proliferate, and we can all find or devise solutions tailored to meet our specific needs. I’m old enough to recall the days when this was not the case. Not too long ago, options were minimal, and the solutions often kludgy, expensive and ineffective.

We all need varied solutions, and while they’re out there, we need to be open to the work of exploring them. It’s not a matter of click, click and done. It is an exploration, and it takes time and effort.

My goal is to always have access to my computer, whether I’m in my chair or my bed. To achieve that, I use two environments. My professional setup is Windows-based, while my personal life runs on Apple. I’ve been able to connect the two environments so that regardless of my position, bed or chair, I get the best of both worlds. Some folks go down the road of using one computer to rule them all, and there are some cool solutions in that vein, but I like two separate computers. Here is the 50,000-foot view of my two systems and why they work so well together.

The Professional Setup: Microsoft

In my business, all of my clients have their data running on Microsoft environments. To serve them, I could use a Windows virtual machine on my Mac OS, but that would be one more layer to manage. Also, the majority of my programming languages are on the Microsoft platform. So, I stick to Microsoft to manage all of my business matters. As for what runs what on my Windows machine, I use an Integra USB mouth mouse for connectivity, right click and left click, cursor up and down, etc. Next to that mouse is a Yeti USB microphone mounted at the precise location that works best for dictation.

On this computer, I have three monitors for the biggest virtual desktop that I can possibly create. On the smallest one, I have the standard, default, Windows on-screen keyboard. The reason these exist is to be able to bring a keyboard up on the computer screen and click characters using the mouse, which replaces the need to type into a physical keyboard. Alternatively, a person can use voice recognition to complete these same functions, but I prefer the on-screen keyboard mixed with voice recognition because it fits my personal style best.

I’ll be the first to admit that Microsoft has an opportunity to greatly improve its on-screen keyboard. However, I don’t
want to spend additional money on a third-party solution. I know they’re out there, but sometimes you have to prioritize financially. Since I already buy so many technological devices, I put my footrest down (so to speak) when it comes to purchasing yet another on-screen keyboard. That said, the keyboard is the final piece of my Windows environment.

This setup works great for me. I’ve had positive experiences with Nuance’s Dragon speech recognition for voice commands. At times, it feels like my computer may not be as powerful as it needs to be to run the software, but I’m working through that. To ensure my work setup is connected to my personal setup, I use a software called VNC, which connects my Windows workstation to the bedroom Apple computer.

**The Personal Setup: Apple**

In the Apple realm, which is mainly for my bedroom, I use a Mac Mini with a monitor attached, and another Integra USB mouth mouse, along with a webcam. This Mac Mini runs on the Mac OS while iPhones run on iOS. iOS is a more mature platform for accessibility, but the Mac OS is quickly catching up to it. When I’m in bed, depending on my position, the monitor and the mouse might need to be adjusted, so I created a neat way to deliver this for my particular needs by attaching a monitor and mouse to a fully articulated arm that comes out from the wall.

In this Apple-dominated setup, I use the Mac on-screen keyboard, which is far more functional than the Microsoft version. I use Siri, as well as Apple’s built-in voice dictation tools for Mac OS. The biggest reason I use Apple in bed is that my phone can be tied to my computer. If someone texts or calls me, I can respond on the computer or answer the phone from computer. This gives me a ton of independence. I can work and do anything from bed.

Also, in the Apple space, the Home app for controlling smart homes is making life easier. I can open it up on the computer and use it to turn lights or fans on or off, or call the nurse. Using this on the computer, I’m no longer tied to the iOS platform and Siri to handle these tasks. The ability to control my environment is my favorite feature of having an Apple computer with me.

Hopefully, some of these insights will help you as you continue the never-ending task of creating a computing environment that serves you and your needs—wherever you are.
When Shawnique and Karsten Cotton were in their early 20s, they started a race to see who would make their first million. From an early age, the two knew how to flip any item and make a profit — a strategy Shawnique, who is now 50, still uses today. But for her, the race to $1 million was put on hold. Not because she became a C7 quadriplegic after being shot in the back by a stranger at a Pittsburgh nightclub in 1991, but because, years later, she battled dizziness, extreme fatigue and sensitivity to light and sound. “I couldn’t understand why I couldn’t hold a traditional job,” says Cotton. “I had a small convenience store back in the ’90s. I’d try to work it myself, but I’d get real sick and ended up having to hire people to run it for me.”

Then, in 2018, Cotton attended a presentation from a fellow quadriplegic who was the peer outreach coordinator for the Brain Injury Alliance. As he spoke, she realized she wasn’t dealing with chronic fatigue syndrome, but with a traumatic brain injury from hitting her head on the nightclub floor following the shooting. Armed with this new information, doctors gave her the tools to rejoin society. “I just have to do things moderately. I plan everything out,” she says. “If someone sends me to a speaking engagement, I prepare three days in advance to make sure I’m well rested. I’ve changed my diet by eating less meat and working toward vegetarianism. My life has done a 180, and I’m grateful.”

Her road to recovery from her TBI led to a successful reign as Ms. Wheelchair Arizona 2019. Her platform was about leadership and financial self-sufficiency — a message she continues to spread as the president of United Spinal Association of Arizona, where she runs workshops on investing and financial literacy.

Cotton is flexing her entrepreneurial muscles again as she prepares to establish an alternative lending business for entrepreneurs. “Now I’m ready to start the race back up,” she says. She got a huge boost when she invested part of the

**Who Wants to Be a Millionaire?**

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**ONE PIECE OF LEGISLATION I’D LOVE TO SEE:** Medicare for All, because my mom died after the insurance company wouldn’t cover her medication.

**CAN’T LIVE WITHOUT:** I have a Quickie manual chair. It’s orange, it’s bright, and I love it because it truly fits who I am on the inside.
Making it Happen

Cotton had a miscarriage after being shot, but became pregnant again three months later. She successfully raised two children as a single mother with an SCI, TBI and little support from disability agencies.

“I made it happen. I’ve never used adapted equipment. I didn’t have resources at the time, so I used a regular crib. I used a regular stove. I carried my baby around on my lap in a manual chair. Had I known about power chairs, I would’ve got one, but there weren’t any agencies helping me.

My rehab sucked.

When I got homecare to help with the cleaning, they were lazy. It was 26 years before I accessed any services again. I cleaned my house, and when my baby would break through the gate, I used to have to crawl downstairs to retrieve him. I washed my walls with a long pole made from mops and rubber bands to make it extend. I cleaned my house every day. I wasn’t the best cook, and my kids ate a lot of prepared food, but they were grateful.

They said, ‘Mom, you can educate so many people because we see them complaining, and you’ve never complained.’ I just kept positive.

$500,000 settlement she received from the nightclub in a long-term annuity.

Unfortunately, her brother can’t continue the race, as he died of bladder cancer in 2017. Watching the obstacles he faced reinforced for her the importance of financial self-sufficiency for those with disabilities. “When Karsten was sick, there were people who took control of his money and robbed him. I want to teach people how to spot situations like these among their caregivers, so they can remain financially independent and not get taken advantage of,” says Cotton. Because of what her brother went through, she is contemplating running for office to make it harder to commit caregiver fraud in Arizona.

In the meantime, she is determined to finish the race. “I’m striving for $1 million just for him,” she says. “But his situation taught me we need proper representation and advocacy for all people. Even with my health issues, I’ve never been one to sit around and mope in the corner. I’m a believer that most things are possible.”

FAVORITE PIECE OF ADAPTED TECHNOLOGY:
The SmartDrive. I didn’t even know the SmartDrive existed until recently.

WHAT DO YOU GET OUT OF YOUR AFFILIATION WITH UNITED SPINAL ASSOCIATION?
Hope, joy and happiness. They gave me a platform to do my workshops, and now I’m back.
Living a year abroad can change you forever.

That’s what happened to Susan Sygall when she went to Australia way back in 1975. While earning credits toward her master’s degree at the University of Queensland, she also took time for adventures.

“My studying in Australia can only be described as a magical time,” says Sygall, a paraplegic since 1971. She heads up Mobility International USA, which, among other things, facilitates cultural exchange programs for people with disabilities from around the world. “Suddenly every single day was absolutely a new experience … food, culture, smells, friends, romances, and perspectives on myself and the world.”

Her adventures included joining a previously all-male wheelchair basketball team, camping for 30 days in the outback — “being the only disabled person and attempting to climb Uluru rock,” she adds — and getting her boyfriend from Berkeley, California, who was also a para, to join her in hitchhiking throughout New Zealand for six weeks.

Once her year abroad came to an end, she wasn’t ready to come home. “I traveled with a new friend who was also studying abroad from Canada, and we took local buses through Indonesia, Malaysia and Thailand on our long journey back home to North America,” she says.

As she traveled, she realized that there were two things from her experience that would affect her next career goal. First, she wanted every person with a disability to have the same opportunity to study abroad. “My other goal was to ensure that people with all types of disabilities realize that we are all part of the same global family,” she says. “We all face discrimination and we all share common history, experiences, joy, fun and camaraderie that you just can’t get from nondisabled people.”

Toward these goals, Sygall cofounded Mobility International USA in 1981 along with her friend, Barbara Williams-Sheng. The organization develops and implements exchanges that focus on disability rights and leadership training. In 1995, MIUSA began administering the U.S. Department of State-sponsored National Clearinghouse.
on Disability and Exchange to increase the participation of disabled people in the broad range of international exchange programs.

Today, there are more international exchange opportunities than ever before. Every year, people with disabilities experience cultures in Europe, Asia, Africa and South America, bringing their canes, wheelchairs, scooters and personal attendants along for the ride. They take crash courses in local languages. They raise money using scholarships, grants and crowdfunding campaigns. They pack efficiently, understanding that whatever they bring they must carry, including any medical supplies. And then they go.

Traveling with a Purpose

The National Clearinghouse on Disability and Exchange says international exchange is traveling with a purpose that goes beyond visiting a country, wandering through museums and enjoying local cuisine. It can involve taking a class, volunteering with a community development project, conducting research or teaching.

There are many opportunities to spend a semester or a year studying abroad. You can earn your master’s degree over two years on the Fulbright Student Program, or volunteer with the Peace Corps. Those with limited time or who simply want to get their feet wet before deciding to commit to something longer might spend a few weeks abroad learning about sustainable business, helping to build a school or immersing themselves in a local language.

Some parts of the world offer a similar level of accessibility to what you find in Washington, D.C., or Berkeley, California, such as curb cuts, pedestrian signals, elevators and all of the comforts that those in wealthier countries know and take for granted. Other places may lack any such amenities and require a totally different approach.

Attitudes can also vary. Some places might still have cultural folklore depicting disability as a sort of spiritual retribution. In some areas you’ll find citizens raised with a sense of solidarity and collectivism, who will happily lift you up a set of stairs to enjoy tea with your friends, or

“People with all types of disabilities realize that we are all part of the same global family.”

Above: Christina Chambers participated in a four-week Spanish-language program sponsored by the Council on International Educational Exchange. In addition to helping her meet her educational goals, the trip sparked a love of travel that led her to also visit Bali, Fiji, New Zealand and Australia.

Left: This waterfall in Ghana was such a spectacular sight that Robinson allowed himself to be carried through the jungle in order to see it.
spend 30 minutes of their day showing you where to find something. In other regions, people may not volunteer to help unless you ask them, or they might even try to block you from going forward if they feel that you shouldn’t be traveling unattended.

International exchange also involves a lot of unpredictability. Even the best-planned program may include unexpected inconveniences such as being separated from the group in a housing situation, or not being able to participate in an outing.

The challenge is worth it. Traveling with a purpose can result in massive gains in confidence, language proficiency and cultural competence, among other personal and professional benefits. Research shows a positive correlation between international exchange and superior employment outcomes. In a study by the Institute of International Education, 68% of exchange alumni report that studying abroad contributed to landing a job or promotion. According to Universities UK International, students who study abroad are 24% less likely to be unemployed six months after graduation, and their wages are 5% higher.

Salesforce sales executive Jake Robinson and Ability360 program specialist Christina Chambers are two wheelchair users with SCI/D who studied abroad as part of their college education. Chambers wanted to improve her Spanish to feel closer to her Mexican roots, while Robinson wanted to push beyond the minimum expectations to graduate college.

Jake Robinson: Around the World in 107 Days
As an undergrad with quadriplegia, the message that Robinson got was “pass your classes, earn your degree and move on.” This wasn’t enough for him, so when a friend suggested he think about Semester at Sea, he looked into it. What he found was a unique study abroad program in which students travel around the world on a ship, visiting and learning about a variety of countries along the way. It didn’t hurt that its website encouraged students with disabilities to apply. Soon, Robinson submitted his application.

“It sounded like a great way to see a lot of different places — four continents! — and at the same time know I would have a home base that was accessible,” says Robinson. “It was just an incredible sounding experience, and I am so glad I did it.”

Following his acceptance to the program, Robinson found SAS staff to be extremely proactive. While he never requested a specific reasonable accommodation, staff periodically checked in with him to make sure that all of his preparations were on track and that he did not have any disability-related concerns. They also offered to connect him with other students with disabilities who had studied abroad.

“As that trip approaches, you start to think about details you might not have thought of before,” he says. “They were just checking in to ensure I felt comfortable and didn’t have growing concerns.”

The ship was almost completely accessible. While most ports allowed an accessible gangway, crew members carried

It was just an incredible-sounding experience, and I am so glad I did it.”

Right: Robinson leans back against a stone wall of the Castle of Sao Jorge in Lisbon, Portugal. Below: Robinson is plank-carried through a Ghanese jungle to see a spectacular waterfall.
him down without a second thought when the stairs were the only option to disembark. Wherever Robinson wanted to go, he had no trouble getting there, and SAS made sure that he stayed in an accessible room at no extra cost.

Over 107 days, the ship took Robinson and his fellow students to various ports around the world. One of those stops included Accra, Ghana, where Robinson joined a tour to a medical clinic in the jungle.

They took a clunky van over a dirt road into the interior before beginning their trek. As they walked along, they passed various settlements, including a house with a goat in the living room and a small village whose local children admired Robinson’s red wheelchair. Then they got to a point where the trail started to look more complicated.

The tour guide turned to Robinson and, signaling his chair, said “I don’t think you are going to be able to take that the rest of the way.” Instead, a few people carried Robinson plank-style while one person carried his wheelchair, and they made their way along a wet, rocky path down into a canyon.

After an hour of hiking, Robinson began to feel some trepidation. How were they going to hike their way out? But the guide urged him on, saying, “This is worth it. Trust me.” The astonishing sight of a remote, gorgeous waterfall showed Robinson that, indeed, it was worth it.

Robinson says although it’s hard to describe a particular skill or ability gained from the program that helps him in his professional life, he knows it’s made a difference. For one thing, he is now more curious about the world around him.

“I’m more willing to say ‘yes’ to any challenge and to be a little extra risky in order to seek adventure,” he says, “whether that’s been additional trips I’ve taken around the world or moving to San Francisco.”

Bonding Over Basketball in Bali
Christina Chambers, 23, discovered her love for travel in 2016 when she decided to study abroad during her time at Arizona State University. That first interna-
tional experience was a four-week, faculty-led Spanish-language program in Seville, Spain, organized by the Council on International Educational Exchange, a nonprofit that provides international exchange programs in more than 40 countries.

Chambers started using a manual wheelchair after getting transverse myelitis at the age of 12 and discovered wheelchair basketball a year later. She enjoyed playing with people who shared a common experience of disability, and approached her time in Spain with the same sense of adventure and personal initiative that she took with sports.

CIEE on-site program staff provided regular support leading up to and during her experience. CIEE Seville offered a variety of housing situations that included more modern accessible options. The ramp into its center, which worked for power chair users who had participated with CIEE before, was a bit steep for Chambers to push her chair up, so CIEE installed another ramp with a gentler incline.

She found a surprising number of places to be reasonably accessible. Thanks to her Voc Rehab counselor, she had a FreeWheel that made it easier to get over cobblestones, and locals or fellow ASU students helped her with any steps that she encountered.

“My study abroad trip with CIEE to Spain was empowering,” says Chambers. “I was forced to push — literally — out of my comfort zone and realized how capable I really am of being independent and traveling the world.”

Since then, she has traveled extensively. By the age of 21, she had visited Spain, Bali, Fiji, Australia and New Zealand.

Her favorite destination was Bali, Indonesia, where she coached a wheelchair basketball clinic for youth. “It may be a cliche, but my life was changed in Bali as I met others with disabilities from a different country and culture than mine,” she says. “I was there to coach and teach them the sport of wheelchair basketball, but they taught me about true resilience, humility and happiness no matter what life throws at you.”

Given that Indonesia was far from the most accessible place she visited, her praise for the local disabled people’s resilience makes sense. She muddled through cobblestone streets, problem-solved when she didn’t have access to the right equipment and allowed others to carry her when necessary.

Despite the accessibility and language barriers, a common experience made it easy for her to come together with this group of locals from Bali: wheelchair basketball, a sport that they all enjoyed. “Our disabilities are the language we truly use to communicate with each other,” she says.

Visit miusa.org to access its expansive resources that include links to locating and applying for grants and scholarships.

THE NATIONAL CLEARINGHOUSE ON DISABILITY AND EXCHANGE

The National Clearinghouse on Disability and Exchange is a project of the U.S. Department of State’s Bureau of Educational and Cultural Affairs. It is designed to increase the participation of people with disabilities in international exchange between the United States and other countries, and is supported in its implementation by Mobility International USA.

The NCDE educates international exchange professionals on best practices for supporting participants with disabilities and spreads knowledge of international exchange opportunities in the disability community. NCDE offers a rich collection of online resources including articles, podcasts, webinars and the A World Awaits You journal publication.

A common misconception is that NCDE advances the participation of people with disabilities in international exchange by directly providing special programs or scholarships. In fact, the goal of the project is to see more people with disabilities accessing the same programs and scholarships available to everyone else. NCDE encourages individuals with spinal cord injuries to contact them about questions related to studying, volunteering or interning abroad.

Visit NCDE at miusa.org/ncde or email clearing-house@miusa.org to learn more.
SPECIAL FEATURE

Working2Walk
Educating our Community - Engaging the Science

Science & Advocacy Symposium (Virtual)
October 22 - 24, 2020

75% off registration cost with discount code: W2W20NewMobility

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UNITE 2 FIGHT PARALYSIS & WORKING 2 WALK

Background
Unite 2 Fight Paralysis (U2FP) was founded by several women with injuries and the mothers of children with injuries (Susan Maus, Bethany Gaines and Marilyn Smith) in 2005. They organized a rally on behalf of the Spinal Cord Injury (SCI) community in Washington DC following the death of Christopher Reeve. The rally was held in support of the Christopher and Dana Reeve Paralysis Act (which would pass two years later).

From that initial rally sprung U2FP’s annual Working 2 Walk Science and Advocacy Symposium. Working 2 Walk was created to be a unique platform to expose and educate the SCI community on the current state of curative treatments.

Working 2 Walk - This Year’s Approach
The core focus of our Symposium is to bring those of you from the SCI community into the movement for curative interventions. We feel that advocating effectively in this space requires a three-pronged approach.

• We should strive for a broader understanding of our Context (educating ourselves on where the science has been, where it is now, what exactly is being done, and who is doing it),
• so that we can develop the most effective Strategy (built upon a solid and broad grasp of the Context)
• which allows us to have a more effective Voice (collaborative, coordinated and united) with which to advocate for curative therapies.

Working 2 Walk is organized around the above approach. Our intention is to stimulate a rich dialogue amongst the panelists who represent the key pillars of the SCI landscape: basic research, clinical research, clinical practice, industry and advocacy. Specifically, how each of us define a “win” and how we can strategize together to achieve a more coordinated effort.

We’ve grouped sessions of this year’s agenda in the following way:

• **Scientific Research:** broadly defined as research done in laboratory experiments and animal models
• **Clinical Research:** research performed with humans
• **Funders:** agencies or foundations that fund research of all kinds
• **Industry:** companies that are trying to bring a research discovery to a clinical product
• **SCI Advocacy:** SCI foundations/nonprofit organizations working to influence all of the above stakeholders

Each session will deliver presentations from these leaders in each of those 5 core areas. We’ll conclude with a panel discussion of representatives from these areas to explore this strategy question: how can we structure this work so that everybody wins? And how can we in the SCI community work with our partners to achieve success?

We need all of your voices in this conversation. So think about our approach and then come prepared to speak up. We have built in plenty of time to facilitate constructive conversation.

Finally, we realize that this work is demanding and difficult. It’s easy for all of us to sometimes lose sight of the fact that we are a community of people with injuries and those that love them, those who research and treat SCI, and those who want to help us reach our goal. So, we’ve added 6 conversations with artists from within our community to remind us of what we can and will do together.

Matthew Rodreick, Executive Director
Unite 2 Fight Paralysis
CONVENING THE COMMUNITY

Working 2 Walk Science & Advocacy Symposium

Our conference is a collaborative gathering that prioritizes the voice of the Spinal Cord Injury (SCI) Community. We bring together research scientists, clinicians, and community advocates, along with investors and industry leaders to exchange information and strategies for achieving recovery from SCI.

FUND THE BEST SCIENCE

Scientific Advisory Board (SAB)

Our elite panel of SCI scientists critically evaluates research proposals and creates the necessary feedback so that funders are assured their investment has the best chance of success.

CONVERSATIONS FOR CURES

CureCast Podcast

Co-hosts Jason Stoffer & Matthew Rodreick conduct interviews with SCI Scientists and Advocates to help unpack cure research and deepen the dialogue with the SCI Community.

RAISING OUR VOICE

Cure Advocacy Network (CAN)

With almost $12M in legislative funding passed by CAN Activists from the SCI Community - the tide is turning. We’re making our voices heard. We’ve passed Spinal Cord Injury Research Bills in Pennsylvania, Minnesota, Ohio and Washington states with new initiatives started in Wisconsin, Texas and Colorado.

Team U2FP

When you join Team U2FP you’re helping us accelerate cures for the Spinal Cord Injury (SCI) Community! Your fundraising efforts help fuel all of our initiatives, pushing us closer to our goal: to achieve functional recovery for those living with an SCI.

Learn more at U2FP.org!
Unite 2 Fight Paralysis’ annual Working 2 Walk (W2W) Symposium will be held online this year, from Thursday, October 22 through Saturday, October 24. This is the place to get up to speed on the state of science to restore the injured spinal cord.

We will provide some background and context, define the problems scientists are addressing and their rationale for doing so. They have come a long way in understanding the biology of spinal trauma. But progress is not on a fast track; there is no treatment close to being approved for either acute or chronic SCI in humans. However, there are some exciting possibilities on the horizon, including some projects now in clinical trials, and some new biotech start-ups hoping to monetize their optimism.

You are the Symposium

One of the unique features of Working 2 Walk has always been that this is not just a research science show-and-tell, but a research science interaction. While the symposium is online this year, all participants are still encouraged to be part of the event. The SCI community has an important role to play in keeping things moving: to remind the scientific community — with your voice and your presence — that there is urgency for treatments.

You will still be able to mix it up with the scientists, and vice versa. Scientists very much want to meet members of the SCI community and their families. It humanizes and motivates their work. The meeting is set up so you can ask any question of any other participant — especially the esteemed scientists. There’s also a Networking Room where you can chat with other participants and share insights. So don’t be shy, if you don’t understand something, ask!

To help frame these discussions, it can be helpful to reduce spinal cord injury to a general range of problems researchers are trying to solve. It is also important to keep a wide view: discovery science is only part of the solution. Therapies start out as ideas that have to be funded. Then, if something pans out with animals, they have to be translated to humans, which means they have to navigate clinical trials, governmental approvals, commercialization and insurance reimbursement.

Let’s start with the most basic question: What does an injury actually do to the cord? (Note: We recognize the medical value of acute SCI treatment development, however our focus is on chronic injury.)

Three research categories:

The spinal cord is usually injured by high impact, a force that exceeds the protective armor of the backbone. There are also numerous ways the cord can be damaged without trauma (congenital, tumor, stroke, disease, surgical error, etc.). Some nerve cells in the impaired zone die right away — they’re gone. Nearby, others are in peril, and many succumb hours and days later as the injury site becomes toxic. Could we REPLACE lost cells or rebuild the mangled cord structure to encourage recovery?

Some spinal cord cells survive trauma but lose their axons, or long extensions akin to wiring. Many of these cells attempt to recover and send out axons but get stuck. Could we unstick the cells, bump up their power, REGENERATE them, and then direct the axons to reconnect appropriately?

Many cells and cell networks in the injured spinal cord are alive but disconnected from the primary information circuits between brain and cord. Can we REJUVENATE the spared parts, tapping into inherent self-repair mechanisms, or perhaps the innate smartness of the spinal cord itself?

Replacement

Cell transplantation is a potential strategy we all seem to get; it’s easy to imagine a new cell replacing a missing or broken one. Of course, it’s not that easy. Which cells are best to use, what’s the right timing to transplant them, where is the best place to put them, what about the immune response that wants to eat any new cells up, and what are the cells actually doing once introduced to the host? This leads us to stem cells, and much reason for optimism, and for caution: because these cells are capable of growth they are capable of too much growth.

In recent years a number of SCI-related cell replacement trials have been undertaken. The Miami Project, for example, has tested implants of Schwann cells (a support cell from the peripheral nervous system). Schwann cells appear to nourish the native cord cells but don’t replace them. Other labs have published positive results transplanting olfactory cells, taken from the nose area. Stem cells have already implanted in various forms in several human clinical trials for SCI, mostly for acute patients but also for injuries considered chronic.
It’s too soon to know what to expect regarding recovery (sample sizes are small) but in FDA-regulated trials, stem cells appear to be safe, and some stem cell efforts have reported benefits to participants.

At this year’s Working 2 Walk, we will meet Mohamad Bydon, a neurosurgeon at the Mayo Clinic in Minnesota. He published encouraging results from a study last year that injected 100 million stem cells into the spinal fluid of 10 patients; the cells were derived from each patient’s own abdominal adipose tissue (fat cells), important because this avoids any immune response or ethical issues. One patient became a “super responder.” Chris Barr, 53, broke his neck surfing in 2017 and was what’s called AIS A — complete injury, no motor or sensory function below lesion level. He later improved to AIS C — some motor and sensory function below his injury, including some ambulation. But after the stem cells, Barr got way better, including speedier walking. You might recall he was on ABC’s Good Morning America being interviewed by Christopher Reeve’s son, Will.

Some patients did not respond at all to Bydon’s stem cells. Barr’s result is cool but not the main point: why do the cells work in some and not in others? The Mayo team doesn’t know, and they also don’t know exactly what the cells are doing. The working hypothesis is that adipose derived stem cells support spinal cord cells, reduce inflammation, increase blood flow and limit formation of cysts. Maybe the stem cells also encourage cells in the cord to regenerate. Bydon wants “to better delineate who will be a responder and why patients respond differently to stem cell injections.”

Note: Another very cool thing about the Mayo study is that a major part of its funding came from the state of Minnesota. Prodded by activists in the SCI community (organized as Get Up Stand Up to Cure Paralysis, and initially led by Matthew Rodreick, now Executive Director of U2FP) the state passed legislation in 2015 allocating $1 million for SCI and brain injury research. The next year, they added $6 million more. Minnesota’s success has become a template for U2FP advocacy developments in other states, including Pennsylvania, Ohio and Wisconsin. Almost $12 million of grassroots money has been funded by states so far. To learn more, or to get involved in your state, see the Cure Advocacy Network page at u2fp.org.

Regeneration

It wasn’t until the 1980s that any real hopes began to emerge for restoring function after spinal cord injury. Age-old dogmas held that the brain and cord are a single set of wires – once damaged they can’t be fixed. Not so! Scientists showed that spinal cord nerve fibers (axons) could indeed grow and reconnect again after injury if the area near the damage is cleared of growth-blocking debris and perhaps nourished with growth additives. This remains an active area of research today; indeed, the injury environment can be made more hospitable to the survival and growth of axons. Also, surviving spinal neurons might also be genetically rejiggered to grow with an urgency they once had, when we were babies.

A major issue in regenerating spinal cord nerves is the formation of a scar-like barrier that seals off the damaged spinal cord. Spinal cord nerves avoid this area. Could it be cleared away? This is now a busy research area, including budding commercial efforts, as enzyme drugs or peptides appear to digest or neutralize the scar so nerve cells can cross the barrier. In animal experiments, significant function has been restored after application of a scar-eating molecule called Chondroitinase, nicknamed chase. Chase is not clinically useful yet – it’s too unstable at body temperature and may have to be dosed repeatedly.

Working 2 Walk 2020 features two researchers who study chase and its limitations, in very different settings. Both have an eye on human follow-up. Molly Shoichet, the Canada Research Chair in Tissue Engineering at the University of Toronto, has found ways to modify chase to be less fragile. She also suggests that delivering the molecule along with another regenerative strategy, such as transplanted cells, might be the answer.

Nick Jeffery is a veterinarian and Professor of Small Animal Clinical Sciences at Texas A&M University. He has had very encouraging results in a double-blinded randomized controlled study of intraspinal injection of chase in chronically paralyzed dogs. These dogs represent a naturally occurring injury model that is highly relevant to humans. One wonders why this hasn’t been more widely discussed. You can ask him.

We will also learn about a regenerative clinical trial now underway hoping to modify the injury area and promote recovery in people with limited arm and hand movement. Presenter George D. Maynard, Ph.D., President and Chief Scientific Officer of ReNetX Bio, Inc., will take us through the process of commercializing a molecule they call Axer-204, or “nogo-trap.” This molecule acts as a decoy to block out inhibitors, thus allowing axon growth.

Candace Floyd, a physical medicine and rehabilitation professor at the University of Utah, joins Shoichet and Jeffery on the first panel of the conference. Floyd studies the basic biology of SCI and will add her experience with larger animal models (e.g. pigs) to help refine preclinical studies of potential therapies - such as chase - toward human use.

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Synaptogenesis by Lin Ning, Neurobiology, Stanford.
First place, 2016 Stanford Neuroscience Institute's Art of Neuroscience competition

Sponsored Content
Neurogel en Marche Association is an association of paralyzed people based in France. In 2004 the association bought the patent to a synthetic bio-material called Neurogel — the stuff was said to act as a substrate to help injured spinal cord cells recover and grow. A European clinical trial for chronic SCI had been planned for many years. Neurogel en Marche persisted, and in 2018 got a trial approved for 12 patients in China. They dropped Neurogel and opted for an activated fat cell compound; the spinal cord is surgically opened so glial scars and adhesions can be cleaned up. The fat cells fill the cavity. Early reports via the famous medical journal Facebook indicate that there was some recovery. Stephana Carelli, a researcher at the University of Milan (working with a team called House of Miracles) was involved in the Neurogel en Marche trial. She will tell us how a committed community based group can pull off a clinical trial.

Science, money and promising trial results are not enough — a treatment has to be approved, then paid for.

One of the more compelling regeneration stories in recent years was the discovery that gene modification could take the "brakes" off spinal cord axon growth. The Zhigang He lab at Harvard deleted a molecule called PTEN in the spinal cord of injured animals. This rebooted robust axon growth in critical sets of long axons that start in the brain and course the length of the cord, and which are the key to major motor function (grasping, walking). Bob Yant, a California guy living with C5 SCI, heard about this, liked the possibilities, formed a company to develop and commercialize the gene technique, and now here we have Axonis, for real.

Joining us at Working 2 Walk 2020 is Joanna Stanicka, Ph.D., CEO of Axonis. Stanicka will talk about potential treatments but also about what it takes to bring a product to market. Axonis first hopes to test a molecule called KCC2, which has shown a regenerative effect to restore stepping in paralyzed mice.

Rejuvenation

It wasn't that long ago that rehabilitation just meant learning to compensate for lost function, using devices and tools. Now we know that rehab — in the form of physical therapy and activity based exercise — can on its own facilitate recovery. Certain forms of patterned activity (e.g., stepping on a treadmill) appear to wake up dormant nerve circuits in the spinal cord, and for some people this seems to unlock some degree of function.

Why is it we hear about these new rehab techniques helping people, but they are not widely available? Part of the problem is that rehabilitation as a field has not convincingly justified itself with cold, hard data. It's time we got organized. U2FP has over the past several years helped specialized SCI fitness centers form the Association of Neuro Activity Based Professionals (ANABP) to share knowledge, set some basic standards and establish proof that activity based therapies actually work. Once the case is made for medical value, it should follow that they be covered by Medicaid, private insurance, etc.

Working 2 Walk presenter Leslie Morse, who heads the Department of Rehabilitation Medicine at the University of Minnesota, has agreed to be the principal investigator to study participant data from ANABP member centers; the goal is to establish the public health impact of activity-based exercise. Morse is with us on a panel with Drs. Bydon (Mayo) and Carelli (Milan). They'll be talking about running clinical trials and validating research.

The biggest story in restoring function has been the development of spinal cord stimulation. In several labs in the U.S. and abroad, people with SCI have been implanted with an epidural spinal cord stimulator in their back. In the SCI trials, many participants have seen significant voluntary recovery of function, including the ability to stand, plus benefits in cardiovascular health, bladder and even sexual function. Investigators have found that the benefits of spinal cord stim don't necessarily require an implanted device. A skin surface stim method has been tested, with good results.

The possibilities of spinal cord stim have fueled interest in the biotech device world. Fledgling California company NeuroRecovery Technologies was bought out by a European start up, GTX. Meanwhile, there's another new west coast start-up, SpineX, that hopes to get its noninvasive device approved. Clinical trials continue all over the U.S. and abroad.

Joining the Working 2 Walk 2020 program is Dr. Candy Tefertiller, Executive Director of Research and Evaluation at Craig Hospital in Denver. She's here on our Industry panel (with Maynard of ReNetX and Stanika of Axonis) representing GTX, a spinal cord stimulation company founded in the Netherlands by scientist Gregoire Courtine. GTX is in position to lead the stim field in the coming years to develop both implanted and noninvasive units. A multicenter clinical trial is coming soon for GTX's noninvasive unit; the trial is focused on incomplete cervical SCI. Tefertiller will oversee participants at Craig. Also joining the Industry panel discussion will be Dave Marver, CEO of GTX.

Funders

Science, money, promising trial results and new companies are not enough — a treatment has to be approved, and then it has to be paid for. These topics are fundamental but not always fully appreciated in a research field that has never seen an idea run the gauntlet from lab to clinic. Working 2 Walk’s Funders and Advocates panel (Friday sponsored content)

Sponsored Content
afternoon) will discuss strategies for financing research by way of government grants and charity support.

Linda Bambrick is a Program Director at the National Institute of Neurological Disorders and Stroke (NINDS). She manages the portfolio of grants and cooperative agreements for spinal cord injury, peripheral nerve injury and axonal regeneration.

Melissa Miller runs the Spinal Cord Injury Research Program, Department of Defense (DoD), Congressionally Directed Medical Research Programs.

Jacqueline Roche is a consumer reviewer and patient advocate for DoD.

Jay Shepard is chairman of the board of directors of the Christopher & Dana Reeve Foundation. He has a daughter with a spinal cord injury.

Jack Jablonski was spinal cord injured playing hockey. He now operates an SCI-specific nonprofit, The Jack Jablonski Believe in Miracles Foundation, which funds promising research.

Community

U2FP is a community-centric organization. Working 2 Walk presents three advocates from around the world on the Saturday morning session.

Perry Cross is Executive President of the Australia-based Perry Cross Foundation. He is a C2 ventilated quadriplegic injured in 1996.

Corinne Jeanmaire was paralyzed almost 20 years ago. Over the years Corinne, from the Netherlands, has been a familiar face at Working 2 Walk. She operates the endParalysis Foundation, which supports SCI science.

Kim Anderson-Erisman is a spinal cord injury scientist who herself lives with an SCI. She is the Director of the Northeast Ohio Regional SCI Model System at MetroHealth Rehabilitation Institute in Cleveland, and is also President of the North American Spinal Cord Injury Consortium (NASCIC).

Wrap-Up Panel

The final discussion of this year’s symposium will explore strategies for creating a sort of “Cure GPS,” so we know where we are, and where we are going. This segment, moderated by U2FP’s Executive Director, Matthew Rodreick, includes representatives from science, advocacy, funding, and industry.

Murray Blackmore, Marquette University
Corinne Jeanmaire, endParalysis Foundation
John Reilly, Jack Jablonski Foundation
Joanna Stanicka, Axonis
Rebecca Martin, Kennedy Kreiger Institute

What Now?

All of this brings us back to you. We believe that bringing all of us together in a single symposium and toward one shared purpose is a necessary step toward finding our way forward and ultimately realizing U2FP’s vision: Every person has equal access to treatments that will restore health and independence after spinal cord injury.

To learn more about our work please visit u2fp.org. To learn more about the Cure Advocacy Network, contact Jake Beckstrom, jakebeckstrom@u2fp.org; for more about the Science Advisory Board, contact Sam Maddox, sammaddox@u2fp.org; to reach Team U2FP, contact Ryan Romine, ryanromine@u2fp.org. To reach Matthew Rodreick, contact matthewrodreick@u2fp.org
THURSDAY, OCTOBER 22, 2020

**Stakeholder Session 1: Clinical Research**
Research performed with humans
Stephania Carelli, PhD | University of Milan
Leslie Morse, PhD | University of Minnesota
Mohamad Bydon, MD | Mayo Clinic

**Panel Discussion with Question & Answer Session**

**Artist Interlude: Painter, Richard Bell**

**Stakeholder Session 2: Scientific Research**
Research done in laboratory experiments and animal models
Nicholas Jeffery, PhD | Texas A&M
Molly Shoichet, PhD | University of Toronto
Candace Floyd, MS, PhD | University of Utah

**Panel Discussion with Question & Answer Session**

**Artist Interlude: Grammy-Award Winning Songwriter and Musician, Eric Howk**

FRIDAY, OCTOBER 23, 2020

**Stakeholder Session 3: Industry**
Companies that are trying to bring a research discovery to a clinical product
George Maynard, PhD | ReNetX Bio
Candy Tefertiller, PT, DPT, PhD, NCS | Craig Hospital
Joanna Stanicka, PhD | Axonis
Dave Marver, MBA | CEO GTX (panel only)

**Panel Discussion with Question & Answer Session**
Matthew Rodreick | Unite 2 Fight Paralysis - Moderator

**Artist Interlude: Videographer, Ben Leclair**
30 years ago, on the 26th of July 1990, President George H.W. Bush signed the Americans with Disabilities Act (“ADA”) into U.S. law.

The purpose of the law is to make sure that people with disabilities have the same rights and opportunities as everyone else in the United States.

Global Technology Services Group remains, as ever, a strong supporter of the ADA as well as the Unite to Fight Paralysis (www.u2fp.org) vision that every person has equal access to treatments that will restore health and independence after spinal cord injury.

2020 is also the 15th anniversary of the Annual Working 2 Walk Science and Advocacy Symposium, which in this Covid-19 year is being live-streamed in Salt Lake City.

Our Global Technology family is honored to support all families coping with disability and congratulates Working 2 Walk on its 15th anniversary of leadership in promoting research into rehabilitation and a wide range of medical discoveries.
FRIDAY, OCTOBER 23, 2020  (continued)

Stakeholder Session 4: Funder
Agencies or foundations that fund research of all kinds

Linda Bambrick, PhD | National Institute of Neurological Disorders
Melissa Miller, PhD | Spinal Cord Injury Research Program, Department of Defense
  Congressionally Directed Medical Research Programs
Jacqueline Roche, MS | Consumer Reviewer Administrator/Patient Advocate, Department of Defense
  Congressionally Directed Medical Research Programs (panel only)
Jay Shepard | Christopher & Dana Reeve Foundation
Jack Jablonski | Jack Jablonski Foundation

Panel Discussion with Question & Answer Session

Artist Interlude: Musician, Freaque

SATURDAY, OCTOBER 24, 2020

Stakeholder Session 5: Community & Organizations
SCI foundations/nonprofit organizations working to influence all the above

Perry Cross AM | Perry Cross Spinal Research Foundation
Corinne Jeanmaire | endParalysis Foundation
Kim Anderson | North American SCI Consortium

Panel Discussion with Question & Answer Session

Artist Interlude: Graffiti Artist, Jesse Sinz

Stakeholders 1-5: Strategy for Success
Representatives from the 5 areas above will explore opportunities for improving strategic collaboration.

Panel Discussion with Representative Stakeholders

Question & Answer Session

Artist Interlude: Filmmaker/Dancer, Kelsey Peterson

Closing Remarks Matthew Rodreick

End of Conference

U2FP Special Feature layout & design: Jessica Frye

Sponsored Content
SUBMERGED.
WHO ARE WE WHEN WE LOSE
WHAT DEFINES US?

Submerged is a documentary film that follows one woman’s quest to find a cure for spinal cord injury — and the journey that unfolds as a result. SUBMERGED is grateful to have U2FP as both a fiscal sponsor and a friend throughout this filmmaking process. We are very excited to share this film project with you all in 2021!

On the eve of Independence Day, 2012, Kelsey Peterson dove into Lake Superior, off the shores of Wisconsin; she hit the lake bottom head first, sustaining a life-changing injury that would rob her of her ability to move her limbs and strip her of her self-identities as an athlete and dancer.

Now she has to redefine who she is as she seeks answers regarding a cure — of body and spirit.

Within the spinal cord injury (SCI) community, Kelsey found peers and allies in her quest to answer the question: Who am I now?

As she grapples with the ebb and flow of hope and acceptance, she talks with some of the top SCI cure researchers in the field and meets with new friends who help give her strength and the will to return to dance. And when a cutting-edge clinical trial surfaces, it tests her expectations and her faith in the possibility of a cure.

Follow the development of Submerged.
• submergedfilm.com/
• @submergedfilm (Instagram)
• Submergeddocumentaryfilm

Photo credit: Tyler Croat
As the global pandemic grinds on, many people with disabilities dream of traveling near or far as a break from the monotony of isolation. But whether it’s a trip to the river or across the Atlantic Ocean, a vacation week away or a day excursion, everyone has big questions — logistical, physical, emotional and ethical. When will it be OK to travel? Is it safe to hop on a plane? Safer to board a train? Is a cruise something to consider or to be avoided? With so much uncertainty, is travel even worth the risk?

Add on top of these concerns the many considerations disabled travelers have been contending with for years, and planning quickly becomes even more complicated. A great deal of advance groundwork and layers of logistics are necessary. These may include researching and securing lodging that is barrier-free, scheduling and paying a team of assistants who will be in close proximity, and arranging transportation that provides access for a wheelchair, ventilator or service animal.
What are the specific travel issues that will face travelers with disabilities during and after the pandemic? Some regular travelers have barely left their homes, others have resumed adventuring while adapting their methods, and many more are still trying to make sense of the new realities and obstacles COVID-19 presents.

I spoke with a number of accessible travel experts, industry insiders and regular travelers to better understand where we are and what the future of accessible travel holds. One thing became clear: What constitutes travel and where and how we travel may never be the same again.

TO TRAVEL, OR NOT TO TRAVEL?
Because clarity about the unprecedented situation surrounding the pandemic is only starting to emerge, how people approach their travel plans varies depending on how much risk they are willing to bear. Back when COVID-19 started ravaging America, accessible travel writer Cory Woodard canceled all of his immediate trips and locked down. “I was not going anywhere,” he says. “I was scared to death about traveling and getting out there, and I thought it wouldn’t be safe at all. How could you monitor it? How could you make it safe?”

Over the last six months, having more knowledge about how the virus is transmitted eased some of Woodard’s concerns. He has still sworn off air travel for 2020, but has since embarked on five successful road trips — three to national parks, one to the beach and one to an alpaca farm — all using his van and a good amount of planning.

“Now, I really feel like I could go on almost all road trips safely. My worries have definitely eased the more that I’ve traveled during the pandemic,” says Woodard.

Yulia Arakelyan and Erik Ferguson also find solace in the control offered by road trips. Normally, they travel the world together as Wobbly, a multidisciplinary performance company specializing in film and movement. Connecting with other performers is an important part of Wobbly’s innovative work, but that’s not an option during the pandemic.

“Travel is meaningful for us,” Ferguson reports, “but it seems like such a foreign concept now. Our life has a one-mile radius, and we aren’t even taking cabs or public transit. We are on hiatus from performance, learning the art of survival in pandemic times.”

They are using the enforced break from creating, teaching and performing to recharge via close-in travel to destinations not far from their Portland, Oregon, home. “Last week we rented a van for two days,” Arakelyan says. “One day we went to the beach and another to Mount Hood. We packed everything we needed and didn’t use any public restrooms or facilities. That felt safe and good.”

Ferguson appreciates the silver linings of being away from his usual concerns. “For me, there was this sense of timelessness and comfort, a comfortable eternity,” he says. “Everything we needed was there. Good food, great friends and our old dog with the wind in his hair.”

Wobbly probably won’t be venturing farther afield for quite some time. “I can’t even imagine thinking about air travel,” Arakelyan says. “I won’t be doing that until there’s an effective vaccine. I think we will be able to travel safely again, but it’s going to be much longer before we get there. This is going to last through 2021 at least.”

Rhona Coughlan, a disability advocate and life coach in Cork, Ireland, feels similarly. With close friends in the United States, Coughlan has traveled to California, Oregon and Hawaii in the last five years. Rhona says these times of isolation make her turn her attention to prospects of travel, but the consequences are daunting.

“I am itching to get to see my friends in Portland,” she says. “But you could give me a million Euros to travel on a plane, and I wouldn’t do it. I wouldn’t even dream of it. I wouldn’t put myself at risk. I don’t see leaving Ireland in the next 13 months.”

A VACCINE’S POTENTIAL
The reluctance to return to air travel shown by all of these travelers matches up with recent surveys of travel plans. A study in June from the global consultancy firm Bain & Company found that most people now working from home consider themselves more likely to plan leisure travel than business travel, and travelers considering leisure travel intend to stay closer to home. No matter what their plans had been for 2020 and 2021, three times as many travelers now see themselves sticking to domestic destinations rather than international ones, if they travel at all.

Despite not travelling since she returned from Hawaii in early March, Sylvia Longmire has sustained herself by maintaining her award-winning accessible travel site, Spin the Globe.

“I don’t know if travel is ever going to go back to what it was, and I’m perfectly prepared to adjust, but I’ve been perfectly happy...
staying at home,” she says.

The recent departure of her sons to spend time in Germany challenges her resolve, but Longmire says she won’t fly again until there is a safe and effective vaccine. “I’m still heartbroken about that, but I don’t know when I’m going to see them again,” she says. “And it’s really, really difficult as a mom to know that, for my safety and for theirs, Germany won’t even let me in.”

Like Longmire, many travelers with disabilities regard a vaccine for the novel coronavirus as a baseline for considering traveling again. As an effective vaccine may be anywhere from weeks to years away, questions remain. Will the pandemic subside entirely or become cyclical? Will the vaccine be a one-time shot that confers long-term immunity? Or will we need a yearly injection similar to our current yearly flu shot? Or will the vaccine last only briefly and require regular boosters to be effective? Will the vaccine be required for travelers, or will it be optional? And will people willingly take the vaccine or will many refuse and put others at risk?

Above left: World traveler Cory Woodard is restricting his adventures to domestic destinations.

Above right: Yulia Arakelyan and Erik Ferguson trot the globe as Wobbly, a multidisciplinary performance company specializing in film and movement. But are staying close to home this year.

Right: Rhona Coughlan misses her American friends but says she wouldn’t get on a plane for a million Euros.
Before cofounding the accessible lodging startup Accomable and serving as the head of accessibility for Airbnb, Srin Madipalli was a research scientist working on genetics. His background gives him a uniquely qualified perspective when it comes to considering a vaccine’s potential.

“My biggest feeling for the moment is that rather than there being a smoking gun vaccine that solves the whole thing, we will have a patchwork of intervention,” he says. “So maybe there’ll be a vaccine that works for some people and a handful of therapies that diminish the seriousness of the virus for others. There’ll be a patchwork of solutions that kind of diminish the chaotic element of it. Instead of it being a catastrophe, it may become more like a nuisance.”

He points to regions of the world with few cases and declining numbers as examples of destinations he is more likely to consider in the interim before a vaccine. “Will I go now? No, because cases are cranking up in London and I don’t want to go through a busy airport. But there are corridors of travel where I see possibilities.”

**REDUCTION OF OPTIONS**

Even if disabled travelers are ready to roam, accessible travel may be harder to arrange. “There are a lot of companies out there internationally that specialize in accessible travel, and they are very small,” says Candy Harrington, author of the Barrier-Free series of accessible travel books. “A lot of operators that specialize in accessible travel may not survive the downturn.”

Woodard maintains relationships with accessible travel operators around the world for his website, Curb Free with Cory Lee, and he is already seeing Harrington’s prediction come true.

“I’ve worked with a lot of smaller tour companies over the past six and a half years since starting my blog,” he says. “A lot of them are really suffering right now because not many people are traveling, much less someone who uses a wheelchair. Then you add in that we literally can’t even travel internationally … so it’s really a struggle for those tour companies. There’s just no way to do business right now.”

Longmire has already rescheduled a family cruise planned for this summer and is now worried about the Baltic cruise she has planned for next year.

“A lot of these operations are...
new and operating with a very narrow profit margin,” she says. “I’m really scared that once travel starts to ramp up that a lot of these companies that provide such an invaluable service to wheelchair travelers won’t be around anymore.”

Those that do remain will have to adjust to the new realities of a post-COVID-19 world. “Travel providers must require masks and/or face shields, the use of hand sanitizer and physical distancing,” says Longmire. “I know it’s awful for people with disabilities who might be restricted from traveling because they can’t wear masks, but I think public safety and public health are the greater concern here.”

Madipalli anticipates a tough year or two for businesses that cater to the disability audience, and he says their ability to rebound will be tied to how they adapt.

“A lot depends on those businesses, right?” he says. “How they’re run and what their resourcing is and how much can they tighten their belts. But then maybe there’s also which of those companies adapt? People will want to travel over the next year or two. So how do those businesses pivot their business models? For example, how do they re-adapt their business models to facilitate travel to places where maybe there isn’t as much risk?”

Those new considerations may change the calculation that many disabled travelers already make each time they plan a trip. As Harrington puts it: “There’s a difference between ‘whoops, your wheelchair may get broken,’ or ‘you may die.’” Disabled travelers face myriad inherent challenges under the best of circumstances. When coupled with a life-threatening pandemic, every trip for a disabled person becomes an existential debate.

ETHICAL CONSIDERATIONS

Madipalli says travelers will need to ask themselves uncomfortable ethical questions as they consider returning to travel. “I have to make sure that I am not taking the virus with me, that I’ve been tested and anyone with me who is vulnerable is wearing a mask,” he says. “This is basic human decency, to feel safe to travel as a human being. That’s not disability-related.”

During mandatory lockdowns prompted by the pandemic, people had to decide their comfort level with going to the grocery store, socializing in public or wearing a mask. The decision of whether to travel now affects not only individual travelers, but also their family support systems and surrounding community. Where a common cold can cause serious issues for an individual with respiratory compromise, a COVID-19 infection could be much worse, even for survivors. Long term health implications could include changes in respiratory function, heart health, digestion and fatigue.

Travelers with disabilities are going to have to balance the desire to explore and get away with the realities posed by the ongoing pandemic. For his part, Madipalli spent the majority of the last six months in his London apartment, seeing only caregivers and family. As the number of positive cases has declined, Madipalli has slowly emerged from his quarantine but he has yet to resume traveling.

“I’m not using public transport, and I generally have not gone inside many buildings,” he says. “If I’ve gone to meet a friend or go for dinner with people, it’s been outside, as I generally have tried to avoid doing things indoors. I’m trying to live my life, while also taking reasonable precautions that mitigate risk.”

If all this talk of risk and planning is dispiriting for dedicated disabled travelers, remember: Eventually, traveling will resume — but it will happen gradually. Barring a medical necessity, Madipalli doesn’t see himself travelling until early next year, other than possibly undertaking some drivable domestic trips. “We will travel,” Madipalli predicts. “But it will just be more local for a couple of years, starting closer to home. Go by train not by plane. Include being sensible and reasonable in thinking about travel.”

Madipalli muses on how this year has unfolded: “If you had told me there would be an international shutdown, I would have asked what you are smoking. It is going to be a strange 12 months. Prepare to be surprised.” That may be the best single preparation travelers — with or without disabilities — can make.
We were supposed to fly to Ohio and spend three weeks at Kelly’s parents’ house, hanging out by the pool while our son, Ewan, played with his cousins. We’d bought tickets in the spring, when the first lockdowns were starting to make an impact on COVID transmission. Surely the end of summer would be a safer time to travel, we thought.

Surely, we were wrong. As our departure approached, the pandemic continued to spiral. Kelly works in the hospital treating COVID patients — she had already seen grandparents walk into the ICU and never walk out. Flying was clearly too risky.

But we are parents to a high-energy 3-year-old and a higher-energy heeler puppy; we both work full-time and had spent every weekend since January building a new house; Kelly’s job has enough sustained stress and emotional toll to affect people like war does, and she hadn’t seen her family in over a year. We needed a break.

Maybe if we couldn’t get to Ohio, we could meet in the middle. With cooperation from Kelly’s parents, we changed our plans to rent an Airbnb house in the mountains, so we’d still get to hang out. It’d be close enough to drive to but far enough way that we could forget about everything to be done at home.

Here are four things we learned hitting the road in the middle of a pandemic.

1. NIGHT-DRIVING HAS ITS ADVANTAGES

Limiting exposure on a road trip involves limiting your stops as much as possible — not the easiest task with a 3-year-old. There’s no way around gas stops, but one night in a hotel is all that we felt comfortable with. So, as counter-intuitive as it may seem, we decided to leave Portland at night. We figured that the only way to put in a long, 10-hour stretch of driving was to do it while Ewan was sleeping.

It took a pre-drive nap and about four cups of coffee, but amazingly enough, the all-night drive proved clutch. We left around 10, and Ewan was asleep in minutes. No traffic, a to-go mug full of cold brew and hours of Hardcore History podcasts let me zone out and crank through the miles while Ewan and Kelly slept (one better than the other) in the back seat. In the middle of the night, gas stations are empty. Kelly was able to fill up, go in for supplies and even use the restroom while keeping contact with people to a mini-
Driving overnight let us do about 14 hours in one push — stopping in the morning to eat a breakfast picnic in a local park and let the kids run around and get some ya-yas out, before pushing on. This turned two potential hotel stops into one, saving money and limiting exposure.

2. BE PICKY ON YOUR RENTAL SELECTION

Our criteria for a rental were that it had to be a manageable two-day drive from both Oregon and Ohio, and have access to outdoor recreation so we could enjoy our vacation while staying somewhat isolated. This put us in Montana, Wyoming or Colorado. Even on short notice, there were a lot of options available, but most were condos or attached townhomes in ski resort areas. Spending a week in cramped resort lodging — where people from wherever may have varying definitions of social distancing — seemed like a bad idea. We took the time to comb through thousands of Airbnb and VRBO options and found a detached home on two-acres of property outside of Fraser, Colorado.

Rather than searching for an accessible home, I looked through photos until I found something that had two bedrooms, the kitchen and a bathroom on the main floor, with only a step or two to get into the house. It wasn’t perfect, but I was more than willing to accept needing help up a step to avoid a multi-unit building in closer proximity to the general public. For those who do have specific accessibility requirements, Airbnb does now let you filter for different features, such as a roll-in shower or a no-step entry, giving you more options and info than a search for a “fully-accessible” home would.

3. BRING YOUR OWN

The house we stayed in claimed to follow “strict cleaning protocols” but to be sure, we also brought our own bleach wipes and cleaning supplies. Kelly’s family got there just before we did, and Kelly’s mom went inside, opened windows to get air flowing and sanitized high-touch surfaces before we went inside. Knowing that the place was disinfected to our standards gave a little extra peace of mind — just like social distancing, we didn’t want to have to trust a stranger’s definition of clean.

To bring my mountain bike, we had to tow a trailer behind our car. One positive is that it gave us space to haul two coolers. Kelly stocked up at our local grocery, her parents did the same, and we both got big meals from our favorite local takeout spots to reheat. With our combined haul, we had enough food to eat in for the entire week. We did a pretty good job of packing but could’ve done better. There were a few times people had to run to the grocery store for small items like extra cheese or butter, which we could have easily avoided if we’d been more thorough in our meal planning.

4. IT’S ALL RELATIVE

All in all, the week was a very pandemic-y sort of success. Sure, there were drawbacks: no stopping to let Ewan explore roadside attractions, no sampling local restaurants and breweries, and Ewan didn’t get to hang out with his cousins. But he did get to play with his grandparents and uncle. And Kelly and I had more adult conversations than we’d had since February and were able to disconnect for a week, wandering mountain trails and floating on glacial lakes, all while keeping risk at a level we were comfortable with. It wasn’t what we planned, and it wasn’t perfect, but we had fun, nobody got sick and I’m certain our cortisol levels are lower than when we left. In 2020, that’s as good as it gets.
I love to travel and get excited just planning trips — but not during this pandemic. Since the arrival of COVID-19, I have had no desire to travel anywhere.

But I had to.

My son needed a very specialized surgery that required me to take my medically high-risk family on an unwanted, unwelcome and scary trip across the nation for a two-week stay in Cleveland, Ohio. We had no choice.

I found myself wringing my hands and racking my brain to determine the best strategies to stay safe from the threat of COVID-19. I questioned my decisions, reviewed and re-planned my trip. I wanted to think of every little thing.

My analytical brain started asking questions: What can I do to minimize exposure to COVID-19? How can I protect myself and my family on the way to and from the airports, during our flights and during our stay? Where do I start?

Here is what I did to prepare, how things actually went and what I learned from being forced to travel during the pandemic.

**BOOKING**

**My Plan:** Health is more important than money, so I sprung for first-class tickets for the only time in my life. It meant more space for us, and even more importantly, around us. I armed my son and husband with face masks, glasses, sanitizing wipes and hand sanitizer. I decided to bring gloves but wasn’t convinced I would always wear them while traveling.

**What Happened:** Thankfully, a friend gave us N95 masks. We wore them unfailingly for all aspects of our travel. I brought and used a lot of hand sanitizer and wipes. I tried gloves once, but struggled with quad hand issues, so I quickly jettisoned them and sanitized, washed and used lotion more.

I think I wasted money on most of the first-class tickets. Only one of the five flights had enough room for real social distancing. If I could do it again, I would inquire about the specific plane configuration. The cubical-style first class seating was superior.

**GETTING TO THE AIRPORT & FLYING**

**My Plan:** I asked a trusted friend, who I knew was diligently self-isolating, to take us from our home to the airport. I brought and used a lot of hand sanitizer and wipes. I tried gloves once, but struggled with quad hand issues, so I quickly jettisoned them and sanitized, washed and used lotion more.

I think I wasted money on most of the first-class tickets. Only one of the five flights had enough room for real social distancing. If I could do it again, I would inquire about the specific plane configuration. The cubical-style first class seating was superior.

**What Happened:** My trustworthy friend and nephew got us to and from the airports, coming and going, with no problems. The flights were definitely the riskiest part of the trip. We flew United, and on two portions of my roundtrip flight, I was seated right next to total strangers — no skipped seats. One lady climbed over me to catch her connecting flight in Chicago. Social distancing was impossible. Literally everyone walked past me twice, within a foot, boarding and deplaning. Thankfully all were wearing masks.

Everyone was allowed to remove their masks in the plane when eating or drinking, including the lady beside me who kept coughing. I carefully kept my mask on, didn’t touch my face and skipped snacks to eliminate mask removal. I repeatedly hand sanitized. We were provided with sealed, boxed food and bottled water and a sanitizing wipe on the plane, so no need to buy airport food. I ate this airline lunch at the airport where social distancing was much easier. All flight staff kept their masks on during my flights.

I was adamant about wiping down my airplane area as planned. But not the aisle chair or airport restrooms — no time. I asked before each transfer into an aisle chair if it had been sanitized and staff always said yes. I used gobs of hand sanitizer anytime I touched anything throughout the flights and airports. I diligently washed my hands when I had access to soap and water. The hardest place to maintain social distancing at the airports was going through security.

**AT THE HOTEL**

**My Plan:** I packed isopropyl alcohol and a refillable mister bottle to sanitize our hotel room surfaces upon arrival. Disinfectant spray was sold out everywhere I looked, so I planned to use 70% rubbing alcohol. It
works, too. To minimize possible exposure, I’d ask the hotel staff to clean only once a week. Still, I planned to spray everything with alcohol after anyone entered our room.

What Happened: The entire Cleveland Clinic campus, including hotel, required non-contact temperature checks upon each entry of all buildings, and mandatory masks. Good protocol! The hotel made it very easy for us to skip the daily cleaning. Housekeeping allowed us to set our trash outside the door for collection and they were great about bringing us requested items like towels and shampoo.

We dropped the ball on the alcohol surface spraying in the room. We were honestly exhausted when we arrived and simply collapsed when we should have been disinfecting surfaces.

FOOD & TRANSPORTATION
My Plan: I requested a room with microwave and fridge so we could make our own food. I Googled the hotel location and found a grocery store three blocks away, and, you guessed it, planned to spray anything we bought with isopropyl alcohol once in our room.

Our hotel is close to the hospital, so there is no need for shuttles. After any outings, I’d spray alcohol on my chair wheels and shoe bottoms when we returned to the room.

What Happened: Grocery ordering and delivery worked great using Instacart, and we dutifully alcohol-sprayed all groceries. Our limited “kitchen” was sufficient, but only because it was short-term. I packed two bottles of foaming soap and still had to buy more, as we washed hands a lot. About half the time, we remembered to spray my wheels and bottoms of shoes. We preferred wheeling/walking to the hospital. We needed to take the clinic’s shuttle three times, but it was sanitized between riders.

Overall, my plan turned out to be pretty good. Key actions were keeping my mask on and staying hyper-aware of anything that I touched so I could sanitize/wash my hands immediately.

We have been home for over a month now. We are all healthy, including my son whose surgery was a complete success. That makes it worth the trip.

BAGGAGE
To manage our belongings, we checked two bags for the three of us and each had a carry-on backpack. We knew our son would not be able to carry anything on the way after his surgery, so we stuffed all of his belongings in with ours. I assumed the outside of checked and carry-on bags were contaminated for 24 hours — it’s my understanding that the virus doesn’t stay more than 24 hours on porous things like canvas — but I knew the inside was clean. So after I opened the bags and got what I needed from them, I washed or sanitized my hands.
In her T3-4 SCI from an auto accident in 2009, Patty Kunze’s right arm and hand were fractured, so her shoulder had to be frozen during the recovery process. Pushing a manual chair proved painful. Physical therapy did not help, and further diagnostics revealed some arthritis.

Although Kunze, who was 48 at the time, dearly wanted to use a manual wheelchair, it was clear she would need to use a power chair. “I would go down kicking and screaming if I could, but the pain won out,” she says. A trained nurse, she also hoped to use a manual standing chair, knowing the value of load-bearing on her legs, but her therapists would not approve it. She felt a sense of defeat and reluctantly accepted that a power chair was the only way forward.

But once she was in her Permobil C300, Kunze discovered the benefits of power. “I found a new freedom I didn’t know could exist since my SCI,” she says. It was easy to board her adapted van, and the elevation feature brought kitchen shelves within reach. Her sadness about having to embrace power fell away.

Kunze’s initial resistance to power had a great deal to do with not wanting to look “more disabled.” But once she made the switch, “My shoulders thanked me, and I didn’t care what the public thought,” she says.

For Jim LeBrecht, embracing power was a much slower process. Born in 1956 with spina bifida, he began pushing a manual chair at the age of 2, and throughout the years he had put his upper body to work in a number of ways. A theater sound engineer since his college days, LeBrecht often carried his body into seating areas or up backstage catwalks. He played wheelchair tennis, did improvisational dance and rode handcycles. “I’ve had times in my life where I felt pain, but then I recovered,” he says. “Until it got to a point where I couldn’t stop the pain.”

An X-ray revealed that LeBrecht had a rotator cuff muscle tear in his shoulder, a common injury for manual wheelchair users. “I was thinking that the longer I use my shoulders and arms as much as possible, the better shape I’ll be in,” says LeBrecht. But he did lasting damage each time he hurt his shoulder, even though he thought he had recovered. He was unwilling to undergo surgery, given the months of absolute dependency and danger of pressure sores it would entail. “The risks of the recovery process and the percentage
chance of it really taking were just not good enough,” he says.

The only answer remaining was a move to power. LeBrecht came to appreciate the benefits of a power chair over a manual one, especially since he lives in a hilly neighborhood in Berkeley, California. “I just couldn’t go out in my neighborhood in a manual chair,” he says.

Energy Preservation
The switch to power is not always about accommodating an injury. For Phil Pangrazio, CEO of Ability 360 in Phoenix, Arizona, it had everything to do with preserving his energy. Injured in 1979 at C6-7, Pangrazio used a manual chair until 2005, when the pace of his work made it hard to get through a busy day without being seriously fatigued. “I knew if I was going to keep doing what I was doing that I needed my energy,” he says. He admits that not using a power chair was a matter of pride. “If you’re in that ‘super quad’ category like me, where you’ve got enough physical ability to push a manual wheelchair, you’re going to do it.”

Using a power chair instead was also a matter of comfort. “It is just easier to sit in a power chair all day long than in a manual,” he says. Manuals are primarily designed for mobility, as upright posture and firm contact with the back of the chair is key to being able to make the most of your available strength and balance. A tradeoff of efficiency over comfort has to be made with a manual chair.

The power chair can have a more reclined back, which supports your upper body weight, making you more comfortable. And given that an adjustable reclining feature is common to many models, you get more control over what feels best over the course of a day. You feel more stable and secure.

The Price of Power
There’s a learning curve when you switch to power. The added weight and extra speed of a power chair have to be considered in ways that are not the case with a manual.

LeBrecht learned about a Permobil C300 with tilt and elevation available from a family who had lost a member to ALS. He paid just $1,500 for it. But most people are likely to get caught in a very long process of selecting a chair, waiting for delivery and then paying out of pocket for a good share of it.

He got lucky, as the cost of a power chair can be steep, commonly in the tens of thousands, and often wheelchair users have to fight with insurers. To increase your chance of winning those battles, try to find a seating professional and provider willing to advocate for you. And, of course, you need to be sure that the provider you work with is in your funder’s network.

It’s an unfortunate fact that a lot of wheelchair options don’t have insurance codes, which means they have to be paid for out of pocket. As you work through the options on the order forms, be sure you know exactly what a feature will cost you. If it’s important enough to you, you may have to pay for it yourself. Things like specialized chair backs, for instance, with ergonomic adjustment,
Putting off Power

Comfort, stability and safety in a manual chair rely on having it very well specified and configured. “An improperly-fitting chair will definitely put you at risk of developing shoulder issues — and fast,” warns Annie Palermo, a physical therapist and researcher at The Miami Project to Cure Paralysis. She says this is because “essentially your shoulders become your hips. They were not evolutionarily made to do that. When you’re putting smaller muscles in charge of propelling your body, they fatigue quicker. And they break down.”

A critical issue is center of gravity — the position of the main wheel axles toward the front or rear of your chair. “If you have to reach too far back for your wheels, you will put wear and tear on your shoulders that can add up over years and cause inflammation,” says Palermo.

In the old days of the ultraheavy Everest & Jennings tanks that many of us used, it was nearly impossible to protect our upper bodies in the long term. A well-specified and maintained modern ultralight wheelchair gives us control over that moment when we make the switch to power. Instead of being forced by chronic pain and injury, we can do it for the greater mobility and independence it has to offer, and at a time of our own choosing.

On the whole, taking care of your arms and shoulders, using a well-configured manual chair, and being extra aware when you engage with disability sports will ward off the day you might be forced into power.

You’ll also want to keep your tires inflated. When they go soft, you have to apply more force and you don’t coast as far. That means more pushes, and more strain, on your tissues over time. Keep those puppies pumped!
Three years after being paralyzed in a 2014 shooting, Elijah Johnson fell into a deep depression and says the only thing that kept him going was his wheelchair basketball team.

“I explained to my coach how tired I was of sitting around the house all day. I felt like I was 15 years old again,” says Johnson, who is now 25. “Everybody around me was going to work, doing stuff with their lives, coming back and having something to talk about, while I was living the same lifestyle as my dog.”

Johnson’s coach suggested he join a support group at Mount Sinai Hospital in New York City. He sat in on a few meetings when he first became an L2 paraplegic, but back then was skeptical they could help. Taking his coach’s advice, he returned to the group, where he met Bill Lehman, a 74-year-old C6 quad.

“Bill asked what I thought about going back to school and getting a job and I told him, ‘I don’t know,’” says Johnson. “Then he said, ‘What if they paid you a little money and then offered you an internship at the end?’” Johnson took that deal and today he is an analyst for Turner & Townsend, a global construction firm.

Lehman’s offer to Johnson is one that Year Up has extended to enrollees between the ages of 18 and 24 since its inception in 2000. Many participants only have a high school diploma or GED when they start and are often either out of work or underemployed. “There are ample stories of young people who were living in homeless shelters during our program, only to finish and get a job making $40,000,” says Lehman.

LEHMANN’S TERMS

From 2009 until he was paralyzed in 2014, Lehman recruited corporate partners for Year Up. The program offers enrollees a year of concentrated and accelerated vocational training for entry-level positions in an array of professions. The year is split between the classroom, where participants receive college credit, and a paid internship with a corporate partner like the ones Lehman helped recruit — big-name companies such as Facebook, Hasbro, PayPal, Fidelity Investments, Bank of America, General Electric, LinkedIn, JP Morgan Chase or American Express, to name a few.

Prior to his injury, Lehman admits he didn’t give much thought to the employment picture of young wheelchair users. It was only after he retired and transitioned to part-time consultancy at Year Up that he had a sudden realization: “Since I was in the SCI world, I began to think, why can’t
we do something similar for these folks like we do for non-disabled people?”

Right now, the number of success stories of wheelchair users at Year Up is low. Although to be fair, the program doesn’t keep specific statistics on how many people with mobility disabilities have actually enrolled and graduated. But prior to connecting Johnson, Lehman only knew of one: Jessie Chin, 27, who happened to be a wheelchair basketball teammate of Johnson’s. Lehman had connected him too.

Chin, a T4 paraplegic and Year Up New York’s first wheelchair-using student, paved the way for Johnson. When the program asked for his opinion on improving accessibility, “I made sure to tell them, 'I'm pretty much independent, but there are people who have less mobility. Let’s make these doors lighter’ or 'Let’s make sure the bathroom is accessible just in case someone like me comes along and needs to use it,”’ says Chin. As a result, the program added automatic doors to its building entrance and to a washroom.

COMMUNICATION AND ACCOMMODATION

As the only current Year Up student using a wheelchair, Johnson was nervous, but it helped him to know he wasn’t the first. “I was sure there would be setbacks, but it was a doable thing because someone had already done it,” he says.

While Johnson worked to achieve his goals, he embraced skills he always had but lacked opportunities to use, like public speaking. He appreciated having Year Up’s full support behind him, even if the organization’s lack of experience with wheelchair users occasionally showed.

“Employers are open to accommodate, but I don’t think there are enough intentional conversations that happen

In February 2020, national representatives from Year Up had a conference call with United Spinal Association to discuss becoming part of United Spinal’s Pathways to Employment initiative. Now United Spinal is proposing a webinar to present the program to its membership.

Bill Lehman thinks the two groups working together will lead to more wheelchair users finding employment success. “That’s why I reached out to United Spinal Association. They have network offices across the country that serve people with SCIs and my hope is that they can help match qualified candidates to Year Up sites throughout the nation,” he says. Year Up currently has offices in more than 10 states.

Though Year Up is willing to admit candidates whose disabilities require more accommodations than Chin and Johnson’s, United Spinal knows that is uncharted territory for the nonprofit and wants to help them navigate it. “The idea of engaging participants with a higher level of disability definitely seemed new to them, but they were interested in promoting the program to our members,” says Abby Ross, chief operating officer of United Spinal Association.

We want those gems, those people who have talent.

“EXPANDING ACCESS TO EMPLOYMENT”

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before potential employees with disabilities arrive.”

Velazquez hopes to demonstrate to corporations how employees with disabilities can energize their teams. “Sometimes Year Up can teach even big-name companies what works and what they can try,” he says. “Maybe being able to see how productive these hires can be and how much they contribute, along with just the effort and the grit that they show, allows people to say, ‘You know what? This might’ve been a talent pool we missed that we need to tap into.’”

**FINDING THOSE GEMS**

Johnson and Chin’s experiences are perfect examples of Velazquez’s theory. After completing the program, Chin went back to school for a master’s in social work and is now pursuing a career as a high school guidance counselor. Johnson made such an impression that not only was he hired where he interned, but his Year Up class of 160 voted him to be their graduation speaker.

Following the success of Chin and Johnson, Year Up New York is open to more students with disabilities, and the national organization is starting a partnership with United Spinal Association [see sidebar] to hopefully bring more wheelchair users into the program.

“We’ve been clear — we want those gems, those people who have talent, and we want to help them,” says Velazquez. “We’re looking for somebody who has already figured out how to traverse their own challenges a little bit and put some thought and intentionality in what they want for themselves.”

Lehman is committed to the creation of more positive employment scenarios for others with SCI. He was fortunate that he already had plans to step down from full-time work when he was injured and that he could do his job relatively easily with no adaptations. He knows others aren’t as lucky and that Year Up must create a more inviting and accessible environment if they want to better serve all people with SCI/D going forward.

“Jessie and Elijah are both paraplegics. They have good use of their upper body, which made transitioning from the classroom to the work environment easier because they can use their hands for various tasks,” says Lehman. He adds that Year Up has more to learn about what quadriplegics need to thrive in the workplace so they can help employers to accommodate them. “I’ve asked them to look into this, but it’s a research area they haven’t worked out yet.”

An optimistic Chin agrees there is work to be done if Year Up wants to attract more disabled applicants. “They could make a better effort of advocating for, and advertising to, people with disabilities. Me being the first wheelchair user to graduate from the program was the first step,” he says. “There’s still a long way to go, but there is in society too.”

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WE’VE BEEN HERE BEFORE

Normally, I’d have spent the last few months tracking spinal cord injury research. I’d have done my thing with new peer-reviewed publications, sifting through the jargon with a pen in one hand and a medical thesaurus in the other, multiple laptop tabs open to university and corporate pages. Every time I’ve produced an article for this magazine, it’s been the same process, the same effort to first comprehend and then translate what’s happening in the worldwide effort to repair damaged spinal cords.

I write with an imagined “you” in mind — “you” being the person I was when my husband broke his neck more than 19 years ago. In a way, I am always speaking to that confused and anxious version of myself: It will be OK, but not right away. Here’s what you need to know, and here’s what you can safely ignore. Here’s who you can trust. Here’s the truth about this injury and how it will, someday, be healed.

Today I find that I’m closer to that 2001 Kate than I’ve been in years, because the pandemic has brought back so much of the emotional and psychological flavor of those days. There isn’t much by way of new research to report right now, especially in the United States. Universities went into lockdown with the rest of us in the spring, and scientists were forced to stop their work and try to come up with ways to make it safe to continue. Those who were working in clinics, doing trials of new therapies with spinal-cord-injured volunteers, had to call it all to a halt.

Call it all to a halt.

Does that sound familiar? To me, these six short words concisely describe both the situation inside my husband’s central nervous system and the early months post-injury in our family. Stop whatever you are doing, right now. Cancel all your plans. We need to figure out what this is.

Most people reading this will have their own story of that abrupt halt. On March 7, 2001, I had been planning to see a friend launch her new book at a local bookstore. My husband had been planning to take our preteen daughters to their Wednesday night choir practice. Instead the girls and I sat at the trauma center waiting room while doctors worked to stabilize him. Our lives as we’d known them had stopped, but we didn’t know it yet.

By Kate Willette

“I know that careful science is tedious, irritating and necessary.”

THE COVID-19 SHUT DOWNS FEEL FAMILIAR

The coronavirus has rolled over us all like a slow-motion version of that night, and as the months pass, I keep having an odd sense of déjà vu — the feeling that I’ve been here before. Our home is in Seattle, where the person then thought to be the first in the United States killed by COVID-19 was reported dead on February 29. Throughout March, April and May, the job was to cancel every plan that involved leaving our apartment. Our lives as we’d known them just stopped, but we didn’t understand it yet.

My sense is that we who have come through the sudden and lasting trauma of paralysis entered the pandemic with a tool set others lacked. I’ve been watching the world catch up, slowly. At first there was just disbelief. This happened in China, and then in northern Italy, but it won’t be like that here. Other people break their necks skiing, but not my husband.
Disbelief was followed by an overload of information, none of which answered the one question that mattered. When will this be over? We all saw the authorities, political and medical, stand up in front of microphones and act out the small, familiar dramas. There were the minimizers (by Easter!) and the realists (12 to 18 months, if we’re very lucky). I witnessed this and thought of the eager optimism of my father-in-law, who was prepared to cling to any bit of hopeful news, confronted with the impassive faces of doctors who steadfastly refused to speculate.

I remember also how frustrating it was to try to extrapolate from what I saw to what was possible. The 2001 me wanted to know things like, what does it mean that my husband has this particular bit of motor return? Can we expect more change? How can we maximize it? The 2020 me pores over the endless coronavirus transmission data, trying to figure out what it means that this city or that state is having a spike, and that one seems to have achieved containment. How did they do it? What can we learn?

Now, as then, the cold truth seems to be that we don’t know enough yet. There’s not enough reliable data, and anyway we seem to be at a place in the pandemic that’s like the early post-injury weeks, where so much is still in flux that we hardly have the questions formed before they change again.

At least I know better than to think there will be a simple or speedy resolution. I’ve learned the hard way to be wary of people selling me hydroxychloroquine, "stem cells," or an untested vaccine from Russia. Thanks to spinal cord injury, I know what a safety trial is and why it matters. I know that careful science is tedious, irritating and necessary.

The pandemic echoes for much of the world what so many of us have endured. The loneliness and isolation, the loss and fear, the confusion and rage — all of it plays out on my laptop and in electronic media, day after day. We hate this. We want to go back to normal. I listen to people talking about missing sports and dancing, and I think, tell me about it. I understand the frustration of people who have been forced to curtail their activities even though their own risk of infection or serious outcome is low. Family caregivers know in a deep way what it is to shift into protective mode, which is exactly what entire communities are now being asked to do. There is a cost.

The distorted sense of time, maybe, is what resonates most strongly. There were days during the hospital in-patient phase when it felt as if I’d been sent to the moon, an airless space outside the normal passing of hours and days. There were no milestones, no activities, nothing to look forward to beyond the next few hours. That’s how the lockdown in March and April felt, and even now I find myself turning the pages of the calendar, surprised to see that another month is gone, resigned to the sameness of what will happen next.

I don’t envy people for whom all of this is completely new. I like to imagine that when the uncertainty of this time has passed, there will be a shared understanding that what each of us does matters to all of us. There was a time when, for my husband, a cut on his heel was just annoying. Now a cut on his heel or anywhere else is a threat to his whole system if we don’t catch it and treat it quickly. This, I think, is also what global travel has created for humanity: A virus in one place, no matter how distant or unheard of, is a threat to all of us. We can learn that lesson. We have to learn that lesson.
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www.unitedspinal.org/pathways-to-employment/

Meet New Member Robin Matulich

Age 66, from Dallas, Texas
C7 Quadriplegia
Volunteer Leader/Teacher at To Be Like Me (tobelikeme.org)

Why I joined United Spinal: I wanted to learn how other wheelchair users live life to the fullest.

What is the one disability-related product you couldn’t live without? My shower/toilet chair. It’s essential when I’m taking care of my basic needs. My day would be immensely more difficult without it.

If you could change one thing in the world to improve quality of life for wheelchair users, what would it be? A life of faith can make a huge difference for individuals facing uncertainty and new limitations.

Meet other members or join United Spinal at unitedspinal.org
I attended a crowded Friday evening event on the fourth floor of a newly-remodeled, century-old building. On the way up, it felt novel to be riding a high-tech elevator in a building that had been there for over a century. After I had been noshing a while, a startled staff member quietly approached and said, "I don't want to alarm you, but the elevator has broken."

Internally, I screamed, but calmly instructed her, "We're going to need the fire department, and quickly." Suddenly anxious, I sat there puzzled. How were they going to get me and my 300-pound power chair down the narrow flight of stairs in an historical building? The firefighters' best solution was to load me into an office chair and carry me down. The only redeeming aspect was that one of the firefighters was gorgeous.

As the two men clamped their hands tightly to the corners of my seat, I shut my eyes and took my mind off the perilous situation by imagining my future with my hunky new firefighter friend. I peeked to see our progress. What I saw, instead, were my dangling legs forcefully swinging like pendulums with each step. First, they rocked up and under me, and then they extended out to squarely and repeatedly kick my handsome rescuer in the "family jewels."

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