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Two airlines broke KENNY SALVINI’S wheelchair over the course of one year, and in doing so they set him on a mission to find out why accessible air travel is so difficult. What he found is a history of failed policy, an industry blinded by money — and a growing voice for change.

Cover and Content Illustrations by Doug Davis

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As I write this, I’m waiting … waiting for an insurance pre-authorization for an MRI. During a cystoscopy a few days ago, my urologist discovered a mass in my urethra that is potentially malignant. On the other hand, it might be a benign, chronic abscess. Whatever it is, I want it out of me, but the insurance company is taking its sweet time to consider whether an MRI, followed by surgery, is “cost-effective.”

The insurance company doesn’t actually do the considering. They contract with another company, American Imaging Management, which will tell them if they should approve the MRI or not. This is the American way of doing what is referred to as “health care,” a system where doctors must be subservient to the almighty dollar. Cost is primary; care secondary. As I wait to hear if I have cancer or not, the management model, which takes much longer to run its twisted course than a doctor’s order, makes me very anxious.

I think back to my lifelong friend, Loon, who got trapped in the management model when he was told he had metastatic melanoma, a deadly cancer. He died in 2010 after a year-long battle, but I still hear his voice on the phone, saying, “I’m lying here in the hospital fighting for my life, waiting … waiting for my cancer treatment, but no doctors or nurses or technicians are here to do anything because it’s the weekend, and next Monday is a holiday. So I have to wait three extra days because no one is working.” Three days is a long time to wait when your life hangs in the balance.

While I wait, the management company, AIM, is deciding whether I need an MRI followed by surgery based on what is called “best practices.” Best practices is another misleading health care term. If you are like me, a 72-year old paraplegic with a neurogenic bladder who has had to self-catheterize five times per day every day for the last 30 years in order to pee, there is no information on “best practices” for your demographic — because no such group is recognized. Doing the math, if there were such a group, each person in the group would have self-cathed about 54,750 times. You think AIM’s cost managers have a lot of stats based on best practices for that group? Just who are these managers and why do we have them? To me, the main reason we have health care managers is that legislators who want to pay less taxes have decided that health care cost management is the way they can get those taxes back in their pockets. Most, but not all of them, share a political worldview based on conserving wealth — mostly theirs. To them, health care for all Americans is blasphemy. You may remember that they tried to ram a “health care” bill through Congress in record time earlier this year. Now they are doing it again but calling it a “tax cut.” Personally, I would call it a health care cut — not a tax cut — and I’m quite certain it’s based on worst practices.

— Tim Gilmer
Doug Davis’s distinctive drawings and caricatures have appeared on the pages of New Mobility since 1998. Over the years, he has contributed more than a dozen covers and scores of interior illustrations on topics ranging from sex to snake oil salesmen. He has won numerous awards for editorial cartooning from the California Newspaper Publishers Association and the Los Angeles Press Club. Doug lives in Pasadena, California, with his wife and son, where he enjoys the great outdoors and plays the upright bass in a bluegrass band.

Aaron Broverman is a freelance journalist with cerebral palsy based in Toronto, Ontario. He has been a contributor to New Mobility for a number of years and is a regular news writer on newmobility.com. His last article of note in the print edition was an interview with Speechless star Micah Fowler. When he’s not covering disability, he’s writing for outlets like Yahoo and Huffington Post and hosting a podcast called Speech Bubble, where he interviews Torontonians involved in the comic book industry.

Since he was paralyzed in 1996, Nick LiBassi has worked in the disability community in various capacities. He is United Spinal’s vice president for partnership expansion, chapter development and the hospital membership program, and he also serves as a committee member on the Disability Advisory Board with Alaska Airlines and a Community Advisory Board member for Kessler Institute. In his personal time Nick is active in working with charities to raise funds for spinal cord Injury research. He also finds time to speak with and mentor individuals with new spinal cord injuries.

From trekking through the Amazon Rainforest to hot air ballooning over the deserts of Israel, Cory Lee demonstrates that anything is possible with enough determination. He was diagnosed with spinal muscular atrophy at 2, but that certainly has not diminished his desire to travel. He has traversed six continents. His blog — curbfreewithcorylee.com — has gained more than 50,000 followers and has been featured in the Los Angeles Times, USA Today, Travel Channel and more. Cory hopes to inspire others to break out of their comfort zones and start rolling around the world.
Your Magazine Helped Me Today

Wow, I was inspired by "Independence: A Quad’s Definition" by Ian Ruder [October 2017]. And a quote by Dave Pierson on Page 25: “Now independence is dictating life rather than life dictating to me. It’s more about doing what I want to do when I want to do it with whatever help I need — and knowing I am able to get that help.”

I’ve been in prison for 20-plus years. It’s hard to be inspired when you sit in a wheelchair and watch life go by. Years ago I started to write a program called “SHIP” (Self-Esteem for Handicapped Inside Prisons). I’m not that good of a writer, so the flame died and I quit and put it in a box.

This magazine lit that flame again and I believe we all have a story inside us. I broke the law but that does not make me a bad person. I have learned how to be a good person. Your magazine helped me today.

Dick Oppen
Walla Walla, Washington

Lifting Up Voices

Beautifully written and thoughtful storytelling. Thank you for illustrating and lifting up these voices ["Independence: A Quad’s Definition"]. I really enjoyed reading it and know I’ll be reflecting on these words of wisdom for some time.

Arwen Bird
Portland, Oregon

Expanded Definition

I think this is important for everybody to understand. I had a narrow definition of independence before I read this article.

Alexandra Shepard
Via newmobility.com

Independence and $$

A big player in independence is your financial resources. Never seen articles about a C6 quad living on $750/month Social Security and welfare. Mostly pics of quads in their $50,000-$60,000 wheelchair vans or cruising the beach on a $20,000 track wheelchair. No offense, but that is so far removed from my reality. My article suggestion: “SCI, Poverty and Independence.” Depressing, eh?

Ken Todd
Via newmobility.com

Reclaiming = 'Claw-back'

The October Bully Pulpit ["Recovery from SCI: What Makes it Possible?" October 2017] scored a bullsEye. “Recovery” is a notion of which many people are fond, and it is easy to use and feels good as it rolls off the tongue. Walking is the least of the issues. Your distinction of “reclaiming” is vastly more accurate, one even might say “claw-back,” since we must drag our way through nearly endless hostile bureaucracies, soul-wearying prejudices and daily ignorance. That movement in itself is a full-time job, although as a group we benefit enormously from those who have rolled before us, clearing obstacles, firmly insisting on rights, reminding the world of our own individual humanity.

Ned Fielden
Berkeley, California

AB Narrative: Misguided

The recent spate of recovery stories overlook the nature, type and severity of spinal cord injuries lumping us all into one big amorphous category and implying that if you’re not walking, you’re not working hard enough. I take it that the popularity of such stories fits neatly into the AB narrative that above all else we all desire to walk again.

Patrick Stenden
Via www.newmobility.com

Exercise a Major Factor

As far as “recovery” being based on the extent of the injury versus hard work, I think both can be a major factor. I guess I’d speculate that a less extensive injury might allow hard work to result in more noticeable progress. In my case, with an incomplete T5 SCI, I’m very fortunate to walk again and do some of the active things I love, such as cycling. I do believe my level of exercise and continued hard work has been a major factor in getting me to this point in reclaiming my life.

Chris Whyte
Via newmobility.com

Affordable Fashion?

Oh great, another expense we can do without. How about a clothing company we can afford? For some reason people think we’re made of money. [“Tommy Hilfiger, Cat and Jack Offer New Adaptive Clothing Lines,” Oct. 27 News online, www.newmobility.com.]

Kevin Leu
Via newmobility.com

Adapted Fashion Needs Support

Finally the fashion business is recognizing what many of us have been trying to do for years. We need all the support we can get to be able to grow, service the community and make the styles our customers ask for.

Stephanie Alves, ABL Denim
Via newmobility.com

Impractical Power Chairs

Those motorized chairs may ride well, but they look like tanks and are miserably uncomfortable ["Fall New Product Releases," Innovations, October 2017]. No way would anything remotely that big be practical or possible for my New York City apartment.

When are manufacturers going to start adapting all this mega-power and gadgetry into power chairs for the rest of us?

Jacquie Tellalian
Via www.newmobility.com

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Disability Groups Sound Alarm Against Attack on ADA

Disability rights advocates are sounding the alarm against H.R. 620, a bill designed to make it harder for people with disabilities to sue under the 27-year-old Americans with Disabilities Act. The bill was voted out of the Judiciary Committee on Sept. 7, and has now moved to the floor of the House of Representatives.

Sponsored by Republican Rep. Ted Poe of Texas, the bill would require a person with a disability who is illegally denied access by a business to notify the offending business in writing of the specific violation. That business would then have 60 days to acknowledge receipt of the complaint, and a further 120 days to make “substantial progress” in removing the barrier. The bill, however, contains no definition of “substantial progress.”

Proponents claim H.R. 620 is designed to stop so-called “drive-by lawsuits” by serial litigants seeking financial gain rather than the actual removal of barriers to access. However, the ADA’s Title III, which deals with public accommodations, does not allow for monetary damages unless the case is brought by the Department of Justice. Some states do have laws allowing for monetary damages, but this bill, ironically, would have no effect at all on those laws.

The Consortium of Citizens with Disabilities sent a letter signed by 232 disability organizations to the House Judiciary Committee that asks, “If, after 27 years, a business has continued to not comply with the requirements of [the ADA], why should a person have to wait more time for enforcement of their civil rights? Should an individual who is not allowed to enter a restaurant because of their race, gender or religion, have to wait before seeking to enforce their civil rights?”

New Mobility’s parent organization, United Spinal Association, continues to work in conjunction with many disability organizations and advocates, such as the American Civil Liberties Union, Paralyzed Veterans of America, Bazelon Center for Mental Health, to fight this bill. United Spinal is continually meeting with members of Congress educating them on the harm this legislation can cause to the disability community. “Our hope is to shed light on why H.R.
620 is not the fix small businesses seek to end the lawsuit issue,” says Alexandra Bennewith, Vice President Governmental Relations, for United Spinal. “Ultimately, the disability community will be harmed and the ADA will be severely weakened. We will continue our efforts with policymakers to educate and advocate on behalf of our members and the disability community as a whole.”

Linda Mastandrea Appointed to Head FEMA Disability Office

The Federal Emergency Management Agency has named Linda Mastandrea, a disability-rights lawyer, Paralympian and long-time New Mobility contributor, to head its Office of Disability Integration and Coordination. Mastandrea, a wheelchair user, has been working in the role since being called to Washington to help with recovery efforts during Hurricane Harvey. She brings years of experience to the ODIC, having worked as an emergency management consultant as well as serving as a disability integration advisor reservist for FEMA.

The ODIC’s primary role is to provide specialized support services to people with disabilities in natural disasters, such as access to appropriate medical care and durable medical equipment, and finding accessible temporary housing if people’s homes have been damaged or destroyed. It hasn’t always been the case that people with disabilities have received effective assistance during natural disasters. There are stories of people being evacuated without their wheelchairs, or of shelters having the ramped entrance blocked or locked.

But Mastandrea says that significant progress has been made since the ODIC was founded in 2010. She hopes to continue that work so that every region and level of FEMA is able to consider the needs of people with disabilities when planning and executing emergency response. “My goal is over time, through working with the regions and the states, that we sort of establish a baseline of what has to happen with emergency response [for people with disabilities],” she says.

Scientists predict that extreme weather events are going to happen more frequently as global temperatures rise. Mastandrea recommends that people with disabilities have a disaster plan in place that includes:

1. Knowing what you will need if you have to evacuate, what to take with you.
2. Knowing where you need to go.
3. If there are a mix of accessible and inaccessible shelters in your area, tapping into where the accessible ones are.

Portlanders Honor John Callahan’s Life and Work

An overflow crowd of friends, family and well-wishers attended the Oct. 27 dedication of the John Callahan Memorial at Good Samaritan Hospital in Portland, Oregon. Callahan, a C5 quadriplegic, was honored for his life’s work as a cartoonist, author and frequent volunteer at the hospital, which is located in the Northwest Portland neighborhood where Callahan, with his flaming red hair, was a well-known fixture, often seen zooming down sidewalks on his daily rounds.

Callahan died in 2010 at the age of 59. New Mobility was one of many publications to publish Callahan’s work, including local weekly Willamette Week. The weekly’s editor, Mark Zusman, a longtime friend and one of many speakers to address the crowd, praised Callahan for managing “to find the light in the darkness.” The memorial, open to the public, consists of 50 of Callahan’s most famous panels, mounted on a steel ribbon that winds through a newly-constructed narrow park, set between a church and the hospital.

“The location is perfect,” says NM editor Tim Gilmer, who befriended Callahan in the last years of his life. “He began life as a swaddled baby, handed over to the nuns at St. Vincent’s for adoption. And his life ended at Good Samaritan Hospital, where he fought his last battle with an infected pressure sore. He will be remembered for his irreverent wit, his minimalistic, politically incorrect drawings, and his talent for exposing hypocrisy.”

To sample his cartoons, visit www.callahanonline.com. To see more cartoons and read about his life, type “Callahan” into the search box at www.newmobility.com.
Q. Recently, I’ve been prescribed a number of different medications that proved to be ineffective, so I replaced them, which left me with a three-month supply of the “unsuccessful” ones that now need proper, safe disposal. I discussed my concern with my state legislators, hoping they would introduce legislation to ensure that free, convenient collection sites would be available, so people would not discard the medications by flushing them down the toilet. Sadly, my concerns were not answered on the statewide level, but my county stepped up and took action by requiring pharmacies and police stations to host medication drop-off boxes. But what good are these programs if they are generally unknown or not available everywhere?

Additionally, because I have been disabled for over 30 years, I have accumulated outdated wheelchairs, an old Hoyer lift and a variety of unneeded medical supplies. The chairs need fresh batteries and everything needs cleaning up, but there are probably people somewhere in the world who could benefit from having access to them. A nearby Center for Independent Living used to accept these, but they ran out of space. Are there other avenues that I might investigate?

— Cleaning house

The federal Drug Disposal Act requires the Drug Enforcement Administration to promote two National Drug Take Back Days each year. That program, in coordination with law enforcement agencies nationwide, has been expanded in many locales. Many states, counties and cities now require deposit boxes at selected pharmacies and other convenient locations so that unknown, partially used or unneeded medications can be dropped off anonymously. The program keeps such drugs off the street and out of the reach of children or people who use them illegally.

Many communities periodically host a general recycling program, so check public announcements that may identify participating pharmacies or other medication drop-off locations. The location of your nearest medication disposal drop box is available at the website listed in resources below. If that doesn’t identify a location close to you, your local pharmacist may know of other programs or may allow you to return all types of medications to them, including those that were purchased from other outlets.

Surplus power or manual wheelchairs, durable medical equipment and supplies can be collected, refurbished and shipped to developing countries where they are not readily available. Global Mobility USA, Whirlwind Wheelchairs, UCP Wheels for Humanity, Wheels for the World, Hope Haven International and several other organizations have been delivering those items in partnership with local groups for years. Some nonprofits have determined that it is often more cost-effective and quicker to provide new equipment rather collect and repair items that might have been “retired” in the United States. In some cases, these charities have established facilities in those other countries so that local residents can manufacture or assemble their own wheelchairs in the future.

There are also organizations that collect, refurbish and distribute used equipment solely within our borders. United Spinal and the Wheelchair Foundation identify many of them in listings on their websites. Some organizations serve a designated geographical region. American Outreach Foundation serves California’s Coachella Valley, and the Triumph Foundation facilitates equipment exchange between consumers in the Los Angeles area.

As for power mobility devices, some of the charitable organizations are refocusing their efforts on donations of manual equipment. Repairing outdated power wheelchairs requires extensive inventories of parts that may not be available from manufacturers years after they were made. Complex wheelchairs and large batteries may be difficult to import into a country that is not accustomed to widespread use of such devices. Many power wheelchairs have also proven to be less durable in developing countries where there may be fewer paved roads, sidewalks and flat surfaces. Finally, there may also be problems when recipients need to replace batteries, both because of unavailability where they live and the high price overall.

Surplus wheelchairs or other medical equipment that can be repaired with minimal effort should not be sent to a landfill. Check with the nonprofits listed in resources or a local organization, like one of the Muscular Dystrophy Association loaner closets, to see if they accept such items. Someone, somewhere may be able to make use of it.

Resources
- Medication disposal locator: dispose.mymeds.org/medicine-disposal-locator/
- Wheelchair Foundation: www.wheelchairfoundation.org/programs/more-organizations
- American Outreach Foundation: americanoutreachfoundation.com
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Athleticism has always come naturally to Ben Clark, a 27-year-old from the UK. Before his injury, he was on his way to becoming an Olympic swimmer. “I competed for Great Britain with the goal of going to the 2012 Olympics, had a scholarship to a sports school and even moved to Australia to train for a year,” he says.

A swimming accident in 2010, however, changed his plans. “I ran into the sea and dove into a wave, and the water was shallower than expected.” He became a C5-6 quadriplegic as a result. But Clark didn’t let his injury put him in a dark hole. “I’ve always had a positive outlook on life and don’t let things get the better of me. I just saw my injury as a new experience.”

After his injury, he gave adaptive swimming a go. “I tried the Paralympic route in 2012, but it wasn’t the same as before,” he admits. “However, I’m still involved as a coach with some very good swimmers.” He’s instead found a new outlet for his love of fitness — making adaptive workout videos — and started a YouTube channel, called Adapt to Perform.

Clark’s love of high intensity interval training (various sets of cardio workouts) is partly why he began making videos. “HIIT workouts have always been something I’ve done. With their rise in popularity, I wanted to show other wheelchair users they didn’t have to miss out,” he says, adding that his best videos are the ones that don’t require any equipment and can be done anywhere. He has made several.

“The response has been bigger and more positive than I could ever have hoped for,” he says. His end goal? “I want to reach more people and inspire everyone to go out and exercise, even if they’re not disabled.”

Watch his videos: Youtube.com/AdaptToPerform

Beam Me Anywhere, Scotty

While it’s always ideal to get out of the house and take advantage of our semi-accessible country, sometimes it’s impossible. Spinal cord injuries and being stuck inside are unfortunate bedfellows. If you’re newly injured and can’t leave the hospital or are on bedrest, the Beam Smart Presence System is one of the coolest ways to virtually get out of the house.

This device can give you a physical presence anywhere. It uses an app similar to Facetime, with an iPad as the head and your virtual eyes, and it’s all put on a robot on wheels, that you control. This is perfect for anyone who wants to still attend classes or wants to work outside the home. Ship it anywhere, and with a strong Wi-Fi connection you can explore wherever your heart desires. It’s spendy, at $1,995, but for anyone that’s stuck in their house, this is a cool new adaptive technology option. Search for Beam Smart Presence System at Amazon.com.

Chronic Pain’s New Cliff’s Notes

Up-to-date literature on how to manage chronic pain for people with SCI is hard to come by, which is why The Spinal Cord Injury Pain Book is a must-download. This 203-page book offers practical tips, including exercise, distraction methods, relaxation/meditation tips and advice from people living with paralysis. It’s available on iTunes: Itunes.apple.com/us/book/id1020549194
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The Mentoring Life

Almost 20 years of coordinating support groups and peer mentoring has made Kenneth Ryno, 57, an expert when it comes to connecting with people with spinal cord injuries. During that time, Ryno, a C5-7 quad, has learned how to read newcomers and tailor his approach for the best chance of helping them adjust to their new reality. Sometimes people just want to talk; other times people just want to listen. But one thing that holds true in all situations is it is always better to show someone what they can do than to tell them about it.

"Many people with new injuries don’t think they can ever get in a kayak or go bowling, and then they go and watch someone else in a chair do it and next thing you know they’re participating. Once you see it, then you can believe it," says Ryno.

On top of his years of experience working with people with new injuries, Ryno’s personal experience has given him unique insight into the rehab and recovery process. He has fractured his neck on three separate occasions. That’s three times in rehab and a whole lot of extra time in hospitals. “Every time I think I’m coming a long way, and I just have to learn again,” he says.

His experiences have helped him hone a simple philosophy when it comes to recovering from SCI: “Get active as soon as you possibly can, in any way, shape or form.”

That approach has led Ryno to a number of jobs in the 38 years since he was injured, but none have been as fulfilling or long lasting as his involvement with the SCI support group at Good Shepherd Rehab Hospital in Allentown, Pennsylvania. The meeting is a long drive from Ryno’s Kunkletown, Pennsylvania, home, but that doesn’t bother him. “That’s fine with me,” he says. “This is what I like to do. I am a mentor.”

After attending the support group on and off for years, Ryno started going all the time in 1999 and soon took on a leadership role. “A friend and I agreed to take it over on the condition that we could turn it around and make it a more outgoing, more active group,” he says. “It had been a very small group in part because it was repetitive, doing the same basics like..."
bowl and bladder and psychological stuff over and over.”

Today the group has over 70 members on its mailing list and its offerings go well beyond the monthly meetings. “We’re very active,” says Ryno. “Together we kayak, shoot clay pigeons, go sailplane gliding, water skiing, bowling … this is what we’ve grown into.”

Ryno attributes the group’s growth and success to connecting with people during, or soon after, their injuries or rehab stays. “Getting someone to come to a meeting and talk with them while they’re in rehab can make a big difference,” says Ryno. “Even if they’re not ready, at least you can plant the seed about the support group, so they know about it when they are ready.”

Ryno has lots of stories of friends he has made through the group, and values the group’s impact on the local SCI community. “It is so rewarding to see somebody come out of that funk, that depression,” he says. “It doesn’t always work, but if you get through to one or two here and there, then those one or two share with others and it keeps spreading.”

HOME AWAY FROM HOME

On the Water

A self-professed “water rat,” Ryno can often be found kayaking in waterways around Pennsylvania. He recently started a new job with the goal of getting more people out and on the water.

“I was not going to let my injury stop me from getting back out in the water again. When I first started getting back into the rivers, before kayaking, I would go down a river with three of the big truck tire tubes. I would have one for me, one for my wheelchair, and one for my cooler. Now I’m all about kayaking. One of the things I love about it is that when you are out on the water, everyone is on an equal level. You can’t really tell whether someone uses a wheelchair by looking at people kayaking. I provided input to a company called BoardSafe to help it develop an accessible kayak launch at Beltzville State Park. Now I am working for them. The dock simplifies everything by using a sturdy frame and accessible handrails to help you transfer out of your chair and into the kayak independently. It makes it safe and easy for everybody. It has been a dream come true for me.”

IF I COULD CHANGE ONE LAW:
I’d fight with everything I have to make sure that every waterway is accessible, whether it be via a floating dock, a kayak launch, a fishing pier or even a pontoon.

WHY I JOINED UNITED SPINAL:
I’ve been following United Spinal since it was Eastern Paralyzed Veterans Association. I joined up in the late ’90s, when I was co-chairman for our spinal cord support group at Good Shepherd Rehab Hospital in Allentown. The advocacy work and the support and training the organization provides are incredibly helpful.
Mik Scarlet is like Billy Idol on wheels.

The leather-clad British journalist, actor, activist and TV presenter ("host" in the United States) with multi-colored spiky hair is also a synth-pop rocker, so the comparison — which he uses and often gets in public — certainly fits. But the punk aesthetic he confronts the world with also signals to his nondisabled countrymen that whoever they think a wheelchair user is supposed to be — he is not it.

Look deeper, and his name will tell you everything you need to know. Chosen because there were too many Miks with the same name in Equity (Britain’s actor’s union), “Scarlet” is a tribute to Scarlet’s childhood hero, Captain Scarlet, from the 1967 kids television series Captain Scarlet and the Mysterons. Like its predecessors — Thunderbirds and Fireball XL5 — its characters were marionettes, and the show used a technique called supermarionation to animate the puppets’ movements and facial features. Captain Scarlet follows a space captain blessed with an alien healing factor called retro-metabolism, which renders him able to survive anything, just like Scarlet himself.

Six weeks after his 1965 birth in Luton, Bedfordshire, England, Scarlet was diagnosed with a malignant tumor called an adrenal neuroblastoma. It was only after an experimental treatment with a new American drug called vincristine sulphate that he survived, albeit with a paralyzed right leg. At age 15, his mother sent him to school despite his complaints of not being able to walk, thinking he only wanted to avoid his German language final exam. He collapsed in front of his geography teacher. Turns out, the same experimental drug that allowed him to survive 15 years earlier had deformed a vertebra, which on that day collapsed and crushed the nerves in his legs, making him a full-time wheelchair user.

Fast forward nearly 20 years: In 1999, as he approached the end of a prolific decade as a TV presenter and journalist, Scarlet was driving around Marble Arch in London when an articulated truck cut the corner and crushed his little red sportscar with him in it. At first, nothing seemed the matter — of course that’s difficult to discern when you’re already paralyzed — and Scarlet continued to work. But pain mounted, and even though no doctors could...
figure out why for a year, they soon discovered the car accident had cracked more vertebrae. But once again, just like Captain Scarlet, he made his comeback. Instead of causing him to withdraw from the world, the experiences did the exact opposite.

“My parents taught me from the first day I could remember that I wasn’t less than anyone else. If anything, I was probably better because I used to get told regularly, ‘You survived something that would kill most people,’ and I still have that little flame of arrogance that burns inside me,” he says.

The Rise of a Star

Back to 1980: Following Scarlet’s onset of paralysis at 15, his mounting experience as a wheelchair user helped him realize he had nothing to lose, and he began to think that everything he ever wanted to do was within reach. Not pursuing it was not an option anymore.

“Doctors always think that if you could get a cure you’d have it, and when I first became a wheelchair user, yeah, I sort of got a bit lost and I thought my future was going to be rather grim. But actually, it marked the start of my life where all the things I wanted to do as a kid sort of happened,” he says.

First on the list was “being in a band,” so when Scarlet was too ill to go anywhere — feeling lost and that his future was grim — he taught himself to play the keyboard, program a drum machine and started writing his own songs. “I became an electronic musician. It was like a Depeche Mode sort of thing,” he says.

When he was well enough, he joined London’s New Romantic club scene and started performing gigs with a band he put together with his brother and friends. They were called Freak UK, and at the height of their popularity they opened for Scarlet’s teenage idol, Gary Numan, on his Emotion European Club Tour in 1991. But how did a punk in a wheelchair front a band and open a European Tour? Was the UK’s record industry really that progressive?

“People would say, ‘Well, he won’t be able to go on tour,’ so he just went on tour. Every time someone told Mik he couldn’t do something, he would just go and do it.”

Wallace was also the lead singer in his band after Freak UK, a dance music act called Eroticis.

But while the music industry didn’t exactly come along, the fans certainly did. “Mik had a really strong following for all the bands that he was in. Freak UK had a really hard core group of people that even today post things online and keep track of any new music coming out,” says Wallace.

The fans weren’t the only ones who saw something there. Around the time of The Emotion Tour, a TV producer spotted Scarlet and offered him a chance to be on television. “I said yes, obviously,” says Scarlet.

At the time, in the late ’80s and into the ’90s, there were British actors with disabilities on television and, along with himself, quite a few disabled presenters, but they didn’t always cover the topic of disability. In 1989, Scarlet hosted a show called Help Roadshow that focused on environmental issues. Then he presented youth programs like Survivor’s Guide and Sex Talk that were more concerned with sex and the latest bands than the environment. They put him on the map as the first disabled presenter ever on British mainstream national television.

Scarlet’s big break came in 1990 when he shifted gears again, hosting a truly unique kids’ show called Beat That, in which both disabled and non-disabled kids worked together to complete a challenge under a time limit such...
as, “Put on a fashion show using recycled materials.” The show was a hit, garnering 2 million viewers per week and worldwide syndication, earning Scarlet an Emmy and a BAFTA nomination (Britain’s Oscars).

“Mik has a very lively way with him in terms of his relationship with the camera, and he can convert that into a kind of rapport between him and the viewer,” says Ian Macrae, a blind broadcaster and journalist. “As a presenter, he’s not straight and down-the-line, but more sparky, more energetic and more interesting to watch. What he does more than many is challenge people’s conventional view of what a disabled presenter should be and how a disabled presenter should look in a more direct way.”

Macrae went on to work with Scarlet as series editor on his next gig, as a correspondent on From the Edge, a news magazine show that covered all kinds of disability issues and aired nationally on BBC2 on primetime at 7:30 p.m. from 1990 until 2000. The show drew in 1.5 million viewers a week and covered everything from disabled parking to personal support with perspectives on politics, the arts, finance and lifestyle, all with a disability angle, and it did them straight — no inspiration porn. From the Edge was part of the BBC’s charter initiative to represent every population that lives in Britain, including those with disabilities. The show was produced by the BBC’s now defunct Disability Programmes Unit.

“In the early ’90s, there were certain people around the BBC who got the idea that disability was the next big battleground in the way that gender, race and sexuality had been,” says Macrae. “They got the idea that there was this other group of people called disabled people and within that group there were activists that were beginning to make a lot of noise.”

The Disability Programmes Unit was part of a national push for more diversity in the media, and one could argue that shows like From the Edge and the effort of the DPU played a key role in the passage of Britain’s Disability Discrimination Act in 1995 and subsequent legislation to improve it in 1997.

“By the time we got to 2000, there was a feeling among senior manage-
disability podcast, blog and online talk show — says that in place of the dedicated disability programming of the Disability Programmes Unit, the BBC is now trying to hire more people with disabilities to work behind the scenes and in front of the camera on all of their shows.

“Broadcasters would justify that by saying we need to have disabled people in the mainstream, which is true, but really you need both [mainstream plus disability culture] because disabled people are not yet truly equal citizens, so there’s still a need for programming to explore disability issues,” says Bott.

The consequence, according to Bott, is less visibility and a more negative attitude towards disabled people. She says there’s been a noticeable shift in attitude over the last few years, and it has been led by the government as a way of justifying cuts to Social Security.

From the early 2000s on, while this shift in attitudes toward disability was happening, and following the conclusion of From the Edge, Mik Scarlet was still in the process of recovering from his 1999 car accident. But while Wallace was nursing him back to health, he still found the energy to rail against the state of things from his bed with his various columns across the internet, particularly on Huffington Post UK.
One of his most vulnerable and passionate columns came in March 2017, when he began to chronicle his switch between benefit programs. Scarlet wrote about how he was given a lower benefit on the new program because an assessor misunderstood a basic medical term, and how they’d lost the medical evidence for his appeal and then suddenly found it again when he showed up in person. When he finally won his appeal, the whole process had taken six months.

“Only after I found the appeal had gone in my favor did I realize the amount of stress the whole process took, and mine was fairly straightforward,” he wrote. “For too many disabled people out there [the new benefit program] has been a disaster. It is an overly complex system with under-skilled assessors and an appeals system that adds to the already existing complexity and waiting times that, however you look at them, are just not good enough.”

Looking Forward
“What I love about Mik is his passion and politics,” says Rose. “He cares so much about disabled people. I saw him about a year ago on a current affairs program we have every morning called Victoria Darbyshire, and he was absolutely losing it big time talking to a politician about the state of things for disabled people. I really thought he was going to have a heart attack because he couldn’t quite believe what this politician was saying and was really shouting at him live on air. That’s Mik. If he believes in something, he’s not going to hold back,” says Rose.

That’s the true punk ethic Scarlet has always stood behind. He can be the progressive pipe bomb as he was in the progressive years, but as conservatism tightens its grip, the government moves away from the social model and veers to the right and Scarlet gets older and wiser, his broadcasting background means he can speak the language of the establishment just as easily.

According to Bott, Scarlet’s magic is in skills as a communicator. Since he realizes you win more friends in high places with honey, he is able to effect real change. If you ask him, he’s always been this way.

“My first trip out in the chair, I went to the cinema, and I couldn’t get in because it lacked access, so I met with the manager and made it so it was sort of accessible. That was fueled because at the time I didn’t know how long I’d have, and I wanted to go to the cinema, so why shouldn’t I?”

He uses his life experience as a motivator. “Instead of looking upon the idea you might die one day as a bad thing, it should force you forward because it should make you think ‘when I go, I want to make sure I’ve done everything I want to do’ — and I want to make sure the world I leave behind is a really nice place to be.”

THE SOCIAL MODEL ACROSS THE POND

In the United States we’re just starting to see actors with disabilities in important roles consistently on television (RJ Mitte, Micah Fowler, Peter Dinklage) but beyond the occasional special report from John Hockenberry, how often do you get to see a wheelchair user hosting a TV show on a regular basis?

Mik Scarlet points to his opportunity to succeed as a TV host as an example of how Britain was ahead of the disability curve in ways people often don’t think of. “It’s really weird because we now look to America and say how great America is because it’s got actors that are disabled coming through, but we kind of forget our own history. Britain was really forward-looking a long time ago,” he says. “I don’t think America has the same thing in the media, and I don’t think they are as dedicated to the social model as we are, so a lot of articles written on online outlets like The Mighty still reinforce the idea that being disabled is about the things you can’t do — and not what you’re stopped from doing by the world around you,” says Scarlet.
I f you’ve ever fallen out of your wheelchair, you’re probably familiar with the view from the floor. It offers a different perspective to consider a room: Couches look rather tall, socks that have disappeared for a few months lie in direct sight, or for Rupaszov — a former fire fighter turned wheelchair-using hit man in the Hungarian action film Kills on Wheels — a tumble to the floor offers the perfect shooting angle to the bleach blond gangster he’s been tasked with eliminating.

The scene, in which Rupaszov (Szabolcs Thuróczy) is carried down a flight of stairs by a pair of burly body guards, before dispatching said body guards with a few well-placed bullets and finishing the job from the floor, is emblematic of Kills on Wheels as a whole: It’s fun, fast-paced, violent, and doesn’t shy away from an unvarnished depiction of the details of living with a disability.

Rupaszov’s superhero level shooting skills are contrasted with his escape from the same house: Pushing up a steep ramp he has to stop a few times to catch his breath and rest his arms. Whether or not he and his waiting apprentices, Zoli (Zoltán Fenyvesi) and Barba (Adám Fekete), are able to evade the police boils down to how quickly they are able to transfer to and from a car and break down their wheelchairs. It is not the quickest process. “I could fry an egg in less time, for fuck’s sake,” grumbles Rupaszov as Zoli fumbles to get the wheel onto his chair amidst the sound of blaring sirens.

The film centers on Zoli and Barba — two young men who are roommates in a group home for people with physical disabilities. Zoli has spina bifida, and Barba has cerebral palsy. Both come off as typical young folk. Zoli is constantly on his phone, listening to house music and worrying over social media posts, while Barba lives in a constant state of nerves over being prepared to “meet some chicks.”

The two collaborate on a complex graphic novel featuring themselves and Rupaszov, their surly creation, who recruits their comic doubles to help in his bloody work for Serbian crime boss Rados (Dusan Vitanovic). This story wraps around other
narratives: Rupaszov trying to win back his ex-girlfriend (Lidia Danis) who is set to marry another man, Zoli’s need for thinly explained back surgery, and Rupaszov giving the young men a booze-laden education in life outside of a care facility. *Kills on Wheels* makes few distinctions between imagination and reality, but the editing and splicing of artwork from the graphic novel helps the story flow smoothly and without confusion.

**SKEWING DISABILITY STEREOTYPES**

Major media’s portrayal of disabled characters is often littered with clichés and stereotypes: Those with disabilities are either an inspiration, or to be pitied, motivated to overcome their disability, or somehow diminished because of it. It wouldn’t be surprising if *Kills on Wheels* fell into the “super-cripple” stereotype in the line of Avatar’s Jake Sully. But other than Rupaszov’s above average ability to aim and quickly fire a pistol from a seated position, the trio’s biggest superpower as hitmen appears to be society’s diminished expectations for them. Nobody expects someone in a wheelchair, or someone walking with a spastic gait, to be dangerous, so their guard never goes up. For an Eastern European gangster, this is exactly when you get capped. Rupaszov might not have the quickest draw in Hungary, but he is certainly allowed closer and given more time to operate than any nondisabled counterpart would be.

What is it like to know fully well what you’re capable of, and have society expect something else entirely? Writer-director Attila Till plays with that tension between experience and societal perception throughout the film. “They were surprised to see a crippled dick like you, huh?” jokes the less than eloquent Rados as he pays Rupaszov for a hit.

Till takes swipes at traditional disability stereotypes as well. Rupaszov is determined to walk again, but his quest amounts to little, and is a source of amusement for Zoli and Barba. In one scene, Rupaszov tries to slap Zoli while standing with leg braces in the parallel bars, and falls to the floor. “You’re doing great, I see,” Zoli deadpans while leaning over him. “Three years and you’ll be running.”

Of the three protagonists, only Rupaszov is played by a non-disabled actor. Both Fenyesi and Fekete have the same disabilities as the characters they play. Fekete is a trained actor, writer and director, currently a member of the TAP Theater Company. Before this film, Fenyesi had appeared on a Hungarian TV show, and was known primarily for his Instagram account, depicting life as a handsome young chair user. This was the first big-screen performance for either, and both were up to the task.

The film comes off as embedded within the local disability community, rather than having a token wheeler or two tacked onto a story. There are more extras with disabilities than any film I’ve ever seen. The adaptive equipment used is spot on. Zoli uses a Kuschall manual chair with Schwalbe tires. Zoli and Barba spend craft time at their group home to glue some old ROHO cushions together to form a pocket for Rupaszov to hide his gun for a hit. These kinds of details give an authenticity not often seen in film portrayals of disability. The cinematography woven in so that it never feels too stale. Members of the generation raised on Tarantino films are probably going to have a better stomach for the gory bits than those who grew up before graphic, gurgling violence became commonplace in film.

If *Kills on Wheels* isn’t a great film, it certainly is good. I’d come out of the theater feeling like I got my money’s worth. In talking with other NM staff who’d screened the movie, most of the critiques centered on plot and the level of violence, rather than the film’s portrayal of disability, which is a bit shocking considering we write about disability issues on a daily basis.

*Kills on Wheels* doesn’t feel like it’s trying to be revolutionary in its portrayal of disability, but it makes a whole-hearted attempt to be accurate and mostly succeeds. It’s a funny, enjoyable action film featuring well-developed protagonists with disabilities, giving screen time to two young actors who actually have disabilities. In today’s media landscape, that’s far enough out of the norm as to be revolutionary in itself.

Currently *Kills on Wheels* is only playing in selected theaters. It will be available via streaming in January.

**MY MONEY’S WORTH**

As a film, *Kills on Wheels* isn’t perfect. Zoli’s personal storyline centers on some sort of urgent back surgery, which he needs to stay alive. Zoli’s mom wants his estranged dad to pay for it, but Zoli refuses out of youthful pride. This part of the story feels strained, a bit cliché and a missed opportunity for a more compelling narrative, but it does hint at a more interesting storyline: how Zoli processes his feelings toward the father he has never known through creating the graphic novel. Unfortunately, exploring that journey takes a back seat to the ostensibly more dramatic medical saga.

Likewise, Barba is interesting and funny, but the film doesn’t fully develop him as a character. Parts of the plot can feel a bit like a formulaic gangster movie, but there is original narrative
Today more wheelchair users are taking to the skies than ever, but outdated laws and training of airline staff haven’t caught up to that reality yet.
Two Broken Chairs, One Mission

I wasn’t looking for a platform. The platform came looking for me. When I was booking my first post-injury flight in the spring of 2016, a cross-country trip from Seattle to the East Coast for United Spinal’s Roll on Capitol Hill, I had no idea what I was getting myself into.

The dream vacation I spent months planning and thousands of dollars on in travel and lodging for my girlfriend, two caregivers, and me turned into every wheelchair traveler’s worst nightmare when United Airlines damaged my head-controlled Invacare TDX so badly that I wound up spending 11 of the 14 days without it at all.

Not even one calendar year later, Alaska Airlines caused $16,000 in damage to another wheelchair on my way back from ROCH 2017. Once is a case of bad luck. Twice is the universe revealing your path. Having two wheelchairs destroyed by two different airlines in the span of a year has a way of thrusting you into a bit of reluctant advocacy with a lot of questions that need answers.

How is it that in the year 2017, in the age of one-day Amazon Prime delivery of damn near anything you desire, a full 27 years since the passage of the Americans with Disabilities Act, that airplanes in America are not wheelchair accessible? Why is it so hard to transport wheelchairs safely? What kind of recourse does someone like me have to hold the airlines accountable when they break what are essentially my legs? What is being done to address what seems to be a systemic issue within the industry?

To answer those questions, I tried to finagle my way behind the curtain of the airline industry, chat with wheelchair travelers with far more expertise than my own, and take a look back more than three decades to see where this pattern of negligence began and what, if anything, is being done to address it.

ADA vs. ACAA: How Airplanes Fell Through the Cracks

Most people recognize the Americans with Disabilities Act as the seminal piece of American civil rights legislation governing the accessibility standards of most buildings and modes of transportation. But few seem to be aware that the Air Carrier Access Act of 1986 predates the ADA by four years. Aiming to ensure that people with disabilities be treated without discrimination in a way consistent with the safe carriage of all passengers, the bill established regulations requiring airlines to provide proper assistance at airports and on board flights, safe transport and timely return of personal wheelchairs and mobility equipment, as well as minor accessibility features of aircraft and some airport facilities. Part of the reason the ADA didn’t address air travel was the belief that the ACAA had already addressed it.

The language within each bill seems to point at equal access for their respective jurisdictions, but the subtle differences between the two laws are where you will find major discrepancies in relation to our basic civil rights and how they are enforced. Whereas the ADA is governed by the Department of Justice, the ACAA is beholden to the Department of Transportation. One glaring omission in the ACAA is
the lack of direct recourse for individuals whose rights are violated.

While the ACAA was written with an implied private right of action — the ability to sue an airline if the rights contained in the bill were violated — a Supreme Court ruling in 2001 held that such a right cannot be implied unless a statute has explicit indication that Congress intended to bestow it in the first place. In layman’s terms, it rendered the bill toothless, only giving those of us whose rights were trampled on the ability to file an administrative complaint with the DOT — a process that isn’t straightforward, and has a disturbingly low rate of enforcement.

**The Accountability Vacuum**

Under the ACAA, the secretary of transportation is only required to review the number of disability complaints all airlines receive (32,445 in 2016, half of which were wheelchair-related issues, according to Air Travel Consumer Reports), but the DOT itself only acts on incidents reported directly to its Office of Aviation Enforcement and Proceedings (merely 723 in 2016). Amazingly, over the last decade, the DOT has levied only a dozen fines to the top five domestic airlines, leaving the impression that our government treats them with kid gloves, to put it mildly.

Take the $2 million fine against United Airlines in January 2016 as an example. While that number looks substantial, the consent order from the DOT orders them to pay only $700,000 in monetary fines. The remainder was “credited” back to United, half of which was written off for flight vouchers dispensed in compensation to wronged passengers, while the other half was reinvested in a mobile app and other efforts to track mobility devices in their system.

That soft treatment continues, as evidenced by the postponement of a 2016 rule published in the final months of the Obama administration that would have required airlines to track and report how many wheelchairs and motorized scooters they carried and how many were broken or mishandled every month. Set to be implemented January 1, 2018, the DOT bowed to pressure from airline lobbyists and delayed the new rule by another year with no input from the public.

Thankfully, Senator Tammy Baldwin (D-WI) has stepped in to champion the cause by introducing the Air Carrier Access Amendments Act (S.1318). The measure would help create a Passengers with Disabilities Bill of Rights along with a federal advisory committee on the Air Travel Needs of Passengers with Disabilities. Most importantly, the senator’s bill would increase penalties for damaged wheelchairs, and allow travelers to pursue legal action in the event their chairs get damaged.

The absence of the ability to properly hold the industry accountable for its numerous violations is a big part of why we can flash forward 30 years since the ACAA was originally put in place and see that planes are the only mode of public transportation that do not have designated spaces for wheelchairs like buses, light rails, trains, and ferries have had for years. Without such a space, the prospect of air travel can seem exceedingly difficult and sometimes, downright scary for travelers who rely on chairs of all kinds.

**Fear and Loathing at 30,000 Feet**

The mere specter of a broken wheelchair at the end of a long flight is enough to keep many from attempting a flight at all. In a recent United Spinal poll of 180 wheelchair users with air travel experience, taken between August and October of this year, more than half (53 percent) of respondents said they have chosen not to fly for fear that their wheelchair might be broken in some fashion that could affect their trip.

“What I find most frustrating is that the system has created an environment where people with disabilities are afraid to fly,” says John Morris, a triple amputee from a car accident in 2012, and the driving force behind the informative blog WheelchairTravel.org. The 28-year-old is a self-described miles addict and staunch critic of the air travel industry. He has amassed more than 500 flights and nearly 750,000 miles in a power chair over the last five years. And while he has only had a single instance where his chair was returned completely undrivable, the all too real possibility of catastrophic damage still rents space in his head with every takeoff.

“That’s in the back of my mind the entire flight,” says Cory Lee, world traveler and namesake of the insightful and entertaining travel blog “Curb Free With Cory Lee.” The 27-year-old living with Spinal Muscular Atrophy has well over 100 flights on six continents as a power chair user. “I’m still very fearful of air travel. I took my first flight with a power chair at 13, and I get insanely nervous even to at 13, and I get insanely nervous even to...”

**Issues Big and Small**

Morris is quick to preface the difference between significant damage and minor
types of damage. “I don’t want to scare people into thinking that every time they fly, they will be faced with a destroyed wheelchair at their destination,” he says. Though Morris has only had that single instance of catastrophic damage, he admits the little ones can add up to larger inconveniences really quick. Even something as simple as a plastic release lever to remove an armrest could drastically affect a wheelchair user’s independence if it happens to be on the only side of the chair from which they can functionally transfer in and out of bed.

In the United Spinal survey, 49 percent of those who had flown domestically in the last five years said their chairs had been damaged by at least one airline. Of those who had issues, 32 percent reported their chairs had been damaged three or more times, with one in eight reporting more than five issues.

Contacts within the industry are reluctant to divulge the details of total damages from year to year, but Morris says Delta Airlines reported a 3 percent rate of wheelchairs damaged when it invited him to a consumer advisory board meeting in 2014. According to Consumer Reports, Delta had 98 complaints of wheelchairs damaged that year. But he says those numbers could easily be skewed by travelers not noticing smaller damages or simply lacking the desire to report them.

“At this point, it’s hard to keep track,” Morris says of the number of times his rights under the ACAA have been infringed upon. Even with his relative good luck with equipment damages, he says denial of preboarding, failure to provide safety briefings, and long delays returning his wheelchair are easily the top three rights that are violated. In 2017 alone, he has filed 10 complaints against carriers for a myriad of issues.

There’s also the issue of people not knowing they can report issues at all. Seventy percent of respondents to the United Spinal survey said they didn’t even know they had rights under the ACAA. Not

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**All Wheels Up — Getting Our Wheels Where They Belong**

Michelle Erwin stumbled into a platform of her own around 2010, when she and her husband tried to arrange a trip to Disneyland with their then-3-year-old son, Greyson, who has SMA. Despite Greyson’s small stature, the Erwins quickly discovered how cumbersome and downright dangerous air travel could be. “And this was with a child. I realized traveling with him was only going to get more challenging,” says Erwin.

Thinking flying with her son would be easier if he could remain in his own wheelchair, Erwin sought to find out what kind of solutions toward that end were in the works. She was shocked to discover there had been no research done whatsoever. So she embarked on a journey to get wheelchairs crash-tested for commercial flights. She began by getting in touch with Q’Straint, the leading wheelchair restraint manufacturer used in most vans and buses. Q’Straint had recently published results showing their tiedowns held up to tests of up to 20 G-force, well above the 16 G-force requirement of airplane seat standards. The numbers made sense. Getting anyone to listen was another story.

Repeated hangups from industry officials, failed grant applications, and losing the family home in Hurricane Sandy threatened to derail Erwin’s passion project, but she stayed the course, establishing All Wheels Up, a nonprofit focused on getting wheelchairs inside planes once and for all. “A lot of the airlines’ answers were ‘no,’ just for the sake of being no, and not for the right reasons,” she says. Team ing with other air travel advocates around the globe, and tireless grassroots organizing, helped AWU raise enough capital to fund the first crash test in Buffalo, New York.

In late September of this year, All Wheels Up got the chance to unveil its proof of concept for the first time at the inaugural Wheelchair in the Cabin Symposium, hosted by Flying Disabled at Virgin Atlantic Airways’ headquarters in Britain. With companies from all over the globe in attendance, Erwin made a compelling presentation of what the future of disabled air travel could look like. Showing a wheelchair being tested with Q’Straint tie-downs at an FAA crash test facility was enough to turn more than a few heads.

By focusing on logistics rather than rights, Erwin has learned to speak the language of the industry and found creative arguments that get the airlines’ attention. Case in point: tarmac turn times. She made the case that it is much easier to load and tie down a wheelchair inside the cabin itself than break it down underneath the plane, and it would increase the turnaround of each aircraft, which speaks volumes in the minds of industry heads looking to save time and money any way possible.

While it’s encouraging that progress is being made, Erwin is quick to point out that changes like these move at a glacial pace. “It took 14 years for the buses to become fully accessible, so we still have a long way to go. Boeing just signed a 10-year contract for their latest production line a year or two ago. Once production begins, the design is set, and no changes can be made. So I’ve got eight years to get it approved and work with designers.”

The biggest hurdle in front of AWU is getting the proper funding to do further crash tests. Erwin is looking at FAA reauthorization bills currently going through the House and Senate. Like the Air Carrier Access Amendments Act, the FAA bills require the study of in-cabin restraint systems for wheelchairs, but Erwin prefers the latter because there are actual purse strings attached in the FAA budget itself that could be put to use right away on subsequent crash tests.

By keeping an in-depth perspective and aligning all the right people, Erwin and All Wheels Up have established themselves as experts in a field that didn’t exist seven years ago. Though the timeline is long and there is still a lot of work ahead, she remains optimistic. “You can see this wave and there is so much happening all of a sudden.”
that airlines went out of their way to convey those rights, either. Ninety-two percent of respondents said the airlines did not share any information about their rights with them.

(Mis)Handling the Problem

When damage does occur, it’s mainly during the loading and unloading process which, at best, points to a lack of empathy and understanding of how to handle our equipment. At worst, it’s blatant disrespect for what is essentially our legs. After a long flight home from a tournament in 2008, Jeremy Hannaford and his teammates on the Seattle Slam quad rugby team were horrified to look out their cabin windows to see Delta baggage handlers throwing their day chairs onto the concrete. “Of course they couldn’t hear us beating on the windows from the inside. One of the flight attendants finally said something to them and they stopped.”

Morris says there’s a bad apple in every bunch, but the majority of damages are accidental. “I think the damage is a result of ignorance and lack of understanding about how to deal with mobility equipment. With a 400-pound wheelchair, you don’t lift it by the armrest.” Click over to his website, and you can watch a YouTube video compilation of baggage handlers from all over the world struggling to wrestle his awkward chair from the tarmac onto the conveyor belt that loads the luggage. Once on the conveyor, the belt is too narrow to carry most power chairs, so handlers often have to break safety protocol and climb up the belt while assisting the chair.

The next, and most cumbersome obstacle — for power chairs especially — is the cargo door height of narrow-body planes like the Boeing 737, one of the most commonly used aircraft for domestic flights. Airline websites say the door height is somewhere in the 36-inch range, but Morris says that can vary depending on the angle of the conveyor. Many power wheelchairs are too tall to fit through the door upright, so handlers have to tip the chairs on their sides, which can cause damage.

Policy Talk: Bills We Need Passed

Contact your U.S. senators and ask them to support the Air Carrier Access Amendments Act of 2017 (S. 1318). This bill would increase penalties for damaged wheelchairs, ensure higher standards for accessibility, and create a Passengers with Disabilities Bill of Rights. To take action on the Air Carrier Access Amendments Act, please visit United Spinal’s Advocacy Action Center at unitedspinal.org/air-travel-rights/.

Other bills to watch that United Spinal has played a hand in drafting and editing are the House and Senate Federal Aviation Administration Reauthorization bills HR 2997 and S. 1405. Both apply funding to continued operations of the FAA and include favorable provisions for the disability community, which include providing a study to Congress on airport accessibility best practices for passengers with disabilities, as well as the establishment of an advisory committee on the air travel needs of passengers with disabilities. As of October, there was a short six-month funding agreement of the FAA, signed by the president, that will expire in March. United Spinal continues to work hard on air travel issues for travelers with disabilities with many other advocacy groups.

Weeks or Months Without Crucial Equipment

The customization that goes into our chairs means that durable medical equipment providers don’t have spares just lying around. Depending on the complexity of your system, the turnaround times for repairs can stretch from hours to weeks, and even months. According to United Spinal’s poll, 36 percent of responders who had their wheelchair damaged were left without one for a substantial period of time, and 50 percent of those had to wait at least a month or more.

During my 2016 debacle with United Airlines, the best its New Jersey-based DME contractor could do for me was give me an ill-fitting, hand-controlled loaner while they scrambled to diagnose and fix mine. I spent five days of my first visit to the Big Apple with a gait belt wrapped around my chest and my arms awkwardly propped on pillows while my caregivers and girlfriend tag-teamed joystick duties in and out of narrow entryways and elevator doors.

A week later when my chair still wasn’t fixed, I had to swap out to a manual chair for another six days through Philadelphia and Washington, D.C. It was equal parts uncomfortable, demoralizing and humiliating.

It wound up taking six months for United to fix my wheelchair. If it weren’t for the dumb luck that my insurance had already ordered a new replacement chair at the same time, I could have been stuck in that manual chair, or even in bed, while I waited.

Gina Schuh, a C5-6 quad and founder of Accessible Arizona, found herself in the same position when the Twion Power Assist wheels for her manual wheelchair were broken by American Airlines on her flight home from this summer’s ROCH. Those power assist wheels are not for convenience — they are crucial to her daily life. “I don’t have the strength to push myself up the ramp of my car,” says Schuh, referring to her adapted Honda Element.

Even though she has a backup manual chair with a set of e-motion wheels (broken and replaced by United Airlines on a previous trip), it’s not compatible with her vehicle’s lock-in system, so the only feasible way for her to leave the house was to be in a regular manual chair and pay someone to push her around. She often had no choice but to stay home for most of the month it took for her equipment to be repaired. “It was just so irritating, because there was nothing I could do,” she says.

Customer Service Fails

Cory Lee, whose short book Air Travel For Wheelchair Users is available on Amazon, says the trouble can start weeks before he even arrives at the airport. In his book,
Lee emphasizes the importance of establishing contact with your air carrier well in advance of your flight, but the effectiveness of that forethought often depends on who you end up talking to.

In a conversation with one Delta customer service rep in preparation for an upcoming trip, Lee’s requests for extra accommodations were completely blown off with audible sighs from the person on the other end of the line, who wasn’t interested in putting in the extra work on his behalf. The Georgia native frequently flies out of Delta’s Atlanta hub and has reached out multiple times to offer to help train staff at the airport, but to no avail. “They’re completely unwilling to listen to anything,” he says.

Service on the back end can be equally as frustrating, especially when your wheelchair gets damaged. I had to do all the coordination between my local DME provider and United Airlines’ New Jersey affiliate, and rarely heard a thing from airline officials until it was all finished. Even though I told the complaint resolution officer I didn’t want them and wouldn’t use them, I got a handful of flight vouchers in an automated response with a canned apology and release of liability statement. It took a full year for United Airlines to send anything resembling a formal apology, which came following my registration of another DOT complaint, against Alaska, this summer.

**Behind the Curtain with Alaska**

To its credit, Alaska Airlines responded in a way most in the industry seldom do, and light years ahead of how United handled my prior situation. I posted one picture on Instagram the night my chair was damaged and woke up to six voicemails the following morning; four from random executives who were contacted by mutual friends, one from the airline’s social media director, and another from the manager of central baggage who left her personal cell number.

Within a couple weeks, I was invited to a roundtable discussion at Alaska Airlines headquarters in SeaTac, Washington, put together by Ray Prentice, the airline’s director of customer advocacy, who saw my situation as a teachable moment for the organization. There were nearly 30 managers from all corners of the organization present, from baggage contractors, transfer teams, web designers, flight control, airport representatives, you name it. “We are all about building relationships with experts to help teach us, and help us become better,” says Prentice.

The opportunity to get behind the curtain with one of the industry’s main players was a real eye-opener because it showed a business that seemed to take the disabled community’s travel hurdles to heart more than I had expected. I got to hear about the airline’s well-developed systems to aid blind and autistic passengers, as well as the steps it was taking to help decrease the amount of damage to mobility devices. Discussions ranged from educating passengers on better ways to communicate their wheelchairs’ specific needs through printable placards, to better internal tracking of outgoing and incoming wheelchairs.

In October, I was invited to one of its baggage handling training sessions focused on better strategies for handling wheelchairs. Prentice says the hope is that by offering them personal perspectives, there will be a better incentive to handle equipment with care. “That was one round. We need to continually engage baggage handlers in various ways so that they understand the importance of these devices.”

While the issue of stowing our equipment under the plane is a crucial component in making it easier for the wheelchair to get from point A to point B, it’s only part of what makes air travel problematic for wheelchair users.

**In-Cabin Real Dangers**

As a wheelchair user, just getting to your designated seat is an arduous task, thanks to multiple awkward transfers in and out of a rickety aisle chair. There are countless reports of aisle chair injuries in the United Spinal survey ranging from severe bruising caused by hitting armrests as passengers are hastily guided down the aisle, to far more serious issues.
like broken bones from falling out of the minimally-sized, unstable aisle chair.

"Half of my body is skin grafted," says Morris. "In some areas it's 1 millimeter of skin covering the bone, so I have to be very aware of how I am being moved around." For those with compromised skin, a minor breakdown can take weeks to heal, leaving behind scar tissue that is even more vulnerable. "Me and the aisle chair don't really get along too well, but I deal with it," he says.

Most travelers share that sentiment, but there are alternative ways to board planes that are readily available but not being used. Take the Eagle 2 and 3 aviation lifters from Australian hoist manufacturer Haycomp, for example. The modular, Hoyer-type lifts are made to fit down the narrow aisle of the plane and can take you from your wheelchair to your airplane seat without multiple lifts up and down from the aisle chair. "I've never seen one in person, but I'm dying to try it," says Lee.

There are other products in the market that can help mitigate some of the transfer issues, like the Comfort Carrier from Broadened Horizons, which consists of a vinyl sling with multiple heavy-duty handles sewn strategically in place for people to grab. Lee prefers the versatility he's found in Transfer Pants, which have similar handles sewn directly into the garments themselves. "They have really been a lifesaver for me."

If you make it through the aisle chair transfers unscathed, sitting on an airline cushion for multiple hours can cause serious problems as well. As someone who has lost four years of my post-injury life to bed rest to heal pressure sores, I take my skin integrity seriously. I have to be in a very specific position on my Ride Designs cushion, so it can’t be used on the airline seat during the flight. Using a semi-deflated ROHO cushion as a buffer, combined with multiple position changes, didn’t prevent me from incurring considerable breakdown. My first stop after the United Airlines flight in 2016 was the Rutgers University Hospital in-cabin issues further highlight that our wheelchairers are not just how we get around; we rely on the custom seating systems for our health and well-being. For those of us who rely on custom DME, it would be much safer if we could take our chairs inside the plane instead of putting our bodies at risk. [See sidebar on page 27.]

Making Cents vs. Making Sense

When pressed about the prospect of getting chairs on planes, Prentice falls back on the airline lobby’s standard arguments. “Are you talking about removing seats from first class? What about the narrowness of the aisles? How would you get back to coach? Which wheelchairs will be cleared and which won’t?” While some questions are valid, it points to an industry still digging in its heels in resistance to change.

Yes, there are quite a few logistical hurdles that would need to be ironed out, but they’ve managed to crash test vans and buses. There are logistical hurdles that would need to be ironed out, but they’ve managed to crash test vans and buses.

There are logistical hurdles that would need to be ironed out, but they’ve managed to crash test vans and buses.

For those of us who rely on custom systems for our health and well-being. As long as it is cheaper to break and pay the occasional fines than it would be to embrace accessibility, there is little incentive to change.

Thankfully, the numbers are slowly starting to skew in our favor, says Erwin, because a lot more of us are starting to fly.
The landscape of the disability community has shifted considerably since the ACA was initially passed. “1986 doesn’t feel like all that long ago, but things have changed enough that the community can travel more,” she says. The data seems to say the same thing.

In 2015, the disabled community spent $17.3 billion on travel, according to a market study by Open Doors Organization. That’s nearly a 30 percent increase from the $13.6 billion spent in 2005. Factor in the ever-increasing number of baby boomers heading toward retirement, and it makes business sense for airlines to expand the scope of services available to travelers with disabilities.

From her perspective, Erwin sees the untapped potential in an underserved community as a potential arms race for the first airline to become truly accessible. “The disability community is a tightknit group and is fiercely loyal to those who serve them well,” she says. It is a reason for hope down the road, but it still means we will have to deal with the status quo for the foreseeable future.

It’s the System, Not the People

It’s been a full three decades since our government enacted legislation to protect the disabled community from discrimination by the airline industry, yet those of us who rely on wheelchairs are still being treated like second-rate citizens when it comes to equal access on flights. The lack of proper accountability over the last 30 years has allowed the industry to get away with violating our civil rights and creating a culture of fear around what is a relatively carefree mode of travel for everyone else.

It’s hard not to take something like that personally, and the inclination is to lash out at the nearest baggage handler or any other airline official. Morris hates being put in situations where he has to hold his tongue, but that is often the case. Because the airline representative standing in front of him is most likely a good person, and would not have done this to him on their own. “The real problem exists in upper management, where executive boards have just decided that it is more cost-effective to violate our rights than it is to uphold them. And that is just a sad thing.”

One of the more frustrating things in this whole situation seems to be the relative silence I’ve heard from the rest of the airlines. I’ve reached out repeatedly to the rest of the big five via email and telephone for comments, and was simply directed to their websites’ respective disability policies. You can’t help but feel like our accessible travel needs will be addressed only in accordance to the next viral video or news story.

It all points to an industry that is too big for accountability, and it knows it. This really shouldn’t come as too much of a surprise. Just look at United Airlines’ now infamous incident from April of this year, where physician David Dow had his nose broken and two teeth knocked out when he was forcefully removed from the seat he rightfully paid for. The public at large was outraged, but wheelchair users weren’t surprised at all. Too many of us know what it feels like to be dragged down that aisle and have figurative or even actual bones broken.

A month later, the DOT announced it would not issue any sanctions against the airline because it reached an out-of-court settlement with Dow rumored to be in the tens of millions of dollars. Morris points out the major difference between Dow’s situation and those of us in wheelchairs rather succinctly. “His civil rights were violated so he could sue the airlines because he doesn’t have a disability, and that is the real problem here,” he says.

All of which highlights the importance of Baldwin’s Air Carrier Access Amendments Act and continued advocacy. Without the proper mechanisms in place to keep the airline industry accountable, we will continue to be treated as second-rate citizens.

I wasn’t looking for a platform a year and a half ago, but my glimpse behind the curtain of the airline industry has reinforced the importance of this conversation between wheelchair traveler, our elected officials, and every airline in every airport across the country. It must continue. As we’ve seen the disability community’s powerful contribution to the healthcare debate last summer, this community is a force to be reckoned with when we are justifiably motivated. This is another situation where it is time for our collective voice to be heard.

Finding solutions to keep wheelchairs safe from damage during air travel is one of United Spinal’s premier priorities. As a member of the Rehabilitation and Engineering and Assistive Technology Society of North America’s Assistive Technology for Air Travel Committee, which held its inaugural meeting in November, United Spinal joined RESNA and other disability organizations, airlines, wheelchair manufacturers, federal agencies and engineers. Together we are writing new standards for wheelchair labeling, design, handling and personnel training to safely transport wheelchairs through the onboarding and offboarding process. For more information go to resna.org/assistive-technology-air-travel-ata.

Resources

AIR TRAVEL RIGHTS:
• U.S. Department of Transportation Air Travel Complaint Form: airconsumer.dot.gov/escomplaint/ConsumerForm.cfm

ADVOCACY ORGANIZATIONS:
• All Wheels Up: allwheelsup.org
• Open Doors Organization: opendoonsfp.org
• United Spinal Association: unitedspinal.org

TRAVEL BLOGS:
• Curb Free With Cory Lee: CurbFreeWithCoryLee.com
• Wheelchair Travel: wheelchairtravel.org/air-travel/

PRODUCTS:
• Comfort Carrier: broadenedhorizons.com/comfort-carrier
• Transfer Pants: transferpants.com
I spoke with paraplegics and quadriplegics who worked in the same job or field for over 20 years to see how they did it — and to look for any unifying traits and similar approaches. Some of what I found was expected: most were confident, had degrees in their fields of employment and fearlessly jumped into their work. Less expected, most said they had little difficulty finding jobs and keeping them. Given that employment levels hover between 30 percent for quads and 40 percent for paras, this was surprising. I wondered if this was attributable to youthful naiveté or good luck, but then I saw the key was their passion. Not just a passion for working — that always helps — but a passion for their specific field, be it teaching, engineering or anything else.

THE POLICE MAN

When a car hit David Estrada on his motorcycle in 1995, it left him a T3 para and ended his law enforcement career before he could graduate from the academy. But while he was in rehab, the chief of the Boston Police Department visited and assured him he would have a job when he was ready. A year later Estrada became a 911 operator for the department. From there he moved on to the Office of the Police Commissioner and became the department’s media liaison. Today, in addition to being a BPD spokesman, he manages its website, Facebook page and Twitter account.

As if that isn’t enough, in his capacity as recruiter and coordinator for Athletes with Disabilities for the Boston Athletic Association, he recruited and coordinated international wheelchair racers for the Boston Marathon and other races. When the bomb went off in the 2013 marathon, Estrada was about 300 yards from the finish line. He quickly sprang into action, gathering information on the bombings for the BPD and checking on all the international wheelchair racers.

While working full-time for BPD, Estrada also earned a law degree and began serving as a peer mentor at Spaulding Rehab Network. His involvement with peer mentoring helped lead him to becoming the executive director of the Boston chapter of the NSCIA (now United Spinal).

“I like being busy,” he says. “I feel very fortunate to have the function that I do as a para, as well as a job I enjoy that gives my life meaning and purpose.” He makes a point of balancing his personal and professional obligations. “I don’t use a lot of vacation days in big chunks, but I do take some occasional time off to spend with my wife and daughter, and I’m home every weekend.”

Somehow, he makes it all work. When he stepped down from his post at NSCIA in 2013, he accepted the position of program manager for Spaulding Rehabilitation Hospital’s Model Systems grant, in addition to working with Spaulding’s exercise rowing program. (see New Mobility, Sept. 2013).

Estrada has now worked the equivalent of two full-time jobs for 12 years. Did I mention he also has a real estate license and helps people find accessible housing?

“I realize not everyone is able to work, but I think if you can work, you should,” Estrada says. “It’s an opportunity to do something meaningful.”

David Estrada helped Patrick and Jessica Downes, who each lost a leg in the Boston Marathon Bombing, obtain handcycles so they could participate in the 2015 race.
THE POLICY WONK

For the past 20 years Jo Donlin has worked in public policy communications for the state of Colorado. “I like what I do, as it allows me to use my intellect and critical thinking skills as well as a good deal of collaboration with others. I also get to teach a lot of people. It’s a good living,” says Donlin, a C5-6 quad since a 1990 diving accident.

It also makes for long and expensive days, as Donlin, 49, requires help with all transfers and foots the bill for her attendant care. Up at 5:15 to be at work by 9 a.m., she’s in bed by 8:30 or 9 p.m., with the lights off by 10.

Over the years Donlin has worked with the media, lobbied, analyzed policy, conducted research and translated a great deal of legalese into everyday English. Her first policy work was as a college intern with the Wyoming legislature in 1989. “Right now, I’m doing a lot of stakeholder engagement and outreach, writing and website work,” she says. “In the process, I teach a great many people.”

She enjoys working with colleagues and building partnerships, and finds that in the process she challenges perceptions of what wheelchair users are capable of. “People aren’t used to seeing quads out doing what I do, so I’m dealing with a lot of assumptions,” she says. “Work enhances my life and provides a paycheck for attendant care, medical bills, insurance and mortgage.”

Is it hard?

“I’ve paid a price,” she admits. “About five years ago I went from full-time to three-quarter time, though in my context it’s full-time. I’m absolutely exhausted.”

THE TEACHER

Joe Jeremias is easy to like. He’s genuinely humble, straightforward and thrives on self-deprecating humor, the darker the better.

He joined the SCI club 30 years ago at 16, when a bike-car collision resulted in a C6-7 injury. Now 46, Jeremias has been a high school English teacher for the past 22 years. He lives in West Hempstead, New York, on Long Island, with his wife Chris, also a teacher, and his 12-year-old son, Daniel.

About five years ago he began teaching English to juniors and seniors at Nike Alternative, a high school for at-risk students. “I’m working with kids who really need help, they’re probably the bottom 5-10 percent,” he says. “They need extra attention, and I have an opportunity to show them they can succeed. This is the most difficult teaching I’ve done, and also the most rewarding.”

His passion is obvious as he explains what he loves about his job. “I have more freedom to do what I want and be creative, and I can teach the kids where they’re at. I feel like I’m treated as a professional,” he says. “I really enjoy it.”

The job is more than just teaching English, he explained. “Sometimes it feels like triage. Some kids are homeless, others are living in dysfunctional families. They might show up after being kicked out of the house. I listen and go from there.”

Does the wheelchair get in the way?

“Yeah, same as any other job, but I’m also able to incorporate the chair into the teaching, either with humor — ‘Don’t make me get out of this chair’ — or as a way to connect, with empathy and understanding, ‘Look, I’ve gone through stuff, too. Maybe not your stuff, but stuff.’”

Like Estrada, Jeremias strives to find the right balance between personal and professional, although his SCI makes it more difficult. “I’d like to be more physically active, but it’s hard to find the time for self-care,” he says.

But the pleasure derived from working outweighs any struggles. “Working is a good thing,” he says. “I’m proud to be working every day … I like being a wheelchair ambassador to the world.”
THE DEFENSE CONTRACTOR

“We’re built to work,” says Kevin Wolitzky, about Raytheon Corporation, the U.S. government defense contractor that’s employed him for over 21 years. As a systems engineer, his work is classified, so he can’t divulge any details of exactly what he does, other than his work provides help to troops worldwide.

Wolitzky was an exceptional high school athlete and attended college on an athletic scholarship. About halfway through the fall term, during a baseball team initiation, a head-first slide into a 6-inch-deep mud pit made him a C5 quad. “I took too steep an angle and snapped my neck,” he recalled. “I immediately lost sensation and knew what happened.”

He quickly returned to school following rehab and became employed less than a month after he started looking. “I began to realize working was possible once I was able to use a computer,” he says. The job also offered some great fringe benefits: Not long after starting, a coworker and fellow wheeler introduced him to Leda, another employee, who eventually became his wife, and now they have three daughters.

Working 40 hours a week is a challenge for Wolitzky. Days begin at either 6 or 7 a.m., when his attendant arrives, allowing him to be on the job between 8 and 9. But it’s worth it. “I’m confident that I’m contributing. I provide a service to my employer and the government, just like any other employee. I’ve developed meaningful relationships and friendships with my coworkers,” he says. “Work provides me with mental stimulation and a chance to use my brain.”

THE FREEDOM-SEEKER

When she realized what life could be like as a wheelchair user, Carol Hickey smuggled a lightweight chair into her native Ireland via a food truck in order to avoid a 34 percent tax. With that act, the then-19-year-old started herself down a path that led to her current job as a territory manager for the complex rehab technology provider Numotion, responsible for Georgia and Birmingham, Alabama.

“I’m a firm believer that everyone has a right to a good chair,” says Hickey, whose job entails educating both professionals and consumers. “My work affords me the satisfaction of giving people options and freedom through mobility.”

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KEVIN WOLITZKY

CAROL HICKEY
Hickey grew up in Ireland, where at age 16 she was hit by an 18-wheeler, leaving her with a T4 SCI. “I had no rights, no opportunities [as a disabled person] in Ireland, and I was determined to obtain freedom and independence,” she says. “I felt like a second-class citizen there. I couldn’t live like that.”

As a child she always dreamed of flying and eventually began doing so using gliders. She visited Pennsylvania in 1990 to fly gliders as part of the Freedom’s Wings program and then managed to win a green card in the lottery in 1993. She says she immigrated for independence, the right to be equal.

Settling in Atlanta, she quickly went about establishing her new life. She worked for the Paralympic Organizing Committee for two years before accepting a position as a program manager for an outreach program educating kids about the Paralympics. In 1998 she began working for a medical company that eventually was purchased by Numotion.

Despite her 34 years on wheels, Hickey still relishes being employed. “I find it very positive and healthy. Even though everything takes longer, I can’t imagine not working. It enhances my life and gives me satisfaction every day that I’m helping people,” she says. “In Ireland I had no rights and was told I would never do things. Now I do them. Everyone should have options. I see myself as equal now, and no longer feel like a second-class citizen.”

“Carol Hickey is shown with coworkers from NuMotion.”

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BEHIND SCI LIFE WITH TIFFINY CARLSON

F or the last 13 years, New Mobility readers have counted on Tiffany Carlson for the latest scoop on interesting people, devices and happenings in the world of spinal cord injury. Through her monthly SCI Life column, she has introduced hundreds of such stories to a wider audience, helping many survivors share resources and messages of resilience.

When not writing for us, Carlson has been a prolific commentator on all things SCI on a number of prominent blogs and websites. She currently works as the executive director of SPINALpedia, one of the leading websites for people with SCI to share videos and stories. She has also been a fierce advocate for SCI research. In 2016, the Morton Paralysis Fund honored her for her work.

But like all good things, SCI Life will come to an end; this month’s issue features her last column. This doesn’t mean you won’t be seeing any more of Carlson — we will continue to showcase her writing — but it does seem like a good time to catch up with her and recognize her 157 NM columns, as well as the changes that have occurred in the SCI community during that period.

Q/A:

SOCIAL MEDIA IS FABULOUS. THANKS TO SMARTPHONES, EVERYONE CAN BLOG AND SHARE THEIR IDEAS AND TIPS NOW. IT’S INCREDIBLE. IT MAKES IT EASIER FOR EVERYONE TO CONNECT AND HELPS MANY NEWBIES TO NOT FEEL ALONE.

NM: You’ve covered a lot of future tech, or cool products that were promised, but maybe not delivered. Do you have a fav?

■ TC: Scewo stair-climbing chair is cool. ActiveHands is a great addition to quad life for others. The wheelchair-accessible cars are cute, too. There are a lot of great inventions being created by SCIs especially. I love all the crowd-funded products being developed, too. The Sixth Digit, a tiny metal peg made for quads, is definitely one of my favs.

NM: What about a person — do any of the people you’ve featured hold a special place in your mind?

■ TC: Everyone is cool. It’s great seeing people get to even better places in life after I’ve profiled them. Like Bre Garza, who was just in high school when I profiled her. She now has her bachelor’s degree and has grown into a beautiful woman.

NM: What about a story or individual that stands out the most in your memory?

■ Tiffiny Carlson: Every column was crafted from the heart. I’m always trying to think, “What would other people like me like to read about?” and I think I’ve done a pretty good job. No one story stands out, but I hope every product or shout-out to a great site helped someone’s life.

NM: How do you think the lives of people with SCI have changed, if at all, in the years you’ve been writing SCI Life?

■ TC: There are more products than ever before, and the strides in technology are so huge. Smartphones, tablets, WiFi … it’s insane and so great to see. All of the blogs and how-to videos by people with SCI have become a great resource, and they are so accessible.
NM: You’ve cultivated a pretty robust presence online. How do you think the relevance of social media has helped or hurt the wheelchair-using community?

TC: It’s fabulous. Thanks to smartphones, everyone can blog and share their ideas and tips now. It’s incredible. It makes it easier for everyone to connect and helps many newbies to not feel alone. At the same time, stalkers and devotees can use it, so it’s not all good in my opinion. Oversharing can be dangerous, so use social media thoughtfully, not for vanity. I have a stalker because of a mistake I made nine years ago.

NM: What about your own life, how has it changed?

TC: It hasn’t changed much. I’m just an old woman now — almost 40. But I might adopt in my 40s.

NM: You wear a lot of hats. Tell me about where else we can find your writing and work.

TC: I love helping the community as a writer and blogger wherever I can, and have done so at length with orgs like Disaboom, Lovebyrd, Easystand, Huffington Post, Ican, SPINALpedia and others. With SPINALpedia, I help the SCI community in the form of blogs and organizing events, social media and more as their executive director. It’s a rare opportunity to really impact the SCI community. Working for nonprofits is great for people with SCI. We can really work for a cause.

NM: What excites you the most about everything that is going on around SCI today?

TC: I think the research keeps moving along, but I definitely don’t think I will live to see anything concrete in terms of full-on walking “like normal” in my life. I think an actual SCI “cure” is still 20-30 years away, but I still believe in advocating hardcore for research. I wish a longtime quad like me with no money could take part in trials, because I’d be down.

NM: What about your favorite accessible place to visit?

TC: My van, just driving is my favorite thing to do. After my last trip when my flight was canceled and my chair broke, I decided air travel is too stressful.

NM: Favorite depiction of SCI in a movie or TV show?

TC: Macaulay Culkin in Saved.

NM: Assistive tech or device you can’t live without?

TC: My power chair. Really! My personal mantra is “don’t hate the wheelchair; hate the injury.” My wheelchair is my best friend. No one else will carry my 140-pound ass all day except my wheelchair, and that’s the truth.

IMMORTALIZED ONLINE

Tiffany Carlson’s unerring knack for finding what is coming next and who’s who in the wheelchair world is perhaps best experienced by browsing her blog, Spin 2.0, found at www.newmobility.com/category/blogs/spin/. It’s where New Mobility first heard about fashion icon Jillian Mercado, “kite-chairing,” (being pulled along on a windy day by kite) and hacks like how to make a Kinect wheelchair-accessible.

So many everyday events turn into adventures for Carlson, even cooking. “I love to bake, but holy cow do my hands fight me! I don’t let this stop me, though. Fresh baked cookies, pineapple upside-down cake, rhubarb crisp … with adapted baking tools, I can make it all!” she enthused in “My Favorite Baking Tools,” www.newmobility.com/2014/11/favorite-adapted-baking-tools/. Oster’s Extra Large Toaster Oven is first on her list, if you’re curious. “Nothing beats being able to easily pull out my cookie sheet or pan without having to bend over. I use Oster’s Extra Large Toaster Oven, and it’s the best $99 I ever spent. Cakes, cookies, pies, it bakes it all.”

The best of Spin 2.0 often ended up in SCI Life (think Sixth Digit), but some topics can’t lend themselves well to tiny formatted boxes. Spin let her delve into weightier, often more personal subjects. Her Project Walk Diaries are the best example of this.

Right as the SCI-gearied gyms were beginning to become a thing, Project Walk opened one in Minneapolis and Carlson wandered over to see what it was all about, and brought her readers along with her. “Was I walking again? Heck no, but it sure felt good to be upright in a way that didn’t require being in a metal frame,” she wrote, after a session. “I guess you can say it felt more natural, as much as it can when you’re paralyzed and have two people helping you stand up, that is. And I can’t wait to do it again.”

Even as SCI Life winds down, as did Spin 2.0, Carlson’s voice will still be included in our magazine. We look forward to seeing what she does next and trust it will be written with great enthusiasm.
SCI and Diabetes Risk: Ways To Improve Your Odds

By Bob Vogel

Q. I’m 45 and a C6 quad for 17 years. I just read Tim Gilmer’s article on diabetes [October 2016] that mentioned a Canadian study saying people with SCI are 2.5 times more likely to develop type 2 diabetes than the general public. I go in for yearly check-ups, but my doctor never mentioned this. Should I get a diabetes test? And if so, what test? Is there a way to reduce my odds of developing type 2 diabetes? If you get it, is it reversible?

— John

T here are some type 2 diabetes basics: A hormone, insulin, regulates the correct balance of glucose (blood sugar) in your blood — signaling the liver when to release glucose for needed energy and when to store it in the liver, muscles and fat cells when glucose levels rise. Type 2 diabetes happens when the body does not respond properly to insulin (insulin resistance), or doesn’t make enough insulin, which causes glucose levels in the blood stream to rise.

Excess glucose levels produce an inflammatory response in the vascular system, which leads to vascular damage. Over time this can cause serious complications, from kidney damage, to vision loss, to heart disease.

“SCI and diabetes are especially dangerous in terms of wounds on the legs because SCI has already compromised blood flow, and uncontrolled diabetes further compromises blood flow,” says Cat Davis, certified rehab RN of Craig Hospital’s SCI Nurse Advice Hotline. “Lack of circulation from damaged blood vessels makes wound healing much more difficult.” The takeaway is to follow steps to prevent, delay, or control diabetes before blood vessels become damaged.

Here are ways to prevent or delay the onset of type 2 diabetes, according to the American Diabetes Association: regular physical activity, maintaining a healthy weight, and eating healthy, protein-rich, low-carb food, fruits (in moderation) and vegetables. If you do develop type 2 diabetes, adopting these lifestyle habits is vital to controlling it. Studies show that for some people these lifestyle changes can “reverse” the condition and eliminate the need for diabetes medication, depending on length of time you have had it, severity, and genetics. Those with a family history of diabetes are at higher risk.

Identifying higher than normal blood glucose levels early is one step in improving your odds. Have your physician order a fasting blood sugar count — which is included in a Comprehensive Metabolic Panel or Chem 20 Panel as part of your annual physical, explains Kathleen Dunn, a recently retired clinical nurse specialist and rehab case manager. If the readings are abnormal, Dunn says your doctor should follow up with an A1C test, which determines blood levels over the past three months. Studies show that type 2 diabetes tends to occur in the 45-49 age range with SCI compared with 60-64 in the nondisabled population.

Another reason to have annual blood glucose tests is that it’s rare for people with either pre-diabetes or type 2 diabetes to have physical symptoms, says Dunn. According to the Mayo Clinic, you can have type 2 diabetes for years and not know it.

Maintaining a proper body mass index is another way to increase your odds against type 2 diabetes. Obesity is thought to be a factor in type 2 diabetes because it creates changes in metabolism that cause fat tissue to release fat molecules into the blood. This interferes with insulin cells and reduces their effectiveness.

Exercise on a regular basis can also tilt the odds in your favor. Regular physical activity along with modest weight loss have been shown to lower type 2 diabetes risk by 58 percent in high-risk populations, according to a joint position statement by The American College of Sports Medicine and American Diabetes Association. Physical activity causes active muscles to pull glucose from the blood to burn for fuel. Benefits are immediate. A single session of moderate physical activity for 30 minutes increases insulin action and glucose tolerance for more than 24 hours. A week of five 30-minute sessions can improve whole-body insulin sensitivity in people with type 2 diabetes. The effects are similar whether activity is done in one 30-minute session or two or three sessions totaling 30 minutes.

Resistance exercise with free weights, Therabands or weight machines also helps with glucose control, according to the joint statement. A randomized controlled trial showed that resistance training for 16 weeks resulted in a 46.3 percent increase in insulin action and a 7.1 percent reduction in fasting blood glucose levels for older men with type 2 diabetes. Resistance exercise should be done at least twice a week on nonconsecutive days.

Ideally, aerobic exercise should be included, too — pushing your chair, swimming, hand cycling or using an arm ergometer, doing seated aerobics, etc. Thirty-minute sessions at moderate intensity, (40-60 percent maximum heart rate) for at least three days a week (ideally five) are recommended.

Talk with your doctor about heart or blood pressure medications you may take.
before starting an exercise program. For instance, beta blockers (high blood pressure medication) are known to lower heart rate response and maximum heart rate. Your doctor can help you adjust your target heart rate accordingly.

Theo Braddy, 57, a C4-5 quad for 42 years, found out the hard way how serious type 2 diabetes can be. Over the years Braddy had put on 50 pounds. He was so focused on his work that he wasn’t paying attention to his diet, drinking lots of sugary sodas or juice with high sugar content.

Three years ago, Braddy’s doctor told him his sugar levels were high and he had to watch his sugar intake. “But I didn’t make the connection that I was heading toward diabetes. I didn’t know how serious it was,” he recalls.

Six months later he became extremely fatigued, like he had a UTI, and was constantly thirsty, so he doubled up on sodas. “It got so bad I went into a sort of brain fog for two days. On the second day I woke up and my vision was blurry, so I went to the emergency room. The doctor said I have diabetes and my glucose levels had become so high I was in a waking diabetic coma. I was close to death!”

He was put on insulin and got serious about exercise and nutrition. “Now I eat a breakfast with little to no carbs, a mid-morning snack, a light lunch, mid-afternoon snack and sensible dinner. For exercise, I do 10-15 minutes every day on an arm ergometer (table mounted stationary handcycle) or hit a heavy punching bag, which is my favorite. I pull my power chair up to it and go to town — at my injury level I only have shoulder and biceps control, no triceps, but that’s enough to work the bag.”

Within six months of his healthier lifestyle he was able to get off of insulin shots, and now controls his diabetes by taking one pill a day. His insulin levels are stabilized, so he went from doing a blood-glucose finger-prick test five times a day to only one each morning.

“If I had known how serious this is, I would have started eating right and exercising the moment I heard my sugar levels were elevated,” he says. “People need to be aware of their blood sugar levels. If you catch rising blood sugar early, you can take steps to manage it before crossing the threshold into diabetes.”

**Resources**
- Diabetes and Obesity: www.diabetes.co.uk/diabetes-and-obesity.html
- Diabetes and SCI: Control Your Carbs and Exercise: newmobility.com/2016/10/diabetes-and-sci/
- Exercise and Type 2 Diabetes: ncbi.nlm.nih.gov/pmc/articles/PMC2992225/
- Spinal Cord Injury and Type II Diabetes: ncbi.nlm.nih.gov/pmc/articles/PMC3821709/
- Target Aerobic Heart Rate: heart.org/HEARTORG/HealthyLiving/PhysicalActivity/FitnessBasics/Target-Heart-Rates_UCM_434341_Article.jsp#.WftsELaZNjt

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We are aloft, gliding silently, high above the green landscape. “You guys seem to be finding lift. I’m getting low, I think I’ll join you.” We hear Jason, another club member, over the radio.

“We still show six knots here, come join,” replies Dale from the back seat of our glider, letting Jason know that there is still lift, and that we’re climbing at about 600 feet per minute.

“There he is, joining our thermal below us,” I say, spotting the other aircraft several thousand feet below. It is great how everybody reports where they found lift, and invites others to join in the fun.

“Got him,” replies Dale.

What a treat! Here we are flying gliders over a mile high, silently circling in a rising column of air known as a thermal. Another glider has joined us and we do a silent pirouette. It is amazing to fly so close to another aircraft. The first time I experienced being this close to another glider, it was hard for me to get used to. From my experience with powered aircraft (when I was a teen, about 100 years ago), we were taught to stay away from other airplanes, but with the gliders you are often flying near others so that you may take advantage of the lift they have found.

I adjust our turn by banking the glider left and right, making our circle tighter and then looser. I am trying to stay in the lift but remain a safe distance from Jason, who is flying the other glider. Keeping him at our three o’clock position seems to offer the best photo opportunity and safety.

“I am getting some great pictures back here,” says Dale.

“I’ll try to keep him pointed off the wingtip,” I reply, watching Jason and adjusting our turn.

I need to pinch myself to see if this is real. It’s hard to believe we are circling with another glider in close proximity and gaining altitude, all with no engine. The fun and challenge of trying to stay aloft never gets old. When I first started gliding, it seemed a mystery that some of the people could stay in the air for so long, but now finding lift is getting to be second nature. We stay in the thermal, circling until it loses its strength at about 10,000 feet, all the while keeping the other glider in sight and positioned off of our wingtip so as to prevent a midair collision. I move the stick left and our glider levels out to fly northward in search of more lift. The rule of thumb for us is that we can glide about five miles for every thousand feet of altitude above ground. At our present height that should allow us to travel 40 miles or more.

* * *

Today is one of those summer days where there are no clouds to guide us to thermals, so we need to just feel around. After some experience, you start to become part of the glider, and if you listen, it’ll tell you where to find lift. When you feel a kick in the pants, wait a couple of seconds to see if the thermal is wide enough to circle in. Sometimes it’ll raise a wingtip, pointing towards the rising air. You simply turn that way and — voila! — you are going up. Of course, there are the more obvious places to find lift, like under puffy clouds if there are any, but as summer wears on, the days of easy lift become less and less frequent. If you can’t find any, you will be back on the ground in 20 minutes.

As we silently slip northward, green and yellow fields checkerboard the ground for miles, crisscrossed by gravel roads and paved highways, while small
towns dot the ground every so often. I relax and enjoy the cruise. The less you control the aircraft the better, as any change in flight path uses energy, and soaring is all about energy conservation. It is surreal to see the world from this vantage point, and know that you are in total control of the aircraft. What an unbelievable feeling of freedom!

In order to grab the joystick, we have built a special cuff that is strapped to my arm. I fly with another pilot in the back since I can’t get a license due to my disability, and relying on adaptations to control the glider would make it unsafe for me to be in the air alone anyhow. Soaring is something that is best enjoyed with a friend, and there are no shortage of pilots volunteering to ride in the back seat. Sometimes I feel bad for the back seat pilot. I fly real gentle … like an eagle ferrying its chick … and probably lull them to sleep at times with the mild turns.

Once airborne I’m experiencing total freedom. In the glider I am a pilot, no longer the guy in the wheelchair. I’m concentrating on finding lift, constantly trying to hear and feel what the aircraft is telling me. We are silently sailing the sky, miles above those on the ground. I totally forget that I am a quadriplegic. Cars creep along at a snail’s pace like dinky toys, farmers work their land, everybody on the ground carries on with their lives, oblivious to your silent perch. The right wing raises quickly, I bank the glider right and we feel the lift shoot us skyward. Circling for several turns, we gain as much height as we can, then silently move on.

“How long have we been up?” I ask. “Nearly three hours,” Dale replies. “It’s been a great flight. Shall we head home?”

“Whenever you want, it’s your flight.” I shoulder check for other gliders and bank to the right, leveling out on track to enjoy the scenery of the long smooth glide back to the airstrip. The beauty of it all seems so surreal. A grin will be chiseled onto my face for weeks. What a day!

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As I get older, I often feel like going to see a fortune teller. I don’t really believe in going to see fortune tellers, but I’d be willing to compromise my convictions if I thought it could help me execute my grand plan.

I’d ask the fortune teller to please tell me the exact day and hour that I am going to die. And if I was confident that the fortune teller’s prophecy was correct, here’s what I’d do. Twenty-four hours before the moment of my untimely death, I would go to the nearest strip club. I don’t really believe in going to strip clubs either, but I’d be willing to compromise my convictions again if I thought it could help me execute my grand plan.

Because a few years ago, I sold my soul to the devil. Actually, it’s more like I sold my soul to the government. I inherited some money. It wasn’t a lot. But as every cripple knows, in order to be eligible to receive certain government services, like Medicaid, you have to stay under certain puny asset limits. It doesn’t take a big inheritance to put you over the asset line. I rely on one such program to pay the wages of the people I employ to get my ass in and out of bed every day. If I took the money, I would lose my service, and thus be stuck in bed. It’s a real inheritance buzzkill.

But the government said to me, “Don’t worry. You can receive your inheritance and still remain eligible. Just sign here.”

So I signed. What else could I do? And with that, all of my inherited money above the asset limit was deposited into a trust. But the devil’s deals always have a catch. And the catch in this case is that any money left in that trust when I die goes to the government.

That sucks. I can’t leave that money to my wife or anybody else. I must bequeath it all to my stingy Uncle Sam.

Hey, I’m all for socialism. I wouldn’t have a big problem with paying for my consumption of public services posthumously if that’s what everyone had to do. Like if everybody who ever walked down the sidewalk or drove on a highway or sat on a park bench had all their surplus money deposited into the public trough after death, then OK, I would gladly do my civic duty, too.

But that’s not how it works. There are certain services civilized societies agree everybody is entitled to consume regardless of their income, race, color, creed, etc. But getting your crippled ass out of bed isn’t one of them. For that you must be penalized. You must pay a luxury tax.

I feel an obligation to protest against this punitive injustice. So, fortunately, I believe there is a loophole in my pact with the devil/government. The alternative to handing all my cash over to the government is to blow every last damn red cent. While I’m alive, the funds in the trust can be spent on things that enhance my quality of life. Going to a strip club would certainly fall under that category. But timing, of course, is everything. So if I know exactly when I’m going to die, I can plan it just right so that I hand my last damn dollar to a pole dancer just as I draw my last breath. Then I’ll collapse in a valiant blaze of glory! Paramedics rush in with defibrillators, but they can’t save me. What a poignant exit!

Now of course all trust expenditures have to be well-documented to prove they are legit, in case the government ever asks. So whenever I gave a pole dancer a dollar, I’d have to make sure she gave me a receipt. (I suppose I’d also have to get a receipt from the fortune teller.)

Like I said, I wouldn’t choose to spend my last hours and my last dime at a strip club under normal circumstances. But under these circumstances, a strip club is the perfect place to go out. It’s a big middle finger to Uncle Sam. He lost out to a stripper!

Put yourself in my shoes. If you had to give the last of your inheritance to either the government or a pole dancer, which would you choose?
EMPLOYMENT OPPORTUNITY

Job Title: Americans with Disabilities Act (ADA) Coordinator (Part-Time)

Description: The Americans with Disabilities Act (ADA) Coordinator will build upon and administer the ADA accommodation program from start to finish. The position will also be involved in the Light Duty/Return-to-Work program. Other duties include but are not limited to the following: Identifies and performs outreach to employees possibly requiring accommodations; educates management and employees on the rights and duties under the ADA; coordinates with management and employees to develop and provide employees effective and reasonable accommodations; develops written materials and other informational pieces regarding the ADA program; develops and maintains internal measures to track ADA status and compliance and maintains and documents records of all disability and accommodation issues ensures compliance with applicable laws, regulations, and policies; assures that workers with disabilities are provided effective and reasonable accommodations allowing them to work productively and safely; assure Township-Sponsored activities, Township Facilities and events address accessibility and accommodation concerns.

Requirements: Bachelor’s degree in social sciences, human resource management, business administration or related field and two years of personnel administration experience are required (or a combination of education and/or training and/or experience which provides an equivalent background required to perform the work of the class); a minimum of eighteen (18) months of experience in a position that involved evaluating and administering reasonable accommodation issues subject to the ADA or §504 and completion of a course on barrier-free design or ADA accessibility guidelines which was sponsored or approved by the New Jersey Department of Community Affairs or a department which oversees the Uniform Construction Code in any other State, the American Institute of Architects, the Paralyzed Veterans Association, or the United Spinal Association, within twelve (12) months of hire.

Salary: DOQ

Hours: Part-Time, three days weekly (not to exceed twenty one hours per week).

Apply: Send resume or application to: Ms. Braedon Gregory, HRIS Coordinator, Human Resources Department, Township of Montclair, 205 Claremont Avenue, Montclair, New Jersey 07042 or email: bgregory@montclairnjusa.org

Closing Date: Job posting will remain open until position is filled.

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• Facilitate new opportunities to lead active, independent lives
• Raise public awareness on issues that impact the disability community

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**House for sale** – CS-6 SCI incomplete. Accessible 4-3-3. Waterfront with access to golf, pool/spa. Dock with boat lift. $775K. Tampa, FL. Contact: TLWilson7@verizon.net

**Chairman HD3 Electric Wheelchair** Excellent condition. Used for 1 yr. This chair tilts, reclines and elevates Max weight 400 lbs. For additional information contact 973-934-1391 for photos. Asking $3800.00

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Rare Patient Voice, www.rarepatientvoice.com

Trusted Mobility, www.trustedmobilityrepair.com

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

Acknowledgements on our website, in New Mobility, in United Spinal e-news or any other United Spinal publication should not be considered as endorsements of any product or service.
Retired paratrooper Max Gretschmann likes going to the edge — literally. The 34-year-old para took a trip to the Grand Canyon just to do this wheelie.

Keating hit a nerve with our online readers:

Just out of ER and the hospital where I stayed for a week. It was a total nightmare. They couldn’t even see my wheelchair on the side. When I get ill again, I’m staying home.

— Suzanne Solberg

Love the poem … hate the reality it portrays.

— Michael Conroy

I have spastic cerebral palsy and I go through just about the same thing. Here’s what I would love to say: If you people have bothered reading your chart you would see exactly what my limitations are! Wow, you just can’t read, apparently.

— Michael Cesarino

This happens every time, nearly word for word, when I go to the doctor. You’d think medical staff would have at least a basic knowledge of SCIs. I’ve had hospital staff not know the difference between a quad and a para! Thank you for sharing this.

— Zona Housh

TOO REAL POEM

After a trip to the hospital, Mary Pierson Keating decided to write down the words of medical professionals and string them together as a poem, which is published as a blog post on newmobility.com. Here’s a taste:

Can you stand?
No I didn’t read your
Chart yet or the intake form
Or how you answered
“What can we do
To make it easier for you.”
Here let me just read …
...
Do you know
How much you weigh?
Can you guess?
No I don’t see what
That has to do
With guessing your
Blood pressure.
No we don’t have
A scale.
What?
The Americans with
Disabilities Act?
I had no idea.
Can you get me a copy?
Really since 1990?
Wow

— Mary Pierson Keating,
newmobility.com/2017/10/
a-poem-about-sci-er

TAKING IT TO THE EDGE

Keating with our online readers:
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– Dr. Per Uddén, Permobil Founder

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