Active
Vent Life

Paris by Firefly  Designing an Exoskeletal Arm  Swimming
Ethos is the best chair I’ve ever had. I love how it looks and that you can’t feel the effects of bumps on the sidewalk. ISO Tech makes it so much smoother than my last wheelchair. It’s a really innovative design.

Paul Moran | Five time Paralympian in sitting volleyball and wheelchair tennis

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Ventilators have come a long way since the invention of the iron lung almost 100 years ago. New technology and changes in society have made it easier than ever for vent users and people with serious respiratory issues to live the lives they want to live and not be confined to institutions or bedrest at home. ALEX GHENIS checks in with an array of people who use vents to see what their active lifestyles look like today and how COVID-19 is impacting them. NICOLE FICARRA writes about how a diaphragmatic pacemaker changed her world.

16 GETTING BACK IN THE POOL
ALI INGERSOLL lived for the water before she was paralyzed, and didn’t let a diving-related SCI stop her from getting back to it. She chronicles the path back and shares swimming tips.

26 HELPING DESIGN A LIFE-CHANGING PRODUCT
ROB WUDLICK joined a small company to help it develop a product to help him and other quads regain function. Three years later the product is improving his life and headed to market.

29 PARIS BY FIREFLY
Zipping around the sidewalks and streets of Paris with his Firefly attached to his wheelchair, ALAN TOY felt like Superman. He shares his experience with Rio Mobility’s power assist system, and we preview the soon-to-be-released new version.
I'm not one to pat myself on the back for my successes and accomplishments — partially because my quad arms make it tricky — since I'd like to think I am aware enough to know that most victories are the product of more than one person's contributions. But one success I am willing to claim fully as my own was the decision to change New Mobility's weekly editorial meetings from phone to video.

That may sound trivial, but you have to understand that the team that brings you New Mobility — a team I am proud to be a member of — is composed of some of the legends of the Introvert All-Stars. It took multiple calls and seemingly hours of persuasion to convince my coworkers that we wouldn't all be appalled at each other's appearances and that there was value in actually seeing our faces when we talked.

I sold them on shorter meetings where no one could get away with multitasking or losing focus, two things I happily owned up to over years of long phone meetings. I believed what I was selling, and I was also confident that seeing our team's faces would build camaraderie and reduce confusion. Two years later, I think we'd all agree the move to video has paid great dividends.

If there is one silver lining to come out of the ongoing pandemic, it may be that people around the world are reaping these same dividends and beginning to appreciate the power of video. Anyone who hadn't already discovered the benefits and potential of video conferencing, and, more broadly, video chatting, has likely received a crash course in the field thanks to COVID-19. Even the most troglodytic Luddites are embracing Zoom and Google Hangouts as a way to stay in touch, because, well, honestly, there aren't a lot of options.

As they do, they'll likely wrestle with the somewhat confusing possibility that an event that forces us to isolate ourselves may actually end up bringing us closer together. I'm not talking about the cheesy "we are the world" unison that many would like to ascribe to these types of crises, but to actually staying in regular and more meaningful contact with friends and family. With time on hand and the knowledge that most everyone is stuck at home, people are reaching out to distant family and long unseen friends they likely wouldn't have connected with during their normal day-to-days.

“An event that forces us to isolate ourselves may actually end up bringing us closer together.”

It's not surprising to me to see that our community of people with disabilities is leading the way when it comes to creative use of video communication. We've learned to harness the power of video to make our voices heard when transportation fails, access is nonexistent, or our bodies simply won't comply. From nonprofit board meetings, to support groups, to advocacy groups, to simple social gatherings, some of the most productive and exciting video chats I've seen in the last few weeks have come from our community.

While I miss the meals out with friends and going to appointments and events, I've grown surprisingly fond of seeing upcoming social Zoom chats scheduled on my calendar. I've "attended" five 40th birthday parties for friends, watched a movie with a friend's kid and played games with a split screen so we could enjoy each other's reactions. And with a few minor exceptions, I can honestly say I really enjoyed each one.
Alan Toy is not a salesperson, but after reading the story he wrote for this issue, the people behind the Rio Firefly would be wise to recruit him. Toy’s story chronicles how the Firefly, a front-wheel power add-on for wheelchairs, transformed a trip he took to Paris. He has traveled on four continents with the Firefly and estimates he has put 5,000-plus miles on it. “Wherever I visit, as soon as I get there, I’m out of the car with my Firefly, and I’m off to explore,” he says. He has gotten so used to people inquiring about the device that he keeps a stack of Rio business cards under his cushion.

I’ve known Rob Wudlick for almost eight years, and in that time he has evolved from a newly-injured quadriplegic to one of the busiest and most impressive advocate/researcher/engineer/writer/you-name-it-he’s-done-it people I know in the SCI community. He helped lead the charge to pass legislation for SCI research funding in Minnesota; he co-founded a research-related nonprofit; he’s advocated at the federal level; and, as he writes about in this issue, he has consulted on a new device with promising possibilities for higher-level quads. And that’s just to name a few of his accomplishments. “I like doing a project and then doing something different the next day,” he says. “Knowing that you are working toward something that is going to change lives is pretty meaningful.”

If I ever decide to get into swimming, I can’t imagine a better guide to introduce me to the wonders of water than Ali Ingersoll. In this month’s issue, Ingersoll shares her passion for the pool, along with some useful SCI swimming tips to help you prepare for warm weather. She’s already looking forward to spending October in Miami in her favorite pool overlooking the ocean. “My husband and I always have it to ourselves,” she says. “We have a glass of wine and then we lounge around on floaties for hours.”
#WillWatch
These are three of my favorite YouTubers ("Beyond the Screen with Social Media Influencers," April 2020). They provide lots of entertainment and insights that everyone can benefit from.
Charity Haynes
Newmobility.com

Switch for Google?
Can Switch Control be used on a Google Pixel phone? ("Switch Control Changed My World," April 2020.)
Chuck Foss
Newmobility.com

Todd Stabelfeldt responds:
I know Google/Android has created its own version of Switch Control called Switch Access, but I have little experience with that particular assistive technology. I do know every manufacturer has pros and cons, but the few folks I knew who were using Android’s version ultimately switched over to Apple’s Switch Control for various reasons, which mainly included ease of use. I know the Tecla Bluetooth interface will use any platform. Here is a YouTube link of me explaining how my setup works with Apple’s Switch Control: youtu.be/kj9Uucdwles. Keep pressing on and digging deep to find what works best for you.

Hotel Planning
I find that many times accessible rooms have only two doubles or one queen ("Dear Hotels, Wheelchair Users Have Families, Too," April 2020). My husband and I want to sleep together, and a queen is a bit tight (I use a lot of pillows, and my husband is a restless sleeper). We have spouses, too!
I always, always call the hotel (not the reservation line; look up the actual hotel’s number) a day or two before we arrive to double-triple-check that we’re getting the room we want. About 60% of the time, it’s not in the system the way we wanted. They can usually accommodate us. Also, if you need to check in late, let them know, because if someone else needs an accessible room with, for instance, a roll-in shower, and they get there before you, you may lose that specific room.
Kathy Stice
Newmobility.com

Fun in the Sun
What a great, informative article, ("Gear Up for the Beach," April 2020)! Thank you.
Kelly Twichel
Newmobility.com

Research Thoughts
I have been telling the story of the “valley of death” for many years as part of giving the picture of SCI research to people interested in the issue ("Crossing the Valley of Death," April 2020). But recently I have come to the conclusion the valley of death is not a real issue for SCI research given the fact that the field is desperate to get a therapy that can really help people.
Can you make a list of all SCI potential therapies of the last 20 years that ended up in the valley of death or that did not even start the clinical trial process? If you have time to do that, let’s put all the available data on the table, and then let’s look at what we are talking about.
If we had a therapy with solid preclinical data that can turn a rat with chronic SCI (BBB score less than 9) into a walking rat (BBB score above 14), I am sure this therapy will fly above the valley of death like a rocket!
Two things should be done yesterday: 1. Commission SCI research to non-academic research organizations. 2. Establish a replication initiative, as we need to know of all the data published — what’s good and what’s rubbish. Then we will know where to put research money in the future.
Paolo Cipolla
Newmobility.com

Salt-Free Secrets
How can I get all my immune system vitamins on a low sodium diet? A lot of these foods ("COVID-19 Nutrition and Shopping Guide," Blog, April 6, 2020) are high in sodium.
Fidel Valenzuela
Newmobility.com

Joanne Smith responds:
I suggest purchasing low sodium versions, like low sodium chickpeas and butter with no added salt. Another option to ensure there is no sodium is to use dry legumes and/or lentils.
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Aisle Take That

Unwieldy and uncomfortable, airplane aisle chairs occupy one of the lowest rungs of design hell. Thankfully, innovators are trying to devise a better solution to help people with mobility disabilities enjoy air travel more. With an ergonomic design and an integrated mechanism for fitting into existing airplane seating, the Row-1 Wheelchair System won the Discovery of the Year Award as well as a Platinum Winner Award at the European Product Design Awards in 2019.

Colorado-based company Molon Labe Seating is hoping to do away with the aisle chair all together with its new Freedom Seat. The novel design comes out of the company’s larger offering of adjustable-width and customizable seats. The Freedom Seat solves the longstanding issue of allowing airlines to easily adapt their seating configuration when a wheelchair user is flying, without having to permanently lose seats and profits by removing a seat. The Freedom Seat simply slides over the adjoining seat, leaving a space for a wheelchair user to sit in their chair and lock down using a Q’Straint docking system. See it in action at airlineseats.biz/how-it-works.

Eye Control

Thanks to innovations from across the computer industry, using a tablet hands-free is easier than ever. But if you still haven’t found the right solution, you may want to check out Eyetell, a free eye-controlled augmentative and alternative communication app for iPad. Eyetell uses the FaceID sensor on newer iPad models to track the movement of the user’s eyes in response to a circle of rotating letters. When you look at one of the rotating letters, it indicates that it has registered the gaze. If you keep following the letter with your eyes, it will be selected. Combined with a powerful, customizable word predictor, this allows the app to offer quick, easy, accurate control.

For more info, visit eyetell.io, or visit the AppStore to download apps. apple.com/us/app/eyetell/id1481070509?ls=1.

Voting: ‘Participation is Powerful’

Did you know that if people with disabilities had voted at the same rate as those without in the 2018 election, 2.3 million more disabled voters would have cast their votes? That’s one of the many eye-opening facts disability advocate and writer Imani Barbarin shares in Vote for Access. The new five-part video series seeks to jump-start a national conversation that goes far beyond mail-in ballots to describe the multiplicity of barrier-breaking innovations needed to make sure every vote counts.

As the host of the series, Barbarin takes a broad, cross-disability approach, covering inaccessible polling places (only 17% nationwide are fully accessible), lack of transportation options, non-functioning electronic voting units and more in five-minute episodes that are engaging and empowering. As Barbarin says in the first episode, “Voting is participating, and in a country that so often relegates disabled people to institutions, isolation and stereotypes, participation is powerful.”

The series was produced by Rooted in Rights and Block by Block Creative, and is available at VoteForAccess.us.
Impossible Yoga

We could all benefit from a little rest and relaxation these days, and any way to safely escape the confines of our quarantine comes as a welcome surprise. Thanks to the internet and the people of the Impossible Dream, you can now do both in one fell swoop with chair yoga classes on board a 60-foot wheelchair-accessible catamaran. The nonprofit has teamed with yoga teacher Natalie Morales to broadcast yoga classes for wheelchair users twice a week from sunny Biscayne Bay, Florida. The one-hour virtual sessions begin at 4 p.m. EST every Monday and Thursday, can be accessed via Facebook Live and are uploaded to YouTube after the conclusion of the class. Each session focuses on breathing, range of motion, balance, community and overall care. All classes are free, but donations are welcome.

For more information, visit theimpossibledream.org or email info@theimpossibledream.org. To participate in the class, visit facebook.com/impossibledreamcatamaran or YouTube at bit.ly/3dccX3G.

Kiss and Tell

When New Mobility contributor Gary Karp wrote and self-published Disability and the Art of Kissing in 2006, it served as a compendium of all the things he’d learned over a long career as an educator, speaker and writer. Each chapter tackled a different topic — from whether sex is still possible after disability, to self-pleasure, to finding a partner — with a short, punchy essay.

Over the next 13 years, Karp married, divorced and returned to single life — experiences that fueled his desire to update the book with new chapters and a new cover. Late last year that desire became a reality when he published the second edition of the book, which is now available through his web site, garykarppeare.com/aok2.

“It’s a topic that I’m passionate about, and I wanted the book to have a fresh life,” says Karp.

Karp, a T12 paraplegic who lives in Phoenix, could never have anticipated the current pandemic or its impact on dating or relationships, but was quick to suggest a chapter on phone sex might be a good addendum. “It’s one of my favorite topics. It’s very, very undervalued,” he says. “It’s an art.”

He has no doubt people will find a way to stoke the flames of love despite quarantines and social distancing. “I think when there’s real intimacy between two people and real attraction and real desire to enjoy, that people find a way to get creative and any way that you can do it is healthy, and I encourage it whole heartedly,” he says.
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.

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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.

**NEILSEN FOUNDATION TAPS UNITED SPINAL FOR COVID RELIEF**

During the devastating hurricane season of 2017, the Craig H. Neilsen Foundation partnered with United Spinal Association to get relief to those in Puerto Rico, Texas, Florida and other gulf states who desperately needed it. United Spinal used its extensive grassroots network to provide grants to roughly 300 individuals, and provided funds to affected chapters so they could support their local SCI/D communities. The program was so successful that when the coronavirus pandemic hit, the Neilsen Foundation knew just where to turn.

“We needed to find a way to directly help the community quickly and effectively,” says Kym Eisner, executive director of the Neilsen Foundation. “Our partnership with United Spinal ensures that these vital resources get to where they’re needed most. This organization is among the best-positioned to respond to the urgent needs that the pandemic has created because of its ability to reach individuals throughout the country. We hope that our emergency relief funding can continue to allow United Spinal to adapt and respond quickly to help the SCI community in these unprecedented times.”

In order to make sure Neilsen’s funding reached as many people as possible, United Spinal quickly developed ways to get the money to those most in need. One of the ways provides direct grants of $500 to affected individuals. Some 1,200 people completed a simple application process that asked how COVID-19 had impacted their situation. Needs ranged from paying caregivers and bills to buying groceries, medical supplies and personal protective equipment.

Despite only hearing about the grant in early April, United Spinal was able to start sending payments just a couple of weeks later. As of writing, United Spinal had already approved more than 600 recipients. Because of the overwhelming response, grant applications have already closed, but Abby Ross, chief operating officer for United Spinal Association, says that if the organization receives more funding from other partners, it may be able to fund more applicants.

United Spinal has also provided grants directly to 33 of its chapters and 17 of its support groups so they can develop and fund their own programs. Chapter plans include: buying Zoom memberships to provide peer-support online; developing a rural peer-support program; providing grocery and meal-delivery gift cards; hiring staff to deliver supplies and groceries to quarantined members; purchasing and delivering PPE to members; helping members with purchasing technology and internet connections to allow them to stay connected online, and more. “Chapters are being really creative to meet the needs of their members,” says Ross.

In addition, United Spinal created a fund for “extraordinary cases” where an individual grant needed to exceed $500, as well as a budget to send PPE supplies directly to chapters. United Spinal distributed 10,000 KN-95 masks to chapters and individuals that might not have been able to obtain them otherwise.

With how quickly the pandemic has changed everything, organizations are having to rapidly adapt and expand their traditional offering to serve their members in this new world. Ross says that when Neilsen contacted United Spinal, “their concern was so genuine, just trying to make sure people had the resources they needed. This grant was certainly outside their regular scope of operations, so we can’t applaud their responsiveness enough.”

— Seth McBride
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GEAR HACKS
By Seth McBride

I’m writing this from my desk as my 3-year-old son naps in the other room. I will write as long as he stays asleep. When Ewan wakes, a rustling sound of him stretching will come through the monitor before he stands up and yells, “Hey Baba! I’m awake in here!” Then I will be done working until my wife, Kelly, comes home. After dinner together, and then reading Yertle the Turtle, I will sit back at this desk and try to write some more.

Kelly works on the frontlines in the ICU treating COVID-19 patients, and our daycare is closed, so my work flexibility means that I’m on duty full time with Ewan and Kenai, our 7-month-old heeler puppy. Child and dog parenting, work, fitness, sleep, washing dishes — there aren’t enough hours in the day for all of these things, so I hack my schedule as much as I can and try to combine activities wherever possible.

Workouts
Everyone in our household is liable to flip out if they don’t get a minimum amount of physical activity. During quarantine, though, my lack of alone time has made me reconfigure what a workout looks like.

If I’m working out, either Ewan needs to be involved, or I need to be wearing Kenai out too. Early in the quarantine, I made a quad-friendly tug-of-war toy for Kenai out of the end of an old tie-down strap I had in the garage (two-packs are $10-$15 from many online retailers or hardware stores). There was already a loop in one end, and I tied a loop in the other. I wrap one loop around my wrist to bypass my grip-less fingers, and Kenai chomps the other.

I roll onto the carpet — better purchase for Kenai’s claws — hold onto my chair with one hand and let her grab on. Swinging her back and forth, I alternate arm motions: rows, bicep curls, straight-arm pullbacks and triceps extensions. I switch arms and do it again. After 10 minutes, she’s panting, and my arms are burning.

Another option involves using Ewan as a weight vest. I’ll transfer out of my chair onto the carpet or the mat in our garage workout space and then flip over on my belly. He’ll climb onto my back, lie down and wrap his arms around my neck. I’ll do a set of pushups, him giggling, me grunting with an extra wiggly 35 pounds of resistance. Then he’ll climb off, I’ll flop over into a seated position and put my legs up onto my handcycle seat or the ottoman. Using two stools and Ewan on my back, I’ll crank out some dips. The benefit of using a toddler instead of a typical weight vest is that he climbs on and off on his own. And when I go by his count — 1, 2, 3, 4, 7, 13, 20 — the reps go by quicker than ever.

The Heeler Sled
Ewan really likes bikes, which is nice, because I really like bikes, so our daily pandemic routine revolves around rides. He’s been on a strider bike — basically a tiny bike without pedals that kids can use before they gain the confidence or coordination to operate them — since he was 2. For a toddler, Ewan puts some distance in, regularly strides for 3 miles or so if we have the time. But Kenai is bred to run and could put 10 miles in at Ewan pace and barely be panting by the end. I thought wearing her and Ewan out were two separate activities, until one day I had Kenai alongside my Bowhead off-road bike with Kelly and Ewan leading.

I was getting frustrated because Kenai just kept pulling and pulling. I finally said screw it, gave up on the leash training and let her at it. Suddenly she’d gone full sled dog, towing me and my 100 pound electric mountain bike like she was racing to Nome. A mile and a half later, she was exhausted and no longer interested in pulling. The same method works on a regular handcycle; just make sure you have good brakes and a chest harness for the pup.
Pedal Bike

I never thought I'd be able to teach Ewan how to ride a pedal bike. The "training wheels off" image I had in my head was of a parent holding onto the seat of their kids' bike, trying to keep up in an awkward, bent over shuffle. Then one day, Ewan and I were watching Brandon Semenuk's segment in the mountain bike film Unreal (bit.ly/2Wk68GF), in which he spins and flips over bus-sized gaps with as much grace and beauty as I've ever seen anyone do anything. At the end of the segment, Ewan turned to me with his serious face and said, "Baba, I want you to teach me how to do that."

"How 'bout we start with pedaling?" I replied.

We went out to the garage and I transferred onto my Bowhead. Using one hand for the throttle and brake and the other for balancing his bike, I was able to ride it down to the sidewalk. Ewan got on, put his feet up on the pedals and I eased onto the throttle. We were off.

Amazingly enough, it worked. The same method was just as effective on my regular handcycle — a Top End Force CC. Me helping him on either bike is easier than if Kelly were doing it. I’m down low, so I don’t have to bend over and kill my back, and the side-by-side position lets me easily ride along and help with balance as needed. Most parents with handcycles should be able to do the same.

As we go to print, he’s still working on the pedaling. I’m not sure what I’m going to do when he’s ready for the flips and spins. Maybe start with some advice I learned the hard way: "If you're going to do a backflip and a half, just go for the double."

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While the world grapples with the COVID-19 pandemic, Chanelle Wimbish, a T6 paraplegic from College Park, Maryland, works to help find a treatment for another devastating disease.

As a clinical research assistant at Social & Scientific Systems, Wimbish helps write the studies that examine the causes and comorbidities of HIV in an effort to find an ultimate cure. Though the world has more of a handle on the causes and treatments for HIV today, as we grapple with the consequences of the COVID-19 pandemic, Wimbish is reminded of the early days of HIV/AIDS.

“There are so many similarities in the panic of it all. Everything is so unknown right now that it’s scary,” she says. “All you can do is follow what the major scientific and health authorities tell us, and with HIV/AIDS, it was the same thing.”

Being in the public health field of infectious diseases, she is able to look to the historical trajectory of HIV/AIDS for solace, hopeful that although there is no treatment for COVID-19 now, that won’t always be the case.

“I have a comfort in knowing science and knowing through my networks and connections that every scientist and every medical professional in the world right now is working on figuring out exactly what this virus does to the body, how best to treat it and how best to cure it,” says Wimbish.

In fact, she is one of them. Because of its experience and international network, the AIDS clinical trials group that Wimbish currently works with recently got assigned to run a treatment study for COVID-19, even though the study is not HIV-related.

Just two and a half weeks ago, she and doctors from all over the U.S. began designing a study with 2,000 enrollees to test a treatment regimen and see if it would prevent the enrollees from dying or being hospitalized. “That is just mind-blowing,” she says, about how quickly it’s coming together and how many people are involved. Her role will be to help create the written document that doctors will follow to enroll individuals and to manage other aspects of the study once enrollment begins.

As a biology major in college, Wimbish probably never imagined she’d find herself on the front lines working toward a cure of a virus responsible for a global pandemic. Her journey began 15 years ago when she interned at an AIDS clinic called Philadelphia FIGHT in her senior year. It was sobering for her to treat it and how best to cure it,” says Wimbish.

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**LAWS I WANT TO SEE CHANGED:** Just the way everything is built, I would love a universal plan, so every building is guaranteed 100% accessible.

**MOST ACCESSIBLE PLACES I’VE EVER BEEN:** Seattle, Sea Isle City in New Jersey, and the D.C./Maryland area because the metro system is awesome — every station has an elevator.
Ten years ago, when I was first injured, I had the goal to walk again. I thought if it happened, cool, and if it didn’t, that was fine too. I went through therapy for the first six months living this 'one day at a time' mindset. In that time I saw no movement, but then one day, I started wiggling my toes. Still, I was focused on the bigger picture of living life as I did before my injury, even if it was in a seated position.

Six or seven years later, I got accepted into a research study and used an exoskeleton for gait training for three months, and at the same time, I got engaged. I’d seen some improvement in my gait training with this exoskeleton, and I was able to walk short distances around the house with a walker or forearm crutches, so I made another goal: to walk down the aisle with forearm crutches. Being an athlete as well, I was always a goal setter, and I worked really hard at any goal I had in any sport I was playing, so that’s how I looked at it.

It wasn’t a matter of, ‘I must do this rehab to walk down the aisle for everybody else’s satisfaction or joy.’ It was me feeling accomplished and working my body as much as I thought I could to reach that goal for my special day. It was a feeling of having worked so hard and being proud of myself. Being the scientist that I am, it was my personal case study developing over 10 years.

to realize how AIDS disproportionately affects black people, and more specifically, black women.

“There is a personal piece there and that, too, was my driver in getting in the field and staying in the field,” she says. “It made me feel sad and upset that the numbers were like that for black women, but it also gave me the motivation to see what I could do to help my sisters.”

But those aren’t the only women she’s helping. Wimbish also works as a peer mentor, participates in spinal cord injury research and blogs about the unique challenges women with spinal cord injuries face. She says her role as an HIV researcher is directly impacted by her SCI and vice versa.

“I recognize, acknowledge and appreciate how vital research is. That both writing and participating in it is important, no matter what the disease or injury is. It’s really neat to see that and feel that connection, whether I’m on one end writing it or the other end participating in it. I know the value of new treatments or a cure first-hand,” she says.

Read Wimbish’s blog at Chanelle’s Cause, chanellescause.com.

A Wedding to Remember

Wimbish accomplished her long-held goal of walking down the aisle when she tied the knot on Nov. 1, 2019.

“Ten years ago, when I was first injured, I had the goal to walk again. I thought if it happened, cool, and if it didn’t, that was fine too. I went through therapy for the first six months living this ‘one day at a time’ mindset. In that time I saw no movement, but then one day, I started wiggling my toes. Still, I was focused on the bigger picture of living life as I did before my injury, even if it was in a seated position.

Six or seven years later, I got accepted into a research study and used an exoskeleton for gait training for three months, and at the same time, I got engaged. I’d seen some improvement in my gait training with this exoskeleton, and I was able to walk short distances around the house with a walker or forearm crutches, so I made another goal: to walk down the aisle with forearm crutches. Being an athlete as well, I was always a goal setter, and I worked really hard at any goal I had in any sport I was playing, so that’s how I looked at it.

It wasn’t a matter of, ‘I must do this rehab to walk down the aisle for everybody else’s satisfaction or joy.’ It was me feeling accomplished and working my body as much as I thought I could to reach that goal for my special day. It was a feeling of having worked so hard and being proud of myself. Being the scientist that I am, it was my personal case study developing over 10 years.”

OLYMPIC TRIALS BY FIRE: At the Olympic trials for the 2016 Games in Rio De Janeiro, I had many personal best swims and placed third and fourth in my races. They only took first and second place, but I was pretty proud of myself.

WHY I JOINED UNITED SPINAL: I wanted to serve as an advocate in a more official group capacity rather than just by myself.
Growing up in the Bahamas instilled in me a deep love of life on and around the water. However, after a diving accident in 2010 made me a C6 quadriplegic, my water life came to a crashing halt.

I passed the months in my Miami hospital room daydreaming about getting back in the water. My SCI stabilized, and I started to get stronger, but a pressure sore I had picked up after the accident raged on. The doctors told me aquatic therapy was not in the cards for me until the wound on my sacrum fully healed. Stuck in bed for nine months, all I could do was focus on healing my body, and I passed my time researching swim instructors. I counted down the days until I was given the green light to enjoy the water.

I have many friends who were paralyzed in water-related incidents and are too afraid to risk swimming again. I had the opposite reaction. I wanted nothing more than to experience that unique feeling of weightlessness that comes with floating in the water. I was ready to submerge myself at a moment’s notice — only maybe I wouldn’t dive this time.

Thankfully, I found Hortensia Aguirre, a swim instructor in Miami with years of experience teaching people with disabilities to swim. Teacher in tow, when I was finally cleared for swimming, I made haste to take the proverbial plunge. I purchased every piece of adaptive swim equipment I could think of, only to have Aguirre tell me I wouldn’t need any of them. She intended to teach me how to swim unassisted. I thought she was crazy, but she was the expert.

When I finally got into the pool, I was the happiest I had been in over a year. The feeling of being out of my wheelchair and simply floating in the water had me over the moon.

GETTING MY STROKE BACK

Even though I was back in the water, I still couldn’t quite figure out how I was actually going to learn to swim. Every day Aguirre created a swim plan for me. One day she would just dunk my head underwater to get me accustomed to the feeling, the next day she would hold my arms and show me how to glide my upper body through the water in order to poke my head up for air, and the following day she would have me float on my back to understand how buoyant my new body was.

Day after day we practiced different techniques. I definitely swallowed more water than I had bargained for on several occasions. Aguirre was aggressive and pushed me because she could see I wasn’t afraid of the hard work or the water. We swam three times a week for over two years together.

Around six months into my training, Aguirre had her hands supporting me under my belly as I practiced swimming with my head face-down in the water. Then she pushed my arms firmly into the water in order to make me pop my head up to get a breath of air. I swam to the end of the pool, rolled over onto my back, and, to my great surprise, realized Aguirre was at the other end of the pool. I had done it all by myself!

Finally, after countless hours swimming, I had completed a length of the pool unassisted and without any devices to help me. Years later, it remains one of the best days of my life since my accident.

Aguirre pushed me to my limit, as she innately understood what I was capable of even when I did not. It was no small feat getting ready for swimming with caregivers, getting into the pool, and figuring out how to use this new body. But time, patience and determination pushed me over the finish line.

Swimming brought the life back into my world. Being able to get into the pool for some laps, lounging on floating mats in the water or hanging out with family and friends for a pool day makes me my happiest. I now eagerly anticipate each spring and summer when it warms up in Raleigh, North Carolina, and outdoor swim season begins. I start each swim session by doing 40 minutes of laps, and then my husband and I lounge around in floaty toys, getting a suntan in the pool.

I look forward to it each weekend and will do so as long as my body allows.

For a more detailed look at how Ingersoll swims, along with more pointers and tips, watch her instructional video on YouTube at youtu.be/FVkJEUfSNjCBY.
SECRETS TO SCI SWIM SUCCESS

There’s no reason to fear getting back in the water just because you have a spinal cord injury or a disability. Even if you are a higher-level quad and do not have any upper body mobility, being able to simply float in the pool on your back or on a floaty toy still has many incredible therapeutic benefits. By mastering a few techniques and adhering to a few simple tips, you’ll soon be loving life on the water.

Two Techniques to Master

Log Roll: Being able to roll onto your back if you find yourself face down in the water is very important for safety reasons. When you are face down in the water, you can create momentum with your arms by pushing down with one and throwing the other in the air to create a rolling movement.

Treading Water: When you are upright in the water, spread your arms out left and right, and create little circular movements back and forth while simultaneously moving your head back and forth. Essentially, you are using your balance to maintain an upright position.

Tips and Tricks

Find a Swim Float: Part of the joy of being in the water is just lying on your back, soaking up the sun, feeling the warm water on your body and enjoying the sensation of weightlessness. Don’t let your body getting tired keep you from enjoying your time on the water.

For higher quads, it helps to find a swim float that makes you feel safe. It’s even better if someone can easily get you in and out of one that requires little effort to inflate. Personally, I use the Floating Hammock Pool Float by Swim Ways (bit.ly/3arIr59). Its sides are inflatable, and it has a nice soft mesh in the middle that allows your body to stay in the water.

Supra Pubic Catheter/Leg Bags: For those who have an SPC, it is imperative to make sure pool water does not get into the stoma because it can very easily cause a urinary tract infection. I learned that the hard way after multiple UTIs, but my urologist taught me to use Tegaderm tape — a transparent, adhesive medical dressing — to make a watertight seal around the entry.

Secondly, there’s the issue of having a leg bag floating around in the water. I purchased a little flip flow valve on the Internet and put it into the end of the catheter so I can remove the bag while swimming. I then tuck the catheter itself into my bathing suit or tape it on to my belly, and voila! No more catheter bag dragging around the pool.

Snorkel Mask: If you want to put your face down in the water, but are worried you won’t be able to lift your head to breathe, consider getting a full-face mask with a snorkel. I tried one out myself in Key Largo this past fall and it worked great.

JONATHAN MERCHANT: Grueling Workouts Paid Off

Jonathan Merchant, a C5-6 incomplete quad, vividly remembers the first time he swam after being paralyzed in a 1999 car accident. It would be hard to forget, given that several years after his injury, his friends suddenly picked him up and chucked him in the pool. Fortunately, he logrolled and started to backstroke on instinct. Then he took swimming lessons at the VA and eventually devised a system — fashioning a device that tethered his legs to the side of the pool to keep him in place as he swam — that let him swim for hours on end in his home pool.

Eventually, he tried out his new skills in the ocean. “When I was thrown into the ocean and started swimming, I had my family there, along with friends and a guy recording me,” says Merchant. “Even though it was my first time swimming in the ocean since my injury, I had rehearsed it over and over during the hours and hours of swimming in the pool.”

He became the first quadriplegic to tackle the Challenged Athletes Foundation Ironman 70.3 Triathlon and has participated in several half-Ironman’s since, swimming 1.2 miles unassisted with the backstroke in the ocean. “It took me over two years to build up the strength and endurance to take on the challenge of the 70.3 Triathlon,” says Merchant. “I endured grueling workouts that left my arms unable to move after the trainer left. At the time, I had a caregiver who made it possible for me to train this hard. Today I still exercise but not nearly as hard as I did back then.”

Although today he’s an incomplete quad, Merchant says that when he was competing in triathlons, his injury was diagnosed as complete. “I didn’t regain function of my core until 11 years after injury. It was only after numerous stem cell treatments that I was able to have more function,” he says. “I still can’t feel half my arms, my armpits and three-fourths of my body. Though I do have function, thank God, below injury now.”
It took a global pandemic to make ventilators a trending topic of discussion, but for thousands of people, they were part of daily life long before COVID-19 and coronavirus entered the common lexicon. Loa Griesbach started using one 18 years ago because swelling on her brainstem after a C5-6 injury impaired her breathing. Chris Tango's vent life also began 18 years ago after an uncommon non-traumatic demyelinating event at the base of his brain. Jesse Collens joined the club 11 years ago when a botched front flip left him with a fractured cervical vertebra. Unlike the common images on the news of sickly people confined to hospitals or nursing homes, all three of these vent users have figured out how to get out and enjoy their lives, and while COVID-19 has slowed their roll, they are looking to getting back to making the most out of life with a vent.

OWNING THE VENT LIFE
Before everything changed and the nation went into quarantine, Griesbach was sitting in the Hawaii sun with her family, celebrating having spent half her life as a wheelchair user. Paralyzed in a rollover accident 10 days after her 18th birthday, Griesbach had decided to celebrate her 36th birthday and the 18th anniversary of her injury in style.

"I'm so thankful that we got to do that before all this COVID stuff happened," she says. "I'll always have that memory."

The vacation also gave Griesbach time to reflect on all she accomplished since her injury, including her mastery of the ins and outs of vent life. It's rare to find someone with a C5-6 injury using a ventilator, but when it became clear that complications from her injury were going to necessitate one, Griesbach accepted the new reality quickly. She remembers the nurse recommending a trach and trying to relieve any concerns she might have about scarring. "He knew I was a girl, and he thought that scars would be an issue for me," she says. "I was like, 'Yeah, do it as soon as possible.' And he said, 'What?' I told him, 'No. I've got to get this tube out of my throat.'"

That same practical approach guided Griesbach’s early days adjusting to the vent. "I did what I needed to do to get to the next moment. And as things got easier, and I was adjusting and stabilizing, then I looked further out and started planning more," she says. "It was sink or swim. You do what you need to do."

Griesbach got right back to doing what she needed to do — speaking at her high school graduation despite still being in rehab and going on to earn two bachelor’s degrees. Since then she has mixed an active social life with work and volunteering.

"The vent doesn’t stop her from finding time for fitness, and a standing frame and e-stim bike at home allow her to stay healthy and strong."

Several years after her injury, Griesbach learned glossophrayngeal breathing, or frog breathing, a technique where you gulp large amounts of air. It allowed her to breathe on her own for a few hours at a time. Now she can stay off the vent for several hours and doesn’t have to be quite as worried about power outages or equipment failure. "Being able to breathe on my own for short periods of time has given me a lot of independence and freedom to do more," she says. Griesbach had some anxiety the first few times she went without the vent but gradually grew more comfortable.

"It was sink or swim. I did what I needed to do to get to the next moment."

Like Griesbach, Tango can breathe on his own for limited periods of time. Rapid demyelination at his brain stem paralyzed most of his body when he was 14 but left some chest muscles intact. With some control, but not enough to breathe entirely on his own, he switched from being intubated to a trach before heading to rehab.

He keeps his chest muscles strong by breathing in sync with the ventilator as much as possible. Because of this, he can breathe on his own, for up to four hours if needed. As he explains, the extra effort helps his lungs regardless: "I'm pretty good about breathing while the vent breathes to keep healthy, and I haven't had a respiratory infection because of that."

Putting in that hard work was part of a long adjustment process that included learning to train his staff to properly use the ventilator and finding his own comfort zone. Now, at 32, it has paid off. "I don’t even notice the vent now when I go out. It’s just kind of there," he says. "I don’t want it to stop me from doing things."

Collens’ C1 injury doesn’t afford him the off-vent breathing luxuries Griesbach and Tango enjoy, so he is on his vent 24/7. He was unable to secure satisfactory care where he was living at the time of his injury, so he moved to Washington. He fought for extra supplies and home care from government programs, and eventually secured a solid equipment setup and round-the-clock nursing assistants. Like Tango, Collens mastered the ins
and outs of maintaining, repairing and using his ventilator. “I’m gonna know more about my equipment and my settings than anyone else,” he says. “That’s important to me.”

Collens enjoys getting out in nature and spending time with friends, but spends most of his time at home and in the neighborhood to ensure help is close in case of an emergency. As an example of why, he mentioned a solo roll around the neighborhood that didn’t go so well. “I was at the end of the street and the ventilator came disconnected,” he explains. “I rolled home just in time, went up to the door, and the nurse heard the ventilator alarm and got to me before I passed out.”

A year and a half ago, Collens switched to a cuffed tracheostomy, in part because he wasn’t getting enough oxygen during his sleep. The cuff controls inhalation and exhalation, and a fully inflated cuff prevents the user from speaking, while a cuffless trach can make breathing less smooth but allows for easy communication. Collens slightly deflates his cuff midday so he can speak with friends and family (and writers), but keeps it fully inflated at night. “I’ve adjusted to it, but it’s not the best,” he says. “Getting people’s attention when I sleep is difficult. I sleep with a baby monitor, so I just make noises and click to get attention.” Once he has an attendant’s attention, he has to mouth words and use his eyes to point for what he needs.

Griesbach and Tango both use cuffless setups, a choice made easier by their ability to breathe on their own. Griesbach appreciates the freedom the cuffless trach gives her, while Tango says that having an inflated cuff makes him “feel like I’m drowning.” Tango uses two LTV 1150 ventilators. He keeps one

COVID-19 has forced Loa Griesbach to juggle the schedules of her caregivers and nurses, but she has adapted. “Right now, the status quo is kind of easy to deal with. It sucks not seeing certain people, but I’m actually more stressed about when things open up again.”
plugged in bedside at night, and the other works off a battery on his wheelchair. He just recently switched to the bedside 1150 when they stopped making parts for the older model he had relied on since returning from rehab in 2002. “I’ve always liked the old vents,” he says. “The old technology is just simpler. I like to over-ventilate so I can talk when I want to, and it’s easier to manipulate the older technology. Just feed me air.”

Griesbach used to use an LTV too, and shares Tango’s dislike of many newer models, noting that what type of vent you use can have a huge impact on how you feel and what you are able to do. Many models she tried “couldn’t be adjusted in a way that made me comfortable and actually disrupted my cognitive ability,” she says. “I was totally foggy and tripped out. I couldn’t think. I couldn’t focus. And I felt like hell.” She points out that not all ventilators work well for all types of abilities.

Now, she uses a VOCSN, a multifunction ventilator that combines ventilation, oxygen concentration, cough assist, suction and nebulizer — functions historically done by five separate devices — into one portable 18-pound unit with easily swap- pable batteries. She helped test the VOCSN during development and now serves as an ambassador for Ventec, the company that makes it (see sidebar, page 22). She says VOCSN’s combination of multi-functionality and portability has been nothing short of life changing. “It makes it so much easier to be mobile without needing to schlep all the devices and cables and batteries and all kinds of stuff,” she says. “It’s really amazing.”

Collens isn’t as in love with his vent, a Trilogy 100. He liked his old LTV, but when Medicare rotated the older models out, he had limited options. “I chose this one because it was quiet,” he says. “What I don’t like about it is the sensitivity to leaks and such is not there.”

**COVID CONCERNS**

As members of the oft-cited “most vulnerable populations” in the era of COVID-19, Griesbach, Tango and Collens have had to adjust to a new reality of heightened isolation, danger and, of course, monotony. With different home situations, medical needs and available resources, each has adjusted in their own way.

Collens’ dry sense of humor is evident when he says things have been “interesting.” A month or so into the quarantine, a buildup of fluid on one of his lungs landed him in the ICU for a 13-day stint. The cause is still unclear, but it was not COVID-19-related.

He’s back home with a PICC line and antibiotics, in as good spirits as possible. He’s been down the same road before and is hopeful this incident will resolve soon. Dealing with serious medical crises has a way of putting things like quarantine-living in perspective.

“Honestly, not too much has been that different during the quarantine,” he says. “I don’t leave my house too much normally because of neck pain, so I had been staying home, doing a lot of computer gaming.”

Outside of a few trips for medical needs, Griesbach has spent the last two months at home, tanning, reading and enjoying her mom’s cooking. “I used to be pretty active and leave my house a lot,” Griesbach says. “Now I hardly go anywhere.”

Still, she says having her nurses and caregivers coming and going, and having more time to ride her exercise bike has kept the quarantine from being insufferable. “I’m still see people, so I don’t feel too trapped. My life has changed, but it doesn’t totally suck,” she says. “It is very different but, it’s not horrible.”

Tango lives at home with his parents in a town of about 20,000 outside of Boston. He spends his typical quarantine day watching Netflix, reading and trying to keep his mind busy. “I’m taking it day by day,” he says. “I was a little bit concerned about some of the worst-case scenarios that were floating out there at the beginning. When you go to the hospital overnight, you’re either on a bed floor or you’re in the ICU, and all those beds were taken by COVID patients. That
was really the only concern. But it seems to be coming back down to a manageable amount.”

In good times, where he goes depends on whom he’s with. “I could get out with someone who is loosely trained, like a friend or PCA — someone who is not a full-blown nurse — and I go out all the time,” he says. Yet even with ability to go out, Tango usually stays close to home. “If I’m not with someone who is properly trained, I stay in town,” he says.

SCHEDULING STRESS
One area where they’ve all felt the impact of COVID-19 is staffing and making sure they have enough people to take care of their medical needs. Collens lives independently with a staff of five nurses who work 12-hour shifts. He had worried about filling an opening during the pandemic, but says it proved no more difficult than normal. His mom lives an hour away and occasionally comes for short periods.

During non-COVID times, Griesbach manages a group of around 10 nurses, caregivers and family members who help her. Some work in hospitals full- or part-time, others work multiple caregiving jobs, but all have had to change their routines. She has had to tell some caregivers not to come because they’ve been exposed or work in environments that are too high risk. “We’ve basically told anyone that’s exposed to not come at all,” she says. “And everyone that’s coming isn’t exposed.”

“It’s really hard to tell people, ‘Hey, thanks. But, no, you can’t come. Sorry, you’re not going to get paid,’” she says. “I really don’t like having to be the heavy. It’s not fun. And it’s not fun, or easy, to figure out what level of exposure is OK, what level isn’t and deciding where to draw the line. It’s a lot of stress.”

The lost shifts and hours tend to mean more responsibility is falling on family members. Griesbach’s sister and parents have picked up some of the harder-to-fill additional weekend and evening shifts, and she has prioritized covering nights with outside staff.

Tango has faced a similar situation, as all but one of his regular nurses work in hospitals. Normally they’d work for him on off days, but the risk of exposure is too high now. “I was just talking to one of my nurses yesterday,” he says. “I can’t have her come back. She works in an ICU that is all COVID. She said she’s like a leper right now.”

For now, Tango is relying solely on his parents. “My mother and father are the only humans I’ve seen for over two weeks, they’ll likely be stuck doing my care by themselves for weeks or months,” Tango wrote in an essay for New Mobility last month. At the time this issue went to press, Tango was hoping to have nurses return June 1.

I’m not going to be a hermit. When stuff opens up, I’m going to go.

AN UNCERTAIN FUTURE
While the current situation is far from ideal, Tango manages to draw out positive outcomes for the future. “I guess the silver lining is that there is going to be a lot of people who know how vents work,” he says. “Hopefully, nursing will be easier to find.”

Griesbach is already thinking through the protocols she will need for returning staff who have been out in the world. “Right now, the status quo is kind of easy to deal with,” she says. “I’m actually more stressed about when things open up again.” What if there is a spike in cases or a second wave? What does a balance of outside and family care look like post-COVID? “Anticipating that transition back to normal is stressful, and I feel like the transition period is going to be the most difficult and stressful. I want to just close my eyes, skip over that and go back to normal.”

Collens is also worried about the logistics of the transition. “I try not to think about it too much, but of course, it’s there,” he says. “I see myself staying isolated for an extended amount of time, just because I don’t know what’s going to happen. I don’t see myself jumping to go hang out with everybody, unfortunately.”

When and what the future will be remains to be seen, but Tango is ready for it. “When stuff opens up again with social distancing, I’m going to go — I’m not going to be a hermit,” he says. “I won’t be reckless, but I’m definitely going to try to be kind of normal.”

Tango is eager to get back to his active social life after COVID-19.
One of the things that became clear in reporting this article is that vent users would welcome innovation that makes their breathing and their lives easier. Multiple users expressed frustration or disappointment with many of the newer ventilators, and a desire to keep using older models for as long as possible. They cited overly-complicated controls, loud mechanisms and, most concerningly, uncomfortable and inadequate ventilation, among other complaints.

At the same time, the news has been flooded with stories of innovation around ventilators as some of the world’s brightest minds have teamed up with businesses and governments to try to address the shortage of ventilators predicted by many experts.

Knowing these two realities, it seems reasonable to ask: Will these collaborations lead to innovation and positive change that will directly help people who rely on ventilators? As with seemingly everything pertaining to COVID-19, the answer is uncertain.

Count longtime vent user and C5-6 quadriplegic Loa Griesbach as skeptical. She points out that not all ventilators work the same, and the needs of full-time users living active lifestyles are very different from hospital patients recovering from infections. The Ventec VOCSN ventilator she uses is an expensive, highly-portable, multi-function device that is just as well suited for an ICU as all the needs of a mobile wheelchair user. Many of the new designs emerging as a response to COVID-19 are the polar opposite: small, cheap to manufacture and singular in purpose.

One of those models is the brainchild of Dr. Albert Chi, a trauma surgeon at Oregon Health Sciences University in Portland, Oregon. The 3D-printed ventilator design he and his team have submitted for FDA approval is about the size of a soda can, requires no electricity and can be printed in three to 12 hours (depending on printer speed) for as little as $10.

Chi and his team started working on the product in February as concerns of PPE shortages grew, and by mid-April they had a working model. Chi acknowledges that his vent isn’t the solution for full-time users, but sees it playing a vital role in the global system and helping underserved communities attain a needed lifeline. “In these hospitals, not only is electricity a problem, but maintenance is overlooked and not all of the vents are functional,” he says.

Not all the ventilator innovation is on smaller scale. This March, Ventec, the company behind the VOCSN, partnered with GM to design a new model, the VOCSN V+Pro, and build 30,000 units for the federal government by August. The V+Pro doesn’t have the multi-functionality of the VOCSN base model, but is certified for the International Standard and FDA-approved for hospital use. Less than one month after the initial contact between GM and Ventec, the first V+Pros were delivered to two hospitals.

Mark SooHoo, Ventec’s vice president for marketing and communications, applauded the industry-wide innovation and noted the need for different types of solutions. “Frontline medical professionals need the level of control and support that critical care ventilators such as VOCSN offer, and not all devices or projects meet this need,” he says.

Griesbach is hopeful all the innovation and attention helps her and others like her. “COVID has brought attention to this market that was really only considered before by people that were acutely affected by it,” she says. “Nations around the world are now aware of ventilators, and how important they are. Maybe they’ll have a different outlook when they see somebody that is using a ventilator.”

— Ian Ruder
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ALL NEW!
At 4 years old, I was a typical little girl doing what little girls love doing — having play dates, dancing around, dressing up in big girl outfits and enjoying the security of my loving family. Then I sustained a C3-4 spinal cord injury in an automobile accident and was unable to breathe without ventilator support.

When I was old enough to go to school, the noisy, cumbersome ventilator made it difficult for me to concentrate, which affected my grades, and I was always tired. I also had multiple bouts of pneumonia and, at age 11, one of these pneumonia incidences landed me in the emergency room. That’s when the on-call pulmonologist asked my family why I wasn’t on a diaphragm pacemaker. We looked at her like she had 100 heads because we, like so many people, had no idea what that was.

When my parents looked into this device and the benefits it could provide, they insisted it would change my life. But I’d already had plenty of surgeries after the car accident and was hesitant to have another one. I finally agreed to have the procedure, and they were right — it has changed my life immensely.

HOW DIAPHRAGM PACEMAKERS WORK

To understand how the diaphragm pacemaker works, you must know the role of the phrenic nerve. It starts in the neck at C3 through C5 and runs down between the lung and heart to the diaphragm, where it serves as a neurological pathway between the brain and the diaphragm. It is composed of motor, sensory and sympathetic nerve fibers, which allow it to send motor information to the diaphragm and receive sensory information back.

There are several components to a diaphragm pacemaker system: surgical implants, an external battery-operated transmitter and antennas that work on the skin.

The transmitter sends a series of electrical pulses to the antennas, which convert them into radio waves and transmit them to an implanted receiver. The receiver sends the pulses on to the phrenic nerve through a small electrode implanted close to the nerve that causes the diaphragm to contract. The contraction expands the space around the lung, which, in turn, results in inhalation. When the pulses stop, the diaphragm relaxes and exhalation occurs. The repeating of this process is what happens in normal breathing.

Because of the word “pacemaker,” many people think the device affects the heart. It does not. There is also the fear that it might burn out the phrenic nerve or wear out the diaphragm. It does neither. Many will ask if you can pace 24/7, and the answer is yes. I only come off the device when I shower. And many others are concerned with the surgery itself. The minimally-invasive surgical procedure usually involves a one or two-day hospital stay and some even undergo the procedure on an outpatient basis.

It’s important to know that not everyone who uses a ventilator qualifies for a diaphragm pacemaker. The most important criteria are that the candidate has functional lungs and a diaphragm muscle, and an intact or repaired phrenic nerve. There is a qualifying phrenic nerve study conducted by neurologist. During this study, the phrenic nerve is stimulated as it would be by a diaphragm pacemaker, and the response of the diaphragm muscle is observed and recorded. For some prospective users, a fluoroscopy test is performed to check how the diaphragm is moving.

A diaphragm pacemaker changed Nicole Ficarra’s life, enabling her to embark on adventures she had dreamed about — including swimming with dolphins.
THE WORLD OPENED UP
After I got my diaphragm pacer, a whole new world opened up for me. I could now breathe on my own and talk more clearly without running out of breath. At first, I only paced at night. But when I started pacing 24/7, I was better able to focus on my school lessons, and my grades improved. Also, as my oxygen saturation improved, so did my appetite. As my speaking voice became clearer, I was able to communicate better, which improved my social life. I was no longer getting as many respiratory infections and, overall, felt much healthier.

The most important change for me, however, was the independence I gained by not being on the ventilator. All of a sudden, I was able to do many of the things my peers were doing. Yes, I still used a wheelchair, but I no longer worried that I would get tired, my ventilator would lose power or its noise would be disruptive.

I graduated from high school, and then went on to earn an associate’s degree in liberal arts and a bachelor’s degree in advertising. After college, I went on a cruise with my friends and no parents — a testament to my new freedom. We toured the Bahamas and, because I now had a diaphragm pacer, I was able to swim with the dolphins! That’s something I would never have been able to do before the pacer.

Today, I am living a great life. I relocated from the east coast to the west coast, regularly attend shows and concerts, and lead an active social life. I share my experience with others so they, too, can have a better life. I represent Avery, the manufacturer of the pacemaker I use, at medical conferences and speak to doctors and other medical professionals, trying to raise awareness of diaphragm pacemakers and the potential these devices have for so many people.

Thanks to a strong record of safety, with over 2,000 users in 40 countries and proven savings of up to $20,000 per year, according to a study published in Spinal Cord, a peer-reviewed journal, reimbursement is offered by Medicare and most private and government insurance. It has full market approval from the U.S. Food and Drug Administration.

If there was one thing I’d say to anyone with a spinal cord injury regarding diaphragm pacemakers, it’s this: Go for it. This device could change your life for the better. It may help you be more independent, healthier and happier.

Nicole Ficarra is the communications coordinator for Avery Biomedical Devices.

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I'm an engineer and a spinal cord injury advocate — more specifically, I'm an engineer who lives with a C4 spinal cord injury. In April 2011, while on a 25-day rafting trip with friends in the Grand Canyon, I dove into the river, broke my neck and became a quadriplegic. Before the accident, I lived an active life and had started a career in the outdoor recreation manufacturing field. From the moment of my injury, my goal has been the same — to get my body back. Post-injury, I've pursued this through many means.

While much has changed since I was paralyzed, my passion for achieving personal victories remains the same. One victory that always remained out of reach was regaining some of the upper-body function lost due to my injury. With compromised bicep and arm function, even the simplest things became more difficult, like brushing my own teeth, feeding myself, using a computer and opening doors.

As an active advocate for SCI, I am continually meeting new people and organizations that share my passions. A connection with a local nonprofit medical device trade organization led to a meeting with Abilitech Medical, a Minneapolis-based company developing products to restore independence for those with upper-arm weakness or injury. The company was working to bring its first device to market: the Abilitech Assist, a wearable, powered upper-limb orthotic.

From the time I met Abilitech founder and CEO Angie Conley, I was interested in her approach as much as her product. Conley, a former senior product manager at Medtronic, is committed to keeping both users and clinicians actively involved in product development. She believes that medical devices are best designed outside of a formal development lab and with continual input from people who live with the conditions addressed by the device. All of this encouraged me, as a quad and an engineer, and I signed on as the fourth member of the Abilitech team in the fall of 2016.

In the early stages, I helped to develop customer requirements by sharing my experience with other assistive devices that I have used. We had an idea of what we wanted to build, but nothing had been developed yet for a commercial product. It was truly an opportunity to develop the product from the ground up. I stressed and demonstrated the importance of stabilizing the body’s core and of adding support and assistance to the shoulder. This quickly led us to a design plan to help individuals with upper-extremity weakness that also provided us with an advantage over other products currently available.

The Assist fits to the arm and requires a small percentage of its power to be provided by the user to enable a greater range of motion. Springs at the shoulder and elbow support the users’ existing strength, and electronics and software customize the spring tension to support lifting objects of various weights. The device is designed to be lightweight, easy to use and comfortable.
JOINING THE TEAM

Upon joining Abilitech, I was immediately impressed by its inclusive culture and the way the company brings people with disabilities to the table. I see firsthand how this leads to successful designs that solve real problems. We bring in consultants from healthcare, marketing, engineering and reimbursement, and consumer consultants are just as important. My insight and opinions, from design considerations to business strategy, are given the same weight as those from any other member of the team, which has helped make my work meaningful and effective.

As part of a startup organization, I wear many hats — from capturing customer requirements with focus groups and surveys, to contributing to the development of the Assist and our hand grip product, which will be our company's second device. I develop test plans, help manage projects, perform research and development, and contribute toward intellectual property. I've also learned about FDA requirements, entrepreneurial fundraising and the importance of designing for reimbursement.

Abilitech will register with the FDA this year, and has recently secured $9 million to support development and commercialization of its products. Later this year Abilitech will begin clinical

HOW IT WORKS

With the help of the sleek, futuristic-looking Abilitech Assist, people with impaired arm function may soon be able to more easily pick up and manipulate objects such as cups, brushes and forks.

The spring-and-motor powered orthotic is a sleeve that is fitted to the user’s arm and takes advantage of the user’s own strength to lift and manipulate objects weighing up to 12 ounces. Thin cables connect the battery-operated motors to the device's joints so users may turn their hands palm-side up and back, bend their elbows, straighten their arms, and lift their arms above their heads. Springs at the device's shoulder and elbow maximize the user's existing function, and, via software, the springs' tensions can be customized for the weights of different objects, such as water bottles or cell phones. The orthotic is attached to a lightweight jacket that is intended to make it feel weightless and allows it to be used for a long time.

The company is also working on a companion product it calls Grip, which will similarly take advantage of any existing hand function to allow users better use of their hands and fingers. To learn more about both products, including when they will hit the market, see abilitechmedical.com.
studies for MD, MS and SCI to support reimbursement, which will make the devices accessible to more people.

Working for Abilitech has been extremely rewarding. I have seen children, and their parents’ amazement, when the Assist takes what little strength they have and provides the remaining power to move their arms and perform functions that were not viable before. It has also been a powerful experience to help students who’ve interned at Abilitech develop new skills while feeling like we are all making an impact for many individuals.

The most rewarding experience, however, has been using the Assist myself to scratch my face, drink from a water bottle and brush my teeth. After using it, my arm muscles feel physically tired, but in a good way. That’s something I haven’t felt in years. I look forward to having my own personal device to help me live more independently and explore whether the Assist can help me build strength. Anecdotally, I feel like I have gained lasting strength, but we will have to run clinical trials to evaluate the effects and long-term outcomes.

In addition to gains in function from using the Assist, many users report a great emotional impact. Our users have goals that include holding their loved ones again with both arms and eating dinner without needing to have someone feed them.

Our team works with many organizations, clinicians and medical institutions across the nation. One of our main clinical partners is Gillette Children’s Specialty Healthcare Center in Saint Paul, Minnesota — one of the nation’s leading pediatric health centers.

This year, we are looking forward to gathering more evidence for the device through our upcoming 75-person clinical study with those who have muscular dystrophy at the University of Minnesota in collaboration with Gillette Children’s Hospital.

Today, we have a functional device that should soon get FDA clearance and be available to those who need something to help them use their arms again. This likely wouldn’t have evolved into the product it is today if it were not for the guidance of others with neuromuscular conditions and my close involvement as a user and engineer on the team.

ABILITECH IN THE FUTURE

People can begin to purchase the Assist this year. Currently, they can visit the Abilitech website at abilitechmedical.com to learn more about our device and sign up for our newsletter. Abilitech encourages people who want the device to ask for it from their doctors or find a clinician familiar with the device on the Abilitech Medical website. People can also contact Abilitech to assist with reimbursement.

After the Assist is available to the public, we will shift our focus to the Abilitech Grip, a hand grip device which, when used with the Assist, will enable users to actively grab things and lift them. The Grip will include an intuitive user interface that allows a powered actuation of the fingers and thumbs in preferred grip patterns. Currently, I use an assistive glove with the Assist device because I don’t have movement in my hands. When the Abilitech Grip is available, I will have function at the shoulder, elbow, and hand to do even more.

INDEPENDENCE RESTORED

Restoring independence starts with defining and understanding independence. When companies like Abilitech integrate first-hand, personal insight from the community, more people will benefit from their products.

My work with Abilitech is the perfect intersection of my passion to advance solutions for people with spinal cord injury. It brings together my educational experience as an engineer, my interest in entrepreneurial endeavors that focus on helping people and my life experience as a quad that brings meaning to me and will help to restore independence in people’s lives.

Rob Wudlick helps to raise funds for SCI research through state and federal advocacy. Also, he works on projects at the University of Minnesota and aids in the development of medical innovations that will help people regain movement.
Man, we were tearing the place up! Paris ... a city I’ve wanted to return to since I was 7. Here I finally was, for five days, along with my friend John, whose solo trip I joined at the last minute. And we were rocking our first full day there. The Louvre, Musée d’Orsay and the Centre Pompidou — three world-class museums in one day. Too much? Nah, let’s watch a spectacular sunset from the top of the Pompidou and then go grab an awesome dinner. C’est la vie extraordinaire.

We are both wheelchair-using paraplegics. I met John when he was a law student at UCLA and I worked at a research center there. John’s paralysis is from a spinal injury. I’m a 68-year-old post-polio incomplete para. I contracted polio in 1953, in Key West Florida, when I was 3, two years before the Salk vaccine was distributed to a fearful nation. For many years I used a brace and crutches to get around. My mother was very pleased to have a son who, though disabled, was still ambulatory. Walking with crutches has some undeniable accessibility benefits, but it is really hard on the back and shoulders.

When I moved to Los Angeles in 1979 to pursue an acting career, I realized that meeting Hollywood’s limited concept of what a person with a disability looked like meant I needed to get and learn how to use a wheelchair. Then I could more successfully audition for the few disabled roles on TV and film.

The unexpected benefit of getting a wheelchair was the revelation that I should’ve been using one all along! It was incredibly liberating to me, and exponentially increased my capacity to travel distances and carry things on my lap. My mother, though, cried when I told her about it. “We worked so hard to get you walking again!” Thanks, Mom, I appreciate that, but seriously?!

Once my primary mobility option was utterly transformed, I spent the next 39 years further blowing out my shoulders by aggressively pushing myself around and travel-
I could no longer get out of my wheelchair and walk up steps with the crutches and brace. Visiting friends’ houses was now difficult, or impossible. I even had to install an expensive ramp to get into my own apartment. And it meant that all travel plans needed to be very carefully researched to ensure that any Airbnb or hotel was completely accessible, with no steps or barriers anywhere. I now had to use airline aisle chairs to be delivered to my seats and wait to be picked up after everyone else had left the planes upon arrival. I desperately needed another “liberation” to make up for my shrinking access to the big, wide world. Then I saw a Rio Mobility Firefly at the Los Angeles Abilities Expo. Aha! My next “Eureka!” moment had arrived.

The Firefly is a one-wheeled, battery powered wheelchair auxiliary device that easily attaches to the front of most lightweight wheelchairs, converting them into racy three-wheelers. I found that I could go up to 12 miles an hour and 10 miles or more on a charge. Yee-haw! I was back in the saddle again. No more shoulder pain while pushing. No more struggling over rough terrain. No lagging behind. No throbbing exhaustion at the end of the day. I was free again, and I took full advantage.

I put more than 3,000 miles on my first Firefly by traveling to far-flung places like Cape Town, South Africa, and eastern Slovakia. I beat the hell out of it, never using my car for local trips, but rather riding in the bike lanes, and zooming around my hometown, Santa Monica, like a kid on a Hot Wheels trike, until I wore it out.

My second Firefly was my salvation in Quito, Prague, Budapest and Berlin, among many other places. In just over a year, I had logged another 2,000 miles of “flight time.” This was my power machine as I took on Paris in mid-April.

John, who is somewhat younger and stronger than I am, was skeptical about my Firefly, especially because I often have to go through an extra level of hell at airports to ensure its safe passage through airline baggage mauling. But by the end of our adventurous first day, I was pulling him back to our hotel!

### Hours of Wonderment

We quickly discovered that many of the major museums and attractions in Paris are free to people with disabilities who can show proof of legitimate membership in our “club.” As wheelchair users, our visually obvious inclusion was usually more than adequate. Not only was our admission free, but we were also usually directed to the front of the queue.

When I arrived at the Louvre, ahead of John, there were hundreds of people ahead of me in line. But five minutes later I was inside. I made a beeline for the Mona Lisa, hoping to avoid fighting the crowd to see her. No problem. As soon as I got to her special hall, I was taken to a spot directly in front of Da Vinci’s most famous lady. Between the unbelievable access and her timeless, knowing smile, I found myself heaving a sob of deeply felt emotion.

After a few hours of wonderment at iconic works like Winged Victory and the Code of Hammurabi, John and I headed out through the Tuileries Gardens and crossed the river Seine to our next stop, the Musée d’Orsay.

The d’Orsay used to be a train station, Gare d’Orsay, and is known to many as the location of the 2007 animated film, *Ratatouille*. In 1986, it was repurposed into one of the greatest art museums in the world, housing French paintings, sculpture and furniture that dates between 1848 and 1914.

Again, to our delight, we bypassed the line, and cruised right into Impressionist art heaven. Every turn or new room drew gasps from me, as I came face-to-face with iconic Van Goghs, Monets, Gaugins, Renoirs and more. These were works I had seen in books my whole life, and now, viewing them in person, I was melting in their beauty. We spent a blissful three hours there, including having a delicious lunch in the Café Campana, under the huge window clock that is so prominently featured in *Ratatouille*.

When we left the d’Orsay, it was late afternoon, and I was ready for a rest before dinner. But John convinced me to go to the terrific modern art museum, Centre Pompidou, which was on the way to our hotel. That led to the aforementioned sunset and dinner.
The next day, John was a bit sore, but, having expended very little physical exertion myself, I was raring to go again. This was Eiffel Tower day, along with Les Invalides Museum and Napoleon’s tomb.

When we arrived at the Tower, there were huge crowds waiting in line to go up. We headed to a ticket office where, once again, we were taken to the front of the line and then escorted to the very next lift up. It was like a VIP dream. We weren’t there 10 minutes before being put on the elevator.

The view from the second level was exhilarating. We spent over an hour taking it in, from one side to the next of the square platform, each offering its own unique perspective of the City of Light.

Next, it was on to see the emperor, or at least his crypt. Napoleon’s tomb is located in the royal chapel that is part of Les Invalides, so named because it used to be a hospital and retirement home for French veterans. Before the Eiffel Tower was built, the gilded dome of the chapel was the tallest structure in Paris. Looking down on the tomb from the gallery above is one of the few things I remembered from my previous visit in 1958. But here we encountered our first disappointment — access to view the tomb is not possible for chair users. Nevertheless, the rest of the museum of French conquest and warfare was also a freebie, so we explored hall after hall of weapons and armor, from prehistory through the disastrous war in Indochina.

When we had enough of cannons, pikes and cuirassiers, it was late afternoon and time to head back to the d’Orsay, where we had dinner reservations in its utterly gorgeous main restaurant. Aside from the delicious pâté de foie gras, the prix fixe menu was quite ordinary, but the room itself was splendid. Originally the d’Orsay train station lobby, the large space is a dazzling combination of huge windows, gilded murals, chandeliers and mirrors to magnify and enhance a room that is, itself, a historical monument. The grandeur of the dinner surroundings is why prior reservations are highly recommended.

**Blissfully Gazing at Art**

Our return trip to the hotel turned into a bit of a comédie des erreurs, as we boarded the correct bus, which, like most Parisian buses was completely accessible — but headed in the wrong direction! After discussing our desired destination with some fellow passengers, they advised us to get off immediately, head back to where we boarded and pick up a bus on the other side of the street. It was a beautiful, full-moon-over-Paris night, so neither of us minded the rather long trip back to the right bus stop. But even though we headed in the correct direction on the next bus, we got confused and got off long before our stop, embarking on another nocturnal exploration of the city, until we finally found our hotel. Once again, the Firefly made it more like an adventure than a trudge.

The next morning, I had tickets to a light show of Vincent van Gogh’s works. But John and I decided to take different paths that day. He went to see friends, and I set off on my own to the Atelier des Lumières, a digital art museum located in a former 19th century iron foundry.

An eye-popping hour of wonderful images and music later, I was ready for more. Consulting a map, I realized I wasn’t far from the Pablo Picasso Museum. This was the only place where I had to “authenticate” my disability by showing my California disabled placard ID. But once I satisfied the ticket taker’s officiousness, I was in again for free and was happy to see I had arrived during a combination exhibit of Picasso’s and Calder’s works.

I passed another hour, blissfully gazing at art, and then I was on the streets again, energized for more exploration. This time my mechanical horse took me through Le Marais, the former “Jewish quarter,” over to the Place de la Bastille, the site of the famous prison uprising, and then back down to the...
A New, Brighter Firefly

After 14 years on the market, the Firefly is getting a major upgrade this summer when Rio Mobility launches the Firefly 2.5 “BK Edition.” In addition to a facelift, the new Firefly offers increased power, better battery life, better tires, enhanced brakes, improved frame docking and more to make the device more functional and easier to use.

“We’re very excited to make some upgrades,” says Alex Hunt, the COO of Rio Mobility. He loves hearing from people that the Firefly changed their life by freeing them to be more independent and travel to places they weren’t able to before. “Now that will be even more true.”

Hunt says the Rio designers worked to incorporate user feedback into the improvements. He is particularly excited about the addition of dual kickstands that allow the user to park and store the Firefly in an upright position. Because the unit can stand on its own, users can roll up to it and just snap it on. “We also put little wheels on the kickstand,” says Hunt. “So, let’s say, you’re taking it from the garage to your trunk. You can roll with it and move it a little more easily, too.”

New safety features include a dual LED light system so users can see and be seen; dual disk brakes with dual disk calipers for more braking power and increased disk and pad lifetimes; and locking brake handles with an integrated bell as well as a color touch-screen with haptic feedback.

Under the hood, the Firefly comes with an improved battery management system and Panasonic GA batteries with a 252 watt-hour battery that passes UN Transportation Testing and is certified to be taken as carry-on luggage on most airlines.

The BK Edition draws its name from Bart Kylstra, the late founder and owner of Rio Mobility. It will be available with a chrome red frame or a metallic gunmetal frame, both with matte black accents for $2,599 — only $200 more than the original’s retail price. “It was imperative that we keep the cost reasonable,” says Hunt. “Our next competitor is maybe three times that price.”

For more information, or to order, call 415/552-6277 or send an email to sales@riomobility.com.

C’est une Catastrophe

I considered it my great fortune when I happened upon the Brasserie le Magenta, which had every outward appearance of being the perfect Parisian restaurant, to have a few happy hour drinks and, perhaps, some escargots or soupe à l’oignon. Happily, the menu

Seine, where I practically flew all of the way across central Paris to the Musée Marmottan Monet, home of some of the most amazing works of art Paris has to offer. This relatively small private museum, often overlooked by tourists, is one of the great art repositories, not just in Paris, but in the world.

The Marmottan was awkwardly accessible via a portable ramp and a tiny, noisy lift. And the second floor was not accessible to me at all, because that elevator was too small to fit even a light, manual chair. But the other two floors of art blew my mind. The main floor had a collection of such beautiful works that I almost forgot to go down to the lower level. Room after room of art by Degas, Manet, Sisley, Pissarro, Gauguin and others delighted my eyes and my soul.

To my great relief, the elevator down was much larger than the one going up. It opened on the most extensive collection of Monet paintings in any museum in the world. I was practically weeping at the beauty of these glorious works by one of the most beloved impressionist painters of all. I can sincerely say that, if you miss this museum while visiting, you haven’t really seen Paris.

After an incredibly soul-enriching afternoon, I was still up for more. My Firefly had plenty of battery juice left, so I went over to the Champs Élysées and the Arc de Triomphe, another place I remembered visiting as a child. But, to my chagrin, the route to the Arc was through a tunnel under the street that apparently only had steps. Thus, I had to relive my memories from across the enormous traffic circle, which would’ve been a suicide mission to try to roll across.

Being on the Champs Élysées, it only made sense to follow it back down to the Place du Concorde and the Tuileries Gardens. Tourists scattered in my wake as I whizzed past them down one of the most famous — and crowded — streets in the world. I thought about using the bike lane in the street, but that also seemed somewhat suicidal. To avoid taking out any pedestrians, I begrudgingly slowed down to a moderate jogging speed until I arrived at the Place du Concord, where thousands of heads had been separated from their bodies during the French Revolution.

With so many cultural, historical and architectural choices at the plaza, I wound up in the Petit Palais. It and its larger and very impressive neighbor, the Grand Palais, were built for the 1900 Exposition Universelle. The Petit Palais now houses the City of Paris Museum of Fine Arts, an eclectic assemblage of art, mostly from the Renaissance to the early-1900s. I gave it an hour before feeling like I had overdosed on art for the day.

It was late afternoon, and I really wanted to see a dinner show of some kind while in Paris. So I headed for the famous Moulin Rouge to see if anything of interest was on the bill. Taking narrow back streets, I cruised past so many little cafes and chocolatiers that I realized I hadn’t eaten since breakfast and was really hungry. The Moulin Rouge had nothing interesting on the marquee, so I headed in the general direction of our hotel, hoping to find a meal on the way.

The upgraded Firefly promises to make travel even easier.

Photo by Joe Budd/joebuddphoto.com
had all of my yearnings listed, and I decided to camp for a while. I detached my Firefly, put it behind a nearby partition to the outside seating area, and settled in for an hour or two of people watching, engaging Parisian hipsters with my bad French, and enjoying an unseasonably warm spring evening over a couple of drinks and good food.

Several hours, and more than a couple of drinks later, I paid my bill and went to fetch my nearby Firefly. Catastrophe! It was gone! The restaurant, I discovered, was next to a drug rehabilitation center, and some of the clients, evidently, weren’t very rehabilitated. Someone had snatched my Firefly, thinking, presumably, that they could get a few Euros by selling it or its parts.

I went into a cold and immediately sobering panic. I had lost my super powers and was now a mere aging mortal in a wheelchair, way too far from my hotel, in a suddenly very foreign city.

The manager ran down the street to where he knew such illegal exchanges took place, but came back sadly telling me that he couldn’t find my Firefly. The police arrived after a long wait. They were sympathetic, but utterly useless. Although they took my report at the scene, they said I would still have to go to a police station the next morning and give another full report, to get the theft on record. The restaurant manager hailed me a cab, and I finally made it back to the hotel after one in the morning.

John was ready to boogie early the next morning, but not only was I without my e-powered assist, I had to find a police station. So, we again agreed to spend our last full day in Paris separately.

The trip to the police station closest to the hotel took up my whole morning, as I waited for an available English-speaking officer to take and transcribe my report. Knowing I needed to have an official police report for my insurance made the long wait a little more tolerable (and well worth it when I got home), but it still seemed like it took forever.

When I left the station with my report in hand, I knew I would never see my Firefly again, but that my renters’ insurance would probably cover most of the cost to replace it. However, my more immediate concern was how I was going to get to any of the places I wanted to see that I had missed in the previous three days. It wasn’t easy anymore, and it was scorching hot for April in Paris, so I decided to stick close to the hotel and maybe pick up a few gifts at the nearby Gare de l’Est train station.

The afternoon wasn’t a total bust, because even the train stations in Paris are worth visiting. Gare de l’Est was the Parisian starting point for the legendary Orient Express. In the mixture of food stations and touristy trinket traps, I found some extraordinarily delicious chocolates and bought far too much for friends and family back home (and for myself, of course). The uphill push back to the hotel, where I had breezily towed John a few nights before, was now a difficult slog. Although the chocolates didn’t really melt that much, by the time I got to the hotel, I was sweating like a pig.

Au Revoir, Paris

John texted me in late afternoon and we agreed to meet at another nearby train station, Gare du Nord, for our last night’s dinner. This station is yet another architectural wonder, and is also familiar to moviegoers, its interior and exterior having appeared in many films, including The Bourne Identity and Ocean’s Twelve. We ate at the Terminus Nord, an Art Nouveau and Art Déco brasserie that has attracted travelers from around the world since 1925. Our meal was delicious, but the push to and from the station pretty much wore me out. I was more than ready to head home the next day. I opted for an expensive cab ride to the airport, instead of pushing back to Gare Nord for the train we had come in on. We upgraded our seats for the trip home on Norwegian Air, so it was a comfortable flight.

My insurance company did cover the cost of replacing my Firefly, minus the deductible. I’m now preparing for a month-long trip to Spain and Portugal with my wife and son. And I expect to take those places by storm as well, with my brand new electric steed ... which I’m never letting it out of my sight in public places again.

But, I’ll always have Paris — where, for three days, I was almost able to travel faster than a speeding bullet and leap tall buildings in a single bound — among my most treasured memories.
Back in mid-2010, I was approached by New Mobility to write a column focused on providing information about managing the health challenges that often accompany spinal cord injury. And thus was born Para/Medic, a bimonthly column that first appeared in the January 2011 issue. Para/Medic was an extension of Bladder Matters, a column I started in 2008 about the unique challenges of, and different options for, bladder management with SCI.

Para/Medic has been a fun and challenging column. I enjoyed looking up peer-reviewed research articles on a subject, then adding in the firsthand knowledge of leading doctors, nurses, nurse practitioners and clinicians, as well as people with SCI.

By far, the most satisfying part of writing the column has been hearing from readers who have been helped by information they gleaned from it. However, all good things run their course, and finding new topics has become more difficult. Rather than risk becoming repetitive, it is time to let Para/Medic fade away. I will continue to keep my eyes open for information that can help readers and myself, as I’m now in my 35th year as a T10 para. As always, if you have a question or idea for a column or article, please contact me at Rhvshark@mac.com.

Of the 42 Para/Medic columns I’ve written, here are excerpts from three that stand out for their breadth of appeal and relevance.

**Strategies to Avoid Pressure Sores**

As in many areas of medicine, researchers’ knowledge of how pressure sores occur continues to evolve. Until the early 2000s, known causes of tissue injury were pressure that reduces or stops blood flow to the tissue, along with heat and moisture. Research shows that additional causes are serious bumps and/or shear (pushing and pulling of tissue against bone), which can damage capillaries and deprive the surrounding tissue of blood. This happens below the skin surface and causes damage from the inside out. In 2007, the National Pressure Ulcer Advisory Panel added “suspected deep tissue injury” to its pressure injury staging scale and, a few years back, the word “suspected” was dropped, which led to the current term “deep tissue injury,” or DTI.

For more on deep tissue injury, I turned to Darren Hammond, a certified wound specialist and clinical support and education specialist for Motion Composites. “These days, many of the deep tissue injuries that clinicians are seeing, particularly with acute rehab stays that are so short due to insurance guidelines, are caused by transfer failures where a person lands on a tire or something hard,” says Hammond. “This is where the research of Dr. Amit Gefen comes into play. Gefen has done important MRI studies that show deep tissue stresses and strains — and how these stresses lead to deep tissue injury.”

Hammond and Gefen worked together. Gefen had established that DTI can be caused not only by an acute incident but also by repetitive small traumas to deep tissues. “We had an ‘aha’ moment,” says Hammond. “I said that some people have poor transfer habits and bump a wheel or plop heavily on the surface they are transferring to. Even though this causes micro trauma, at the end of the day when doing a mirror-skin check, things look good.” The problem is that every healed micro trauma becomes scar tissue that is less resilient then regular tissue, thus more susceptible to injury.

**Bladder Irrigant Solutions for UTI Reduction**

Saline is an irrigant that many of us were introduced to in rehab, where we were taught to add 30cc of saline after each cathing. Dr. Michael Kennelly, director of urology at Carolinas Rehab in Charlotte, explains that using saline should help dilute residual urine and sediment, and help prevent stones and stop bacteria from colonizing.

Another option is to add distilled white vinegar mixed with saline to the bladder. This supposedly creates an acidic environment that is hostile for bacteria. Kennelly emphasizes that it is important to have a discussion with your doctor before trying any irrigant solutions, and the vinegar-saline solution is a good case in point. He says the solution can irritate the bladder and cause inflammation, which weakens the bladder wall’s defense mechanism and makes the bladder more susceptible to infections.

The only FDA-approved solution...
Fracture Risk and Treatment Options with SCI

The average person with SCI loses 28 percent of their bone mineral density within the first 16 months of injury, according to Dr. Douglas Garland, an orthopedic surgeon and former director of neurotrauma at Rancho Los Amigos Rehab Center. Around that point, BMD loss slows down but continues at a rate of 1 percent per year. However, the good news is BMD in the lumbar spine rebuilds, reaching normal within 10 years of injury. In addition, for reasons unknown at this time, 30 percent of people with SCI gain back much of their BMD in other areas as well.

Osteoporosis is diagnosed when you’ve lost 32 percent BMD, which puts you in the “fracture threshold” (where a minor fall or missed transfer can cause a break). A 50 percent loss of BMD is considered the “fracture breakpoint,” where minor incidents like stretching or even rolling over in bed can cause a fracture.

It is important to have a basic knowledge of fracture management with SCI because this is an unfamiliar area for many doctors and orthopedists, says Garland. In the event of a fracture, referring the treating physician to the journal article “Pathologic Extremity Fracture Care in Spinal Cord Injury” is a good idea, he says (see online article for link).

Although every fracture is unique, Garland says most non-displaced fractures (when the bone is still lined up) can be treated non-operatively with pillow splints, immobilizers or careful bracing, sometimes custom made. Also, he says it is important to be sure they are well padded and can be opened for skin inspection: “In the case of femur and some tibial fractures, intramedullary nails can often surgically fix the fracture. This is preferred over screws and plates because screws can pull out of osteoporotic bone.”

Read the rest of the article: newmobility.com/2016/04/fracture-risk-treatment-options-sci

Para/Medic Topics

Here is a list of 42 health topics covered over the years of Para/Medic columns. Each column can be found online by typing in the corresponding topic in the search engine at newmobility.com. Additional columns on SCI, bladder and urinary tract can be found by searching for “Bladder Matters.”

General Health
- Appendicitis
- Autonomic Dysreflexia
- Cancer Screening
- Cardiovascular Disease
- Deep Vein Thrombosis (Blood Clot)
- Diabetes
- How to Find a Qualified Surgeon and/or Seek a Second Opinion
- Foot Care Tips
- Gluten Sensitivity, Celiac Disease
- Hospital Stay Survival Guide
- Managing Edema
- Spasticity Relief
- Winterizing an SCI Body

Osteoporosis, Bones and Fracture Management
- Bisphosphonates (medications for osteoporosis)
- Bone Growth Stimulator to Aid Fracture Healing
- Charcot’s Spine
- Girdlestone Surgery for Hip Complications
- Heterotopic Ossification
- Fracture Risk and Treatment Options with SCI
- Spinal Stenosis
- Syrinx

Bladder and Urinary Tract
- Anticholinergic Medications and Dementia
- Bladder Cancer: Increased Risk?
- Bladder Irritant Solutions for UTI Reduction
- BioFlow, for Indwelling Catheter Users
- Guidelines and Options for Indwelling Catheter Users
- Options to Manage Bladder Spasms
- Using Antibiotics Responsibly

Bowel Management
- Megacolon, Bowel Program Frequency
- Options For Dealing with Hemorrhoids
- Peristeen: New Option for Bowel Management
- Preparing for a Colonoscopy

Shoulders
- PRP: A Non-Surgical Option for Shoulder Repair
- Total Shoulder Replacement in Wheelchair Users

Skin
- Cellulitis
- Cushion Options for Severely Compromised Skin
- Deep Tissue Pressure Sores
- Strategies to Avoid Pressure Sores
- Summertime Skin Protection
- Unna Boot Compression Therapy for Wounds
- Winter Skin Protection

UTI Antibiotics and Tendon Rupture (Fluoroquinolones)
I learned to love and train horses as a teenager before I was paralyzed, and I feel incredibly fortunate to have a stable of them living on our property. The nice lady who owns them does all their care, but I am able to visit as much as I want, and I take full advantage of the privilege. My daily sanity-break involves walking the dog and stopping to visit the horses.

The first time I visited them, they were afraid of me or my power wheelchair. I called and called, but they stood back and stared at me. Finally, I decided to ignore them, and turned so the back of my chair was facing them, against the gate. I leaned back, closed my eyes, and enjoyed the sun. About 10 to 15 minutes later, I could feel hot breath on the top of my head. From then on, they have been very comfortable with me.

I knew that horses are smart, but experiencing them after my disability, at a slower and calmer pace, has made me realize they are far more intelligent than I once thought.

A few years ago, we had a horse that had foundered on grass. She didn't want to stand up and I could tell by her eyes that she was in a lot of pain. She looked at me as if to ask for help.

“Where does it hurt?” I asked. I know, I’m one of those nut-jobs that speaks to animals as if they understand. But I think sometimes they do. Maybe it’s not the words, but more that they can feel what we mean.

To my amazement, she curled around and touched her back foot with her nose, then looked right at me. I was blown away. Was it a coincidence or did she comprehend? The veterinarian later confirmed that the foot was swollen and very sore, and with diet and medicine she made a full recovery.

The horses may be squabbling with each other, biting and whinnying, but when I approach, they calm down and stop bickering. They seem to recognize they can’t be rough with me and often gently rub my face with theirs.

A couple of weeks ago, a new horse, Rosie, put her head over my shoulder from behind and rubbed her face on mine. Then she rested her head on my chest while I rubbed her face. I noticed her eye, which was looking right into mine, was slowly closing. Her breathing got heavy as her head pressed into my chest, and then her eye closed. She had fallen asleep. I sat there in the sun, with a fast-asleep horse draped over my shoulder, for 10 minutes or more. It was one of those moments you remember forever.

On another occasion, as I wheeled around inside their pasture area, Total, the big, old standardbred former racehorse, walked right over, stopped with his nose close to mine, and stared at me from close range. He leaned down to sniff my feet. Then he did something unexpected: He gently grabbed the toe of my boot and lifted my foot off the foot pedal. He sniffed my legs, and came up to sniff my hands. He gently grabbed my hands with his mouth one at a time, and lifted them.

It dawned on me that he was wondering why I couldn’t move my hands and feet. He had noticed that something was different. I think he was wondering why I didn’t stand and use my hands like other people.

The Daily Visit

“Hi horses!” I holler as I head down from the house. The horses raise their heads to look at me. “How’s the horses today?”

I see they are heading to the gate where they can reach over and get close to me. I wheel up to the gate, turn around to face the sun and swing my cup out of the way, as horses are very inquisitive and first-class drinking-straw thieves. They seem to prefer if you are casual and trusting, so looking the other way and ignoring their approach puts them at ease.

Today my buddy Indy approaches first. He is a super-friendly gelding. I have my back turned, enjoying the sun like usual, when my phone dings. Continuing my ignore-the-horses facade, I start texting as Indy reaches over the gate. I feel his breath down the back of my neck, but I give no reaction. He breathes harder to get my attention, and gets nothing. I feel whiskers on my neck, and ignore him some more, so he ups the ante and reaches over my shoulder to see what I’m doing. He’s very interested in the cell phone, wondering what I’ve got.

“It’s a phone. I’m texting with my friend,” I say.
I keep texting while talking to Indy, and his nose keeps blocking the phone as he tries to see what I’m doing. He is totally focused on what’s in my hands. I wonder to myself if he has important horse-stuff to get to.

“I’ll take a selfie of us,” I say, opening the camera app. “Say cheese!”

Indy and I look at the phone. The camera fires and takes a picture. Indy even looks like he’s smiling. It makes me wonder if horses have a sense of humor. I sit there, rubbing his face, and he rubs his cheek against mine. I gently kiss his muzzle, and he turns and gently mouths my cheek, as if to reciprocate. I’m surprised that a 1,200 pound animal would try to mimic me, but I go with it.

In this trying time we are going through, we all need our sanity breaks. That makes my time spent with these gentle giants even more soothing.

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In furtherance of Mobility Works’ commitment to improving accessibility, we are pleased to announce we have agreed to the nationwide modification of a number of our policies regarding adaptive devices. For additional information regarding these changes, please see the class notice for Community Resources for Independent Living v. Mobility Works: http://bit.ly/3d5WMv4.

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Meet New Member Jessica Gardner
Age 34, from Johnstown, Pennsylvania
Cerebral Palsy
Ambassador for Ms. Wheelchair Pennsylvania

Why I joined United Spinal: To form bonds, establish friendships and share experiences. Also, to advocate for and empower other wheelchair users.

Can't live without: My Canine Companions for Independence service dog, Ford, is essential. He gives me the freedom to live a more productive life, whether he's retrieving dropped items, opening doors, or putting my footrests up and down so that I can transfer independently.

If I could change one thing in the world: I would eliminate service dog fraud. When a person misrepresents their dog as a service dog, it puts me and my legitimate service dog at risk to be attacked and traumatized.

Meet other members or join United Spinal at unitedspinal.org

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I've been working on a replacement shower chair for a long time. I'm told it's coming, but I'll believe it when I see it. In the meantime, I'm using a really dilapidated bath chair. So the other night, I'm in it, doing my thing with my nurse, when, without any warning, the back mesh portion comes completely undone from the frame. I feel gravity hit hard when it lets go, and I fall backwards. If I were a skinnier dude, I would've found myself bent in some sort of hardcore yoga pose with my head on the tile, or worse. Luckily, I have some extra padding that kept me supported enough in the frame to stay upright.

Once we knew I wasn't in immediate danger, I chuckled. My nurse started to laugh and didn't stop. Through her tears, she called my wife in and they busted up together. "What's up, ladies?" I asked. My wife grabbed her phone and snapped a pic to show me what the fuss was about. As I imagined, the mesh back was nowhere to be seen, but the Y of the reclining cable was still there. It now rested perfectly in line with the top of my butt crack and split out with a cable extending out and over each cheek. It looked very convincingly like I was wearing a G-string.

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