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No one wants to worry about the possibility of losing more function or suffering from increased pain, but scar tissue and cysts in and on the spinal cord can cause just that for a small percentage of people with SCI. Ali Ingersoll went to China because she feared a cyst would destroy her quality of life. She shares the good, the bad and the weird that came from her sojourn abroad. Tim Gilmer talks with Ingersoll and other wheelers dealing with these unfortunate circumstances to learn how to handle spinal cord complications. Gilmer also interviews Dr. Wise Young and Dr. David Darrow to better understand how researchers are working to restore function.

Cover Illustration by Doug Davis

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By Ian Ruder

As the leaves start to turn and the days grow shorter, I find myself daydreaming about the idyllic days of early summer; back when I could count on the sun to warm my quad bones late into the night; back when the rains held off long enough to allow me to explore nature in my power chair; back when I had a full stable of excellent doctors I could rely on. That last memory may not seem like it fits, but when I look back on this summer, the series of unfortunate (and sometimes inexcusable) events that left me questioning the medical profession and struggling to find competent care providers will no doubt be near the front of my mind.

A mere three months ago I considered myself lucky when it came to doctors. I had a wonderful physiatrist, a trusted urologist I considered a friend, and a new primary care physician who seemed young and enthusiastic. Then it all fell apart.

It started with a letter. The envelope looked like the many other bills and insurance requests littered across my desk, but inside was a solitary sheet informing me my beloved urologist of 15-plus years was ending his practice in two weeks and moving away. Just like that — gone.

A few days later I went in for a long-scheduled physical with my new PCP. Believe it or not, I actually found myself looking forward to getting to know him and developing a rapport like the one I had with my previous doc. He quickly disabused me of that fantasy with a perfunctory exam and business-like demeanor that made clear he had other places to be. He handed me the form to get blood work done and then let me know he was leaving his practice.

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He explained that he was opening a new practice about a half mile away and offered a sign-up form to be kept in the loop on details. My lukewarm feelings about our burgeoning relationship grew even colder when I found out he had selected one of the city’s least accessible buildings for his new office, and his new practice wouldn’t be accepting my insurance. Wonderful.

“He had selected one of the city’s least accessible buildings for his new office, and his new practice wouldn’t be accepting my insurance. Wonderful.”

The following week held a first visit with a colorectal specialist I’d been waiting over two months to see. She’d come highly recommended so I’d decided it was worth the extended time dealing with some frustrating symptoms. Again, I naively counted down the days to my appointment, excited by the prospect of getting answers and relief.

On the doctor’s request, I reworked my morning routine schedule and did all the not-so-fun extra prep the morning of the appointment. At 11 am, two hours before I was supposed to be there, the nurse called to say that unfortunately she was going to have to reschedule my visit. For when, I asked, informing her I’d been waiting for months and had been dealing with some relatively serious issues. A couple of seconds later she politely told me that it looked like the first opening was in six weeks. Would I like to take that?

Next week brings the official end of summer and the annual visit with my physiatrist. We’ve been together for over 20 years and normally I’d look forward to catching up. But after this summer? Well, let’s just say that if I could cross my fingers, I would.
My introduction to Ali Ingersoll came via a memorable piece she wrote for PushLiving.com about dating as a quad. She candidly described instructing her caregiver and mom on how to position her for sexy photos she would share with prospective dates. Her writing wasn’t salacious or lewd, but honest and informative — in other words, exactly the kind of voice New MOBILITY thrives on. “I am big believer in helping people,” she says. “If I can help one person going through spinal cord injury, whether it’s with dating, swimming or something else, that’s my way of paying it forward.” After you read Ingersoll’s recounting of her trip to China for spinal surgery, find more of her writing at quirkyquad.com.

Executive Editor Josie Byzek can’t recall exactly when she first met Mike Ervin in person, but she also can’t forget the time the two of them took part in an ADAPT action in Memphis, Tennessee. “We were protesting in the governor’s office, and Mike ordered a pizza from a desk phone,” she says. “I wonder if the cops ate it.” Byzek is but one of countless disability activists and leaders to have crossed paths with Ervin over his long career. As a fellow Chicagoan, Ervin knew advocacy icon Marca Bristo well, and we couldn’t have found a better person to memorialize her.

Birds of prey and wheelchairs. That was the essence of Bob Vogel’s pitch for the story on falconry in this issue. I’d be lying if I said that coupling was instantly appealing to me, but when I talked with Vogel, I could tell he might be onto something by the enthusiasm in his voice. Vogel was born too early to be a true part of the extreme sports generation, but he is a kindred soul who has done or tried pretty much everything out there. If falconry is cool enough for him, it’s cool enough for New MOBILITY.

Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org
“This article needed to be published.”

**Inspired Writing**
Spot-on reporting. Top shelf journalism. ("Beyond Inspiration: A New Narrative," August 2019). As a lifelong writer and former daily journalist, this (sadly) IS the attitude of most mainstream editors and reporters. This article needed to be published — and I am sharing it on every platform I have.

*Steve Wright*
Newmobility.com

**The “I” Word**
Ahhhhh, yes. The "I" word. Some people appreciate it because, through it, they get SOME form of positive attention. I've been involved with adaptive sports since I broke my back 18 years ago. One could argue that the adaptive sports scene is largely fueled by inspiration. There are countless grants and opportunities for people with limited abilities to participate in adaptive sports, but resources for those same individuals to start a small business or work to reach a higher standard of living are few and far between. I would MUCH rather be regarded as an equal, as opposed to being someone's short-lived "inspiration."

*Seth Arseneau*
Newmobility.com

**Behind the Curtain**
What an insightful read about a side of the speaking industry I knew nothing about ("Confessions of a Motivational Speaker," August 2019). Turning away from the simple tricks so that the real message can take center stage.

*Barry Friedman*
Newmobility.com

**Helpful Advice**
Thanks for your insights. I live with cerebral palsy and think deeply about the world, its systems and my place in it. I have dabbled in public speaking and hope to get back into it. I'll definitely carry with me a lot of what you have learned and observed.

*Areal Stinger*
Newmobility.com

**Striking for Access**
Our group “South Fraser Active Living” (part of Spinal Cord Injury – British Columbia) has been bowling a couple of times, and we are fortunate that the local lanes have four or more traditional ramps ("Opening Up the Lanes," August 2019). We have found that it is impossible to get the ramp ready yourself, someone has to hold the ramp up between each chair user and of course it’s tricky to line it up, etc. It is bowling, after all! This device seems to hook up on each chair, I'll see if we can find a video, but because it attaches, does that mean everyone has to have their own [IKAN Bowler]?

*Marney Smithies*
Newmobility.com

**Writer Kenny Salvini responds:** You do not need a Bowler for every person, but the ease of sharing depends on which style of mount is required. For chairs with swing away footrests, the ratcheting clamps are easily attached and removed within minutes. For chairs needing the utility rail attachments, it's a bit more labor-intensive but not impossible. The brackets themselves are fairly sleek and would not be noticed when the bowler is not attached. We bought extra mounting brackets for a recent event and brought in a handful of assistive technology professionals from our local DME providers to attach them to people's chairs so they could test it out. For a more long-term solution, I would suggest that each person who wants to bowl get their own set of mounting brackets to have on their chairs at all times.
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I had this happen once. I flew into a small airport where a loaner chair just wasn’t going to happen. I kept the airport manager in his office as I sat in an airport wheelchair for six hours. They had to fly my chair in. Ugh. Needless to say, I always double-check with the crew that my chair is not still on the bridge when they close the doors.

**Mona McAleese**

I have had more issues with the people that get you to your seat in that aisle chair. I’ve been dropped and slammed into the side of the plane, resulting in injury. They don’t move me without someone else (my wife) guiding them. Sorry, but they are usually grossly under-trained.

**Todd Bade**

**The Mixed**

I have flown a fair amount of times myself and never — knock, knock — lost my chair. Here’s the thing I do to that’s worked over the last 34 wheeling years. Gate tag for sure, wheel yourself to the connecting flight, make a deal with the flight attendant, or the escort, to watch your chair go down and get loaded. Then upon arrival, sit on the left side of plane as much as possible, and you’ll see your chair come off. Now, if I could only convince them to stop putting my chair in a place where it gets squished with forward slamming luggage when landing.

**Crista Lawrence Adamson**

**The Good**

Lots of horror stories out there from wheelers who are flying. If any new wheelers out there are now too scared to fly, DON’T BE. Since being in a chair for over 30 years, I have flown at least 50 times. Consider me lucky, but all my flights were pleasant, and the airlines treated me well, even giving me a few free upgrades to first class. I always use the gate tag, so the chair is taken from the jetway, then loaded directly onto the plane. Then when I arrive at the destination, the chair is one of the first things unloaded, and it comes up to the jetway.

**John Dains**

My father-in-law flew with a chair for years with nothing but wonderful experiences! Now my multiple sclerosis makes it my time to take a chair. I have been from Chicago to Mexico three times last year alone! No problems, and the help in Mexico was fantastic! The U.S. should take some examples from the air service reps in our southern U.S. neighbor!

**Laura Ringle Markley**

My wife and I just flew from St. Louis to Los Angeles for business, and both trips were smooth as could be. We don’t fly often, and I’m always a nervous wreck, but I always gate tag my chair and make sure at least one attendant is invested in my situation. So far so good. Oh, and I always try to fly direct, no layovers.

**James Schramm**

**The Bad**

An airline I won’t mention left my chair on the tarmac during a connecting flight last year. It was returned to me the next day. They said I would have to wait five hours for a loaner to arrive, so I left in the airport’s chair and dared them to arrest me. They did not, and came and got it after my chair arrived.

**Jack Spencer**

Kristen Parisi’s blog post recounting a cross-country summer flight in which she arrived home but her wheelchair didn’t inspired a number of readers to share their air travel stories in the comments section (“When the Nightmare of an Airline Losing Your Wheelchair Comes True,” Sept. 3, Newmobility.com).

**United Spinal Association**

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

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

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

The Department of Transportation’s mid-year Air Travel Consumer Report showed that airlines damaged 1.62% of wheelchairs and scooters enplaned between January and June 2019. That may not seem like a lot but imagine if airlines broke or injured the legs of every 62nd passenger — the equivalent of 1.62%. Do you think they’d get away with that? Keep up with the stats yourself at transportation.gov/airconsumer.
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Three Fridas, One Vision
Mona Lisa in a power wheelchair. The Last Supper attended by people with an array of disabilities. The Girl With A Pearl Earring if she had a facial difference.

These are but a few of the reconceptions of classic works of art in Tres Fridas, a new show highlighting the lived experiences of people with disabilities and challenging modern ways of thinking about disability. The show, which debuted September 7 in Chicago, is the work of Reveca Torres, Mariam Paré and Tara Ahern, three talented female artists with disabilities.

Torres and Paré, who both have spinal cord injuries, met online over five years ago and quickly bonded over their shared artistic backgrounds, Mexican heritage and love of Frida Kahlo. They joined up with Ahern, a fellow Kahlo fan and a photographer with muscular dystrophy and scoliosis, to recreate Kahlo’s famous Dos Fridas, inserting themselves as the two Fridas. They came away from the project wanting to do more. “The experience moved us profoundly,” says Paré. “Our goal was to demystify disability and present it in a different way to the public — almost normalize it by putting it in a format people understand and including it in art history. ... This way, people can see the similarities that we share instead of our differences.”

The exhibition ran from Sept. 7-22 at Bridgeport Gallery, but Paré says the trio hopes to take the art on tour in the near future. You can follow the Tres Fridas Project on Facebook and Instagram at @TresFridasProject.

#IndependTips
Nobody is better positioned to share useful tips and resources for people with disabilities than people with disabilities. That simple philosophy underlies the daily IndependTips that nonprofit NMD United has been creating and sharing online since the beginning of 2019.

Each IndependTip takes the form of an easy-to-share video, infographic or image containing a short piece of advice or insight. From pithy to obvious to insightful, the IndependTips are all practical.

Just as NMD United is led entirely by people with disabilities, the IndependTips are brainstormed, polished and designed by NMD board members. President Emily Wolinsky says the IndependTips align with the organization’s focus on helping people with neuromuscular disorders. “We’re not looking for a cure, we’re looking for resources to be independent,” she says.

Wolinksy isn’t sure how or if the IndependTips will continue in 2020 but says the organization has considered publishing a daily calendar and a book. Search #IndependTips on any social media platform to get your fix and check out NMD United at nmdunited.org.

Drop something? Toss a handled bag on the floor, scoot the dropped object into it, and snag the handle with your reacher.
Barker Breaks Big

Vogue, the most influential fashion publication in the world, recently featured the multi-talented model, actor, activist — and wheelchair user — Emily Barker on its blog. Barker’s Instagram feed @celestial_investments may initially come off as any other showcase of the young, stylish and good-looking, but start reading the captions and you’ll find thoughtful content meant to challenge readers’ notions of disability. That, as Barker told Vogue, is by design: "We live in a culture that only values the way things look at this point, so being able to derive some content and meaning from that is important." You can also find Barker on The Death Panel podcast, which does regular deep dives into healthcare policy and the disability community.

Access Guru

Just a few years after helping found United Spinal Association’s Greater Philadelphia Chapter, Randy Duchesneau is taking his advocacy efforts to a different level as an accessibility specialist for the U.S. Access Board’s Office of Technical and Information Services. As one of four new hires this June, Duchesneau, a quad and power wheelchair user, is helping define accessibility standards and guidelines.

Duchesneau has a lengthy resume working on disability issues, but says he saw the new job as a chance to expand his knowledge base. “I wanted to learn more about what accessibility requirements were and to be in a position to help others understand as well,” he says. Since starting, he has been involved in discussions on access requirements for autonomous vehicles and voluntary guidelines for wheelchairs on airplanes. He has found the experience empowering and urges others to make their voices heard through official channels. “It’s one thing to complain about accessibility on Facebook, but it’s much better to have your voice heard in public comments or a forum where there is a chance for change.”

The Access Board is an independent federal agency that promotes equality for people with disabilities through leadership in accessible design and the development of accessibility guidelines and standards. Created in 1973 to ensure access to federally funded facilities, the Board is now a leading source of information on accessible design. The Board develops and maintains design criteria for the built environment, transit vehicles, telecommunications equipment, medical diagnostic equipment, and information technology. It also provides technical assistance and training on these requirements and on accessible design and continues to enforce accessibility standards that cover federally funded facilities. Learn more about the Access Board at access-board.gov.

Advocacy Matters

As part of September’s celebration of national SCI Awareness month, United Spinal Association rolled out four new videos highlighting the advocacy efforts of members from across the country. Filmed and edited by videographer Hannele Lahti, the short videos profile Washington member Kenny Salvini; Washington, D.C., member Shannon Minnick; Puerto Rico member Elvis Segarra; and Colorado member Quinn Brett. “I think the biggest misconception about people in wheelchairs is how people are thought of,” says Salvini, United Spinal’s Advocate of the Year. “You hear, ‘confined to a wheelchair,’ I’m not confined to this wheelchair. This wheelchair gets me out doing life and living a life I never could have imagined when I first got hurt.” To see the rest of their stories, visit youtube.com/user/UnitedSpinalTV.

Randy Duchesneau is working to improve accessibility at the national level.
BIRD IS THE WORD

Birdability founder Virginia Rose is passionate about birds, nature and the trails that lead to both, and she is certain there’s at least one disabled person like her in most cities. “If there is a me here in Austin, then there is a ‘me’ everywhere,” says Rose, a wheelchair user for over 45 years. “And so my big goal is to find the person in all of these places who can tell us where all those accessible places are.”

She’s off to an amazing start, having already identified 34 wheelchair-friendly trails for birdwatchers in Austin and roping in eight Birdability captains from Mississippi to Pennsylvania to find and document similar trails in their own cities. Plus, she regularly leads bird walks for disability groups in Austin and speaks at birding festivals around the nation about the importance of letting folks know what accessibility is already available.

Her four-prong approach is to identify:
1. Audubon members or other birders who have mobility impairments.
2. As many wheelchair-friendly areas to birdwatch as she and her captains can.
3. Other people with mobility impairments interested in birding who may never even have heard of the Audubon society.
4. The most accessible birding festivals with officials open to placing accessible bird walks on the schedule.

“If everyone knows those four prongs, they can start making their own to-do lists in their various worlds to make it happen,” says Rose.

She also has a seven-point checklist that purposefully falls short of ADA accessibility for people to use on trails in their own towns. “If we get into the weeds of having everything ADA accessible, we won’t get anywhere,” she says. “We can’t formulate ourselves into all these codes that are meant to free us that then end up restricting us. My philosophy is difficulty and uncertainty lead to empowerment and joy. I believe that so strongly with my heart and soul because I’ve lived my whole life like that and I’ve been in a wheelchair for 46 years.”

More information, including her seven-point checklist, are available at birdability.com.

MANU HERAS, INTREPID EXPLORER

In the past five years Manu Heras has hitchhiked, “front-packed” and van-camped through all the continents except Antarctica. “I’ve been in many wild and inaccessible places,” he says. “Once, in Panama, I heard there was an isolated and beautiful beach following a trail through the jungle, so I said to myself, go! The trail wasn’t too bad until I found a creek crossing the way. Still, I wanted to discover that beautiful beach, so I had to choose — go through that creek or follow the seashore and hope to pick up the trail. I ended up in the Caribbean pushing my wheelchair and trying to avoid getting my camera wet! After more than an hour in the water trying to find a clear spot in the jungle, I was able to get back on the trail and to the beach. Yeah! It was so beautiful.”

Here’s his kit:

- Thermarest NeoAir lightweight sleeping pad — “It’s comfortable and thick enough to avoid pressure sores and rest my body,” he says, although it’s a little narrow.
- Mountain Equipment Co-op backpack — “Nothing special,” he says, “I got it in a yard sale.” He carries two other bags on the back of his chair as well.
- A lightweight sleeping bag and lightweight three-person summer tent
- MSR WhisperLite International stove
- A pump water filter
- A portable toilet
- Travel hand controls, “plus tools, an extra inner-tube and extra bearings, a first-aid kit, some clothes and catheters — at least 40 pounds in my front pack!”
- And, of course, a FreeWheel.

His advice for anyone else wanting to travel extensively and as affordably as possible? “Don’t be scared — you’ll figure things out as they happen,” he says. “Just be patient, open, creative, flexible and a little bit ready!”

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

Acknowledgements on our website, in New Mobility, in United Spinal e-news or any other United Spinal publication should not be considered as endorsements of any product or service.
Stefan Henry grew up as a big fan of comics and animé, building Legos and yearning to follow in Tony Stark’s footsteps as the next Iron Man. A C5-6 SCI at 14 only increased his desire to build an exoskeleton, and today he lives a dual life that Stark would envy: CEO of an assistive device company by day, designer/inventor by night.

“I’m still designing my exoskeleton, but it’s something that will take a lot of time and money to build and in the meantime, I could be building things to help other people,” says Henry, an engineer by trade. The first of those things, funding his Tony Stark dream, is an eating tool meant to help those recovering from a stroke and those with low dexterity use utensils independently. There are countless other eating tools, but this one is meant to address frustrations Henry and his fellow quadriplegic Eli Ramos have with adaptive technology. “If they’re not an eyesore, they’re incredibly expensive for no reason — $60 for two slabs of metal put together. There’s never an in-between,” says Henry.

Together, the two founded Level the Curve to provide that holy trinity: adaptive technology that not only functions but looks good and is inexpensive. Their eating tool costs $25, is 3D print-on-demand and can be customized with any color. “Since we know the field first-hand, we care more about having all those three things together. Eli and I are both quadriplegics and we’re looking at our competition like, ‘We’re never going to buy this stuff.’ They’re too expensive, they break easily, and often you have to get someone to put them on you for you,” says Henry.

But just because they know the field and live the reality doesn’t mean investors are lining up. Henry, Ramos and their other co-founder, Henry’s nondisabled childhood friend Khan Sakeeb, are used
Henry breaks down the challenge of being a boss with a disability and the very different ways his disability is viewed by his team and by potential investors.

“It’s a funny duality. Among my co-workers, I’m definitely their boss. There’s a brotherhood relationship between myself, my engineers and our support staff. But, when you go out to get investors, you have to work twice as hard to make sure you and your product are taken seriously.

My company is very new. I’m new, and I can sense an instant twinge of judgment around my disability like, ‘He doesn’t know what he’s talking about. He’s just getting started and doing things because he thinks he can.’ I have to break that barrier.

A lot of these investors have been around for 20 years. They feel even though the people on our team have lived it, we haven’t designed enough tech. To really be taken seriously we have to go in there, present and show some of the engineering and whatever is necessary for them to believe us.

When we do, they’re completely shocked. You literally hear gasps. It’s funny. But we don’t get to see it enough because we’re often not even taken seriously enough to get in the door. We’re working on getting more people to realize who we are and we’re trying to take a grassroots approach.

‘“We get them to try it out, tell us whatever feedback they have and whenever they end up loving it, they just tell other people about it. We’ve really been as grassroots as possible, and so far we’re building a bit of a following,” says Henry.

It’s how they plan to keep going: take their products to hospitals and rehab centers and see if they’ll take it seriously. For anyone that does, they’ll be rewarded because Level the Curve is not a one-trick pony. The Eating Tool is only one of many products they have planned, including portable, telescoping ramps and a device for charging electronics.

“We’re working on this device we call Gia — after a god of energy — and what it does is hook up to your manual chair and when you’re rolling it will actually help you charge your phone or any device you put onto it,” says Henry.
Unfortunately, an active life on wheels can put more demands on the shoulders than they were designed for. Just as time, age and injury can cause ambulatory people to face knee and hip surgery, wheelchair users often end up with shoulder damage that requires surgery.

Fortunately, rotator cuff repair techniques exist and continue to evolve. A surgery developed in 2007 called SCR — superior capsular reconstruction — is able to mend many severe rotator cuff tears that previously would have been considered beyond repair. Before this discovery, severe tears required reverse shoulder replacement. RSR is a complex surgery that generally limits wheelchair users to a power chair, as it is unclear how long the materials used to reconstruct the ball and socket would last under the rigors of pushing a manual chair. Also, a recent study reports higher complication rates from RSR for wheelers than the general public.

As the lifespans of people with spinal cord injury become more comparable with the general public, surgeons are becoming more creative with shoulder restoration. Regardless of the type of repair, recovery is a long and arduous process. It starts with no weight bearing — pushing and transfers — for 10 weeks to six months. Then the real work begins, rebuilding muscles strengthened by years or decades of daily activity that had quickly atrophied during the post-surgery rest period.

Here is a look at shoulder surgery rehab from the experience of four wheelchair users, along with a clinician’s explanation of the process. All four had over 30 years on wheels and diligently maintained their shoulders in hopes of countering the added wear and tear of their active lifestyles, but still found themselves facing surgery. Although three of the surgeries were SCRs and one was a unique “save” where the only viable tendon was the infraspinatus, they all had similar recovery experiences.

“Unfortunately, surgery is the easy part,” says Erica Platil, a physiotherapist, PT assistant, and certified athletic trainer who works in Denver, Colorado, and has over 30 years in the rehab field. “Rotator cuff surgery rehab generally takes about a year for maximum recovery.”

**DIAGNOSIS AND SURGERY**

Bill Bowness, 60, in his 42nd year as a T12-L1 para, is currently rehabbing his third rotator cuff repair. His right rotator cuff was done in 2015, and his left in 2017. “My right shoulder started acting up again, especially during transfers and/or lifting my arm up. It got to the point that it hurt so much that it was time to get it fixed,” says Bowness. He went under the knife earlier this year to repair a full-thickness, medium-sized tear of the supraspinatus tendon — the tendon that runs on top of the shoulder and is responsible for lifting the arm. Due to the severity of the tear, Bowness’s surgeon chose to perform SCR, which reinforces the repair with some type of graft. In Bowness’s case, that meant a tendon from a cadaver sutured into anchors drilled into the shoulder bones.

“Over the years, my right shoulder started hurting and aching more and more. It finally got to the point where it was so bad I couldn’t sleep at night, and I couldn’t lift my arm up over my head,” says Doug Garven, 52, in his 30th year as a T6 para. An MRI diagnosed a complete tear and retraction of his supraspinatus. Garven’s surgeon was able to reconstruct it using the SCR technique. “My surgeon said a repair for this type of injury usually takes about 45 minutes, but mine was so bad it took him two hours.”
The Stages of Healing

Understanding the three post-surgery phases of healing and what is going on in the body during each can be helpful says PT Erica Platil:

- The first three weeks post-surgery are known as the inflammatory phase as inflammatory cells multiply around the surgery site. During this phase, the arm is still in a sling and movement is limited to using a squeeze ball, and some neck and scapula stretches.

- The repair phase, also known as the proliferation phase, starts around week three or four. In this phase healing cells rapidly multiply and start rebuilding around the repaired area. This is also where gentle range of motion is started.

- The third phase, the remodeling phase, starts at around six weeks, around the time the arm is released from the sling, and therapy begins to include more ROM and lifting light weights. In the remodeling phase, scar tissue forms and matures, reaching maximum repair strength at about 12-16 weeks after surgery.
“My right shoulder had been bothering me for a while,” says Matt Feeney, 56, in his 31st year as a T9 complete para. “One night I went to transfer from my bed to my chair and the shoulder collapsed. I had intense pain on the head of the shoulder and it shot down my arm, and all the strength just went out of it.” He managed to get into his chair and his roommate helped him transfer into his car and get to the emergency room. The ER doc examined him, suggested a workup with an orthopedist and gave him painkillers that enabled him to finagle slow and difficult transfers. “By the next day I was able to transfer but I didn’t have any lateral strength,” he recalls.

Feeney underwent SCR reconstruction surgery to repair a full-thickness retracted tear of the supraspinatus tendon and also a full-thickness tear in his infraspinatus tendon. “My surgeon said I really did a number on my shoulder, and he had to do some extensive work to put it back together.”

“My left shoulder had started to ache as years went by,” says Don Lively, 58, in his 38th year as a C7 quad. “One day I was getting out of the pool and something popped. It felt like somebody stabbed me in the shoulder, and the pain radiated down my arm.” Lively couldn’t lift his arm to shoulder height and he had to hold his body at an angle to prevent the shoulder from pushing out of the socket when wheeling up a slope. In 2011, an MRI showed all of his rotator cuff tendons except for his infraspinatus tendon — which attaches the muscle of the shoulder blade to the top of the shoulder — were beyond repair. However, because Lively didn’t have much arthritis, his surgeon felt that even with one fixable tendon, his biological joint would last longer than the only other option, a reverse shoulder replacement. Lively agreed, and his surgeon deftly rebuilt what he could with the infraspinatus.

THE RECOVERY

Perhaps the toughest part of rotator cuff repair is immediately following surgery. For six weeks, your arm must be completely immobilized in a sling with an abduction pillow. At around two weeks, under the careful guidance of a therapist, your arm can be taken out of the sling to hang and do slow circles. Around week three or four, the therapist will carefully guide you through range of motion exercises and slowly build to you performing ROM under your own power. At the six-week mark, the sling can come off and muscle building can gradually start, under guided therapy.

All four people I spoke with said that while using a sling they needed assistance to sit up, dress or change positions. Garven and Bowness had arranged to borrow power chairs and Hoyer lifts, and since their wives are both physical therapists and able to assist them, both were able to go home the same day as their surgery. Lively spent three days in the hospital, a week in a rehab hospital and then returned home. His insurance rented him a Hoyer lift and hospital bed and he was fortunate to have the resources to pay out of pocket for an attendant to come in every morning to help with bathroom duties, showers and getting dressed. “Our house is flat with smooth floors, so I chose to stay in my manual chair and use my good arm to get around,” he says, adding that he used an “alternating wheel push” until he healed. His wife Gail, a C5 incomplete quad, was able to use the Hoyer lift to get him into bed and undressed in the evening.

Feeney’s acute rehab was the toughest. Medicare and Medicaid covered his power chair rental and a stay at a skilled nursing facility. After visiting four SNFs, he found one that looked great and assured him it would secure an air mattress to prevent pressure injury before he arrived. It didn’t.

He was still on heavy pain killers when he arrived at the SNF and was placed on a firm mattress. It took four days before his air mattress arrived. When it did, it was incorrectly assembled, resulting in motor failure that rolled Feeney, in slow motion, onto the floor — on his good shoulder. “After 10 minutes of hitting the call button and yelling, I used my...
cell phone to call the front desk for help,” he says. The events caused a pressure injury on his tailbone. He called a wound-care rehab and was admitted the next day. “The lesson I learned is to have a friend or family member as a medical advocate, and have them frequently visit, especially if you’re going to be on pain medication,” he says.

For wheelchair users, the big question following rotator cuff surgery is when they can start weight bearing and working on transfers. “This is another gray area and varies from surgeon to surgeon, as well as with each therapist,” says Platil. “Because the healing peaks at around the four-month mark, waiting until then to begin transfers offers the least risk for re-injury, especially if you fall and have to catch yourself with your repaired arm.” Both Feeney and Lively were cleared to use a transfer board and then slowly start working on independent transfers at 10 weeks. Bowness’s surgeon is more conservative and told him “no transfers for four months.”

Garven’s surgeon said “absolutely no pushing your chair and no transfers for six months, and that goes for small tear repairs as well as major ones!” At first, Garven thought that was too long, but it turned out to be great advice. “Within the first week of going back to my manual chair I flipped onto the floor and I had to climb up my shower bench to my chair — exactly what the doctor said not to do. I was terrified I might have re-torn my shoulder. It turned out to be OK, but I’m very glad I waited so long. I can’t imagine if this had happened at the three-month mark.”

REBUILDING MUSCLE

“Unfortunately, muscles atrophy fast,” says Platil. “By the time a wheeler’s shoulder repair is cleared for transfers, they have a long, slow, steady road of work to rebuild strength. In general, it takes about a full year to get back to the level of function — pushing and transfers — prior to surgery.” Both Lively and Bowness say the “full-year to gain maximum function” is right on the mark.

“At the four- to six-month mark, I usually work with them twice a week and have them do their prescribed PT exercise — 15-30 minutes of rehab exercise — on a daily basis,” says Platil. She adds that wheelchair users in shoulder recovery should do prescribed rehab exercises, but no more and no harder than prescribed. Prescribed harder workouts like handcycle or strength training are limited to three days a week max. “Doing additional workout will not speed things along but is likely to set a person up for re-injury because as a wheelchair user you are always using your arms so there is no time for them to rest, and muscles need to rest to rebuild.”

Bowness feels this may be why his first shoulder repair needed to be re-done in four years. “I probably pushed into transfers and then sports too early, which is likely why I re-tore it a second time,” he says.

“A difficult thing to remember, something which is often very frustrating, is it takes about six weeks to build up muscle, and it isn’t linear — sometimes it builds, or it may plateau for a bit,” explains Platil.

In addition to patience and perseverance, body weight becomes a factor, especially in transfers. It helps if one is able to get their weight down before and while recovering from surgery. Lively kept his weight at a svelte 130 pounds, which probably enabled him to do car transfers a quick four months following his surgery. “And still, I ended up on the doorsill of the car the first time I tried it,” he says. “To this day my left arm is a little weaker, but I do have full range of motion. I can lift my arm over my head, transfer and push my chair, so it is pretty good.”

“By the six-month mark, when I was cleared to go back to my manual chair and work on transfers, my shoulder was really weak,” says Garven. “And using a power chair for six months caused me to gain about 15 pounds.” He was able to do sliding board transfers right away. And now, seven and a half months post-surgery, he is able to do transfers to his car, bed and shower bench with no sliding board. “At this point when I do a transfer, it feels like I weigh 500 pounds.”

Garven’s big goal now is to build his strength enough to transfer in and out of his beloved ‘74 Porsche Carrera, as well as in and out of his handcycle.

LIFE GOES ON

“This whole process has been an exercise in patience, and I’m finding out I have a lot more patience than I thought. But right now I feel like I’m running out,” says Feeney. At eight months post-surgery, he can do a lot of his own transfers, but still needs a sliding board for some, like chair-to-car. Feeney also laments putting on weight during rehab. “I probably gained 15 pounds — I’m the heaviest I’ve been since I was injured.” He can do a 20-mile handcycle ride, but still needs help getting from his handcycle into his chair. “I’ve come a long way, but it’s frustrating. I feel like I plateaued in the last month. I’ll keep doing what they tell me to do and hope I make a breakthrough in the next few months, but there is a little concern here.”

Bowness found that following all three shoulder surgeries, by the time he was released for transfers his shoulder had atrophied. “I’m 16 weeks post-surgery, and my shoulder is doing fine, but it is super weak,” he says. He is pushing a manual chair but still has to use a sliding board for transfers. On his first two surgeries, his shoulders came back good and strong but not as strong as before the surgery, he reports. “This time I’m going to make sure I’m 100% before decide to get back to sports. I’ve been through this three times, and I’m here to tell you, there is a full life after shoulder surgery.”

RESOURCES

- A Non-Surgical Option For Shoulder Repair, newmobility.com/2015/07/non-surgical-option-for-shoulder-repair
- Shoulder of Fortune: Surviving Shoulder Surgery, newmobility.com/2017/08/shoulder-surgery
- Shouldering the Load, newmobility.com/2005/09/shouldering-the-load
- Total Shoulder Replacement in Wheelchair Users, newmobility.com/2015/09/shoulder-replacement-wheelchair-users
I knew my six months of being sentenced to strict bed rest before, during and after flap surgery, doing everything 24/7 from bed — including eating, peeing, pooping and working at my computer — would be difficult. But I wasn’t prepared for what happened at the end of my sentence when I attempted my first transfer out of bed.

As I pushed off from the mattress, both arms and shoulders instantly gave way, as if I had gained 100 pounds overnight. The pain tore at my shoulders and torso, and waves of wooziness threatened to take me down. I landed with the middle of my back on the very front of my ROHO cushion, my butt hanging way below in a half-reclining position, clutching the tubing of my chair, hanging on for dear life.

My wife and daughter frantically pulled, pushed, lifted and clawed at me, barely managing to hold me in mid-transfer, but their combined strength could only be sustained for another minute or two. I had to muster my strength to help, regardless of the pain. Giving up would mean dropping to the floor, with no one else to help, no Hoyer lift to pick me up, and possible damage to the tender transplanted flesh that covered my left buttock, which had been remolded during my flap surgery.

I grimaced and pushed up with all my might. The pain intensified and I began to feel nauseous. Gradually, with help, I managed to inch my way up, resting my lower back partially on the cushion. I took deep breaths to fight off nausea and gave it another try, but only gained a few inches. I tried again.

This time I made it to safety, with my butt partially on the cushion. But the cushion, a ROHO high profile, had rolled back, making sitting there impossible. With better handholds on my wheels, once again I pushed up while my wife and daughter struggled to unroll the front of my cushion and lay it flat. With their help, I completed the transfer. Then I hung my head, resting and bearing the pain.

You would have thought I had just completed the most challenging American Ninja Warrior obstacle course of all time, not a simple bed-to-wheelchair transfer.

The Days of Small Gains
Six months of bed confinement may be necessary for flap surgery, but it is hell on muscle wasting, not to mention posture, which it turns out is more important than I could have imagined. I had a long way to go to regain my strength, range of motion, coordination, technique and freedom from pain — all of which was necessary to reclaim reasonable quality of life for a 73-year-old man with 53 years of wheelchair life behind him. My first priority was to regain the range of motion I had lost in my arms and shoulders, critical for transferring and wheeling.

A decade or so earlier, I had managed to avoid shoulder surgery when I sustained a moderate rotator cuff tear. It took three months of physical therapy and another three months of stretching, home exercises and light weight lifting. Had the rotator tear been severe, surgery would have been much more likely. Drawing on that experience, I felt confident that a similar course of action would be needed to recover from bed confinement.

Since I was technically homebound, Medicare paid for a physical therapist, Melissa, to treat me at home. In our first session, after she helped me with a shaky transfer, she examined me in my chair. My right trapezius (the muscle that slopes down from neck to shoulder on both sides), where the pain was most intense, had noticeably atrophied. I looked lopsided, as if the muscle had disappeared. My left trapezius was less painful and looked OK by comparison. All of this was no doubt due to having to lie on my right side for several months. Melissa offered a temporary diagnosis of damage to the right spinal accessory nerve, which originates at the base of the skull, travels down the neck and innervates not only the trapezius but the rotator cuff muscles. On my right side I also had adhesive capsulitis, commonly known as frozen shoulder.

She suggested that I get a nerve conduction study done to validate her diagnosis as soon as I was able to leave the
house. In the meantime she gave me several stretching exercises to do while in bed, where gravity was minimal and pain not as severe. Going slow, everything in moderation, was best so as not to further inflame the damaged areas. Repetition was the best course of action.

While sitting in my chair, at first I worked on posture — sit straight, shoulders back, gradually lift my head and try to stare at the ceiling (not easy after six months in bed). I also did multiple reps of shoulder shrugs (I had never thought of shrugging my shoulders as exercise, but it was a non-stressful start to build back my trapezius muscles over time). Holding my arms straight out in front of me and lifting them as high as I could was much more difficult than in bed, more painful, more limited. Wall-walking helped: I positioned my chair near a doorframe and tried to walk my fingers up the wall, keeping my arm straight, as high as I could. The doorframe helped support the weight of my arm. The goal was to increase the height slightly each day but stop when I started feeling pain. Eventually, over several weeks, I gained some range of motion while sitting, first by wall walking, then by gradually lifting my hand off the doorframe. At this point I started working with bands, doing light strengthening exercises.

A LONG SIX MONTHS
Once I was no longer homebound, the nerve conduction study confirmed the spinal accessory nerve damage. Next, a physiatrist examined me and wrote a prescription for specific physical therapy work at a local gym. By this time I was transferring with extreme care and wheeling better but had to have someone drive me to PT appointments since transferring into my stock minivan had become impossible.

At the gym, Kyle, my new PT, pushed the limits of my range of motion in both shoulders while I lay on my back each day, being careful not to inflame my injured and atrophied muscles. Increased range of motion was first priority, to be followed by strength training, culminating with increasing the weights, week by week, for a total of about two months.

In the gym I warmed up with stationary handcycling (cycling in reverse to strengthen previously under-used muscles) and worked on strengthening rotator cuff muscles, pectorals and more strenuous trapezius work.

It took six months to get back almost all of what I had lost, first with light stretching in bed, then stretching while sitting in my chair and doing light band work, and finally with physical therapy and working with weight machines in the gym. To this day, more than a year after that first painful transfer out of bed, I am still trying to get back the full range of motion and strength I had prior to my flap surgery ordeal, but I am mostly pain-free and independent again.

I have learned the importance of regular stretching, exercising and not spending long stretches of time in front of a computer, no matter your age. And I will do everything in my power to avoid being sentenced to another term of bed confinement.
On the walls of the second floor conference room of Access Living, Chicago’s independent living center, are eight staff pictures from throughout the center’s nearly 40 years of existence. The staff gathered every five years from 1980 through 2015 for a group photo. The only person in all of those photos is Marca Bristo.

Bristo was the leader of Access Living — most recently holding the title of president and CEO — from the day it opened in 1980 until she resigned for health reasons the week before she died on Sept. 8 at age 66. In 2017, she was diagnosed with cancer.

Her impact and influence stretched way beyond Chicago. The mayor of Chicago, the governor of Illinois, both Illinois U.S. senators and members of Congress, including Speaker of the House Nancy Pelosi, put out statements of condolence. Former U.S. Senator Tom Harkin of Iowa talked about Bristo’s life and legacy on the PBS national news program NewsHour. Former President Barack Obama said in a statement, “Marca had a remarkable way of bringing out the best within us. For me, she was a trusted voice and a persistent, buoyant spirit.”

A Leader From the Beginning

On a summer day in 1976, Bristo was hanging out with some friends on a pier on a beach in Chicago when a dog knocked her shoes into Lake Michigan. Bristo dove in to retrieve the shoes, hit bottom and broke her neck. From then on she used a wheelchair full time.

Access Living was one of the first CILs in the U.S., so even though Bristo was only in her 20s and had worked as a nurse before her injury, she was suddenly a key leader in the fledgling independent living movement. The original location was in a storefront, but in 2007 Access opened the four-story building in downtown Chicago that was designed, built and financed by a team Bristo organized. This transformation illustrates Bristo’s leadership style.

Playwright and author of the novel Good Kings Bad Kings Susan Nussbaum is one of the people in the first Access Living staff photo. “A lot of people helped her of course, but I can’t imagine anyone else that could go the distance and build Access Living from a tiny storefront to a huge deal that rescues so many lost people, like I was,” she says.

Nussbaum became a quad in 1978 when she was run over by a car. She met Bristo a year later at the Rehabilitation Institute of Chicago. “Even as a cripple, she looked cool and beautiful, which kind of annoyed me. I was still in that lumpy, inert stage of rehab. A year later, I heard that a disability rights organization starting up and Marca was in charge. I immediately called her and asked for an interview. When I came in the door, I looked around that little storefront, with crip working away at various projects, and recognized them as my community. I
thought, ‘I don’t have to feel self-conscious here. I fit in.’ It was a floaty feeling, like a heavy weight off my shoulders.”

Bristo was that escort into the disability community for thousands of people. She recruited politicians, philanthropists and business leaders to support Access Living and its building project and to serve on the board and committees.

Bristo co-founded the National Council on Independent Living and was its chair for many years. President Clinton appointed her chair of the National Council on Disability in 1994, and she served until 2002. “I will remember Marca for a lot of reasons,” says Kelly Buckland, executive director of NCIL. “But the one that most often comes to mind was my first NCIL conference in 1989. Marca was president of NCIL and led a march on the White House to get President George H.W. Bush to support the ADA. That led to a meeting between the NCIL leadership and the White House the next morning, and eventually led to White House support for the ADA.”

**Bristo was deeply committed to advocacy, and she knew that successful advocacy works on many levels.**

Threading the Advocacy Needle

CILs are supposed to be all about serving and empowering the grassroots. Activists, including those of us who founded Chicago ADAPT, met and organized at Access Living and still do. That often put Bristo in the middle of tensions, with activists nurtured and supported by Access Living protesting against the powerful people Bristo was trying to charm.

Bristo was deeply committed to advocacy, and she knew that successful advocacy works on many levels. In an interview with New Mobility’s Josie Byzek that appeared in *Mouth* magazine in 2000, Bristo said, “Voluntary compliance only goes so far. Deeply-rooted patterns of discrimination require both a carrot and a stick. If there’s no consequence for violating the law, people will go on violating it.”

So while Bristo developed personal relationships with and won the genuine respect of powerful and influential people, Access Living earned a reputation as a CIL with strong and effective advocacy that would engage in lawsuits, street protests or whatever tactics would win.

Amber Smock, who is deaf, is Access Living’s director of advocacy. She says, “While a lot of people felt Marca was intimidating, I knew her as a warm and generous and fun person. Yes, she could have high expectations and she would let you know if you didn’t meet them. But she was wise enough to both be challenging and to be challenged. She had great conviction that what she was doing was the right thing and it could be very uncomfortable to disagree with a person who had such a proven track record. But she could still hear you and was willing to take guidance and change tack. She still respected and loved you as a person. And when push came to shove, she’d take great risks with you right by your side.”

Smock says, “She had very broad shoulders, literally and metaphorically. I leaned on them, as did everyone. Her loss means I need to stand on my own and let other people lean on me.”

Bristo met her husband of 32 years, Bob Kettlewell, when he was a staff member for former U.S. Congresswoman Cardiss Collins. Bristo and Kettlewell had a daughter, Madeline, and a son, Sam. Madeline gave birth to their only grandchild, Beatrix, in July.
Brook McCall is weighing her options. She is worried. Seventeen years ago when she left Craig Hospital with a C4 SCI from a fall, she had been told, almost as an afterthought, that she had a small, bubble-sized cyst just above her C4 damaged cord, and that it would be a good idea to keep an eye on it, as if that is even possible. Odds are it would not be a problem, they said, but scar tissue from the injured cord can cause tethering, sometimes giving rise to a cyst, also called a syrinx, which can trap cerebrospinal fluid and expand, sometimes climbing higher in the spinal cord. While tethering, also called adhesions, in various degrees occurs in virtual all SCIs, when a cyst forms and traps CSF, it’s called syringomyelia, which affects an estimated 10% to 20% of SCI survivors. Serious complications can follow.

Eight years later, McCall noticed that one of her eyelids began drooping intermittently. Was this a sign of Horner’s syndrome, a symptom of syringomyelia she had been warned to watch for? A drooping eyelid may seem like an unlikely symptom related to spinal cord injury or disease, but it is a symptom nonetheless.

“I went to a neuro-ophthalmologist in San Diego,” she says. “He said it was ptosis, the medical term for drooping eyelid, and nothing to worry about. I wanted to believe him, but as the drooping came and went, I knew it wasn’t normal. I mentioned Horner’s syndrome and my cyst to every new physician I encountered, but it was always casually brushed off. I stopped asking after one blankly said, ‘Horner’s syndrome! That’s really serious, you don’t want that.’ He was right, but I tried to let it go.”

Following spinal cord injury, most of us who are paralyzed think in terms of what has been lost below the level of injury. But what is more worrisome is the possibility that damage can also go the other way, ascending to higher levels in the cord, resulting in possible additional motor and sensory loss, increased spasticity, pain and more. Worse yet, it can happen years after the initial injury.
A small cyst in Brook McCall’s spinal cord has left her looking for answers.
Four years passed with no changes, but the thought of Horner's syndrome stuck in her mind anytime she felt pressure on her eyelid. Not long after that she went back to Craig Hospital for a reevaluation. "I requested an MRI, but they didn't think it was needed. That year I went from having little to no pain to having severe low and mid-back pain with intense spasms and stiffness. I went to Oregon Health Sciences University and got opinions from two different neurosurgeons.”

She had two MRIs and a CT scan. "The first neurologist told me it would not be worth it to work on me because he wasn't concerned about what I had to lose because of my limited function as a high quad. I told him, 'How dare you say that? I have a lot to lose.' But he really didn't care."

The second neurosurgeon was more compassionate. "He said it looks like I needed to have untethering surgery and drain the syrinx in order to preserve what function I had. If I ignored it, symptoms other than Horner's syndrome could possibly come into play — further loss of motor and sensory control, more pain, more stiffness and spasticity." The syrinx had moved and expanded, and McCall had seen the MRI films. "It was upsetting to look at," she says. "The cyst was small at first, but it had moved up a full vertebra, then narrowed and went all the way to my brainstem. It was a hard conversation to have."

After a good deal of consideration, she decided to go back to Craig Hospital, have another evaluation and see Dr. Scott Falci, a respected neurosurgeon with well over 1,000 untethering/syrinx surgeries. His initial assessment was that she is not in immediate danger, but she is still uncertain about how she will proceed. In recent months, the stiffness, pain and spasticity have increased dramatically, and the thought of a fluid-filled cyst expanding near her brainstem is a constant worry. Although Falci can't predict what the specific outcome of surgery may be, he claims to have a 90% success rate at stopping further expansion of the cyst, at least.

**Loss of Strength: A Major Symptom**

Kent Petersen rehabbed at Craig Hospital but didn’t see or hear of Falci during his initial stay. At the age of 58, he injured his spinal cord at the T7 level in a serious skiing accident that also broke ribs, punctured a lung and fractured his neck. "I was an all-out skier, hauling ass when it happened," he says. Fortunately, there was no damage to his spinal cord from the neck injury.

Almost two years passed before he started noticing he was losing strength in his left arm and hand. "It was a gradual loss over a few months, but when it got to where I couldn't write, I contacted Craig Hospital and went in for an evaluation. I had no idea what it was. It was a scary proposition."

They did an MRI on his torso, neck and head. That’s when he met Falci. "He said it was a problem with adhesion — scar
Dr. Wise Young on Syringomyelia and Untethering Surgery

Tim Gilmer: Do you agree that many doctors are still not truly knowledgeable about untethering?

Wise Young: Yes, true. There is a saying that old ideas die with the people who hold them. In other words, few people learn new ideas or change old ideas.

TG: I see uncertainty and lack of widespread knowledge about untethering and syringomyelia among SCI survivors and many doctors. Why?

WY: A number of misleading theories concerning syringomyelic cysts dominated neurosurgery for a long time and are still being taught. Many of these theories stem from the assumption that syringomyelic cysts are solely a pressure-induced phenomena. It wasn’t until the 1990s that the first MRI flow scans showed cerebrospinal fluid flowing inside syringomyelic cysts. This suggested that the cysts resulted not only from pressure but obstructed CSF flow due to adhesions. Once this was accepted by some neurosurgeons, it became clear that this was why decompression of syringomyelic cysts alone had such high failure rates. The answer was not to relieve that pressure in the cysts but improve CSF flow in the spinal cord.

TG: What about the difficulty in identifying and differentiating symptoms?

WY: Ascending loss of function occurs only when there is sudden occlusion (and pressure) built up in the syringomyelic cysts. Most of the time, the cysts grow so slowly that there are little or no symptoms. Before the advent of widespread spinal cord MRIs on people with SCI, syringomyelic cysts were relatively rare clinical occurrences and not detected until the sudden pressure induced enlargements of cysts. Today syringomyelic cysts are often detected incidentally on MRI scans when other symptoms require MRIs of the spinal cord.

TG: What about prognosis? Many different outcomes seem possible.

WY: Prognosis depends on the nature and extent of obstruction of the cerebrospinal fluid flow. Most people, including doctors, do not realize that the choroid plexus in the fourth ventricle makes about 2 liters of CSF a day, half of which goes rostrally (towards the head) and half of which goes caudally (towards the tail of the spinal cord). I think that prognosis is quite poor when surgery only decompresses the syringomyelic cysts without removing all adhesions and restoring CSF flow in the spinal cord.

TG: Why do you think people with syringomyelic cysts sometime find it hard to choose surgery? Is it because results are not always definitive or lasting?

WY: People with syringomyelic cysts are receiving conflicting advice, some of which is wrong.

T"People with syringomyelic cysts are receiving conflicting advice, some of which is wrong."" 

WY: People with syringomyelic cysts are receiving conflicting advice, some of which is wrong. As for results not always lasting, this is true of decompressive and shunt surgery by itself. However, untethering surgery that restores CSF flow by removing all adhesions is usually successful.

TG: What is needed to diminish uncertainty and promote knowledge about this field?

WY: Neurosurgical societies should form committees of experienced surgeons to recommend the best practice. It may be useful to establish a registry of syringomyelic cyst surgery and their outcomes. Currently there is no effective non-surgical treatment.
tissue adhering to the dura,” the outermost covering of the cord. In other words, he had a tethered cord. Petersen had never heard of it. It turned out there was also a small cyst above T7 that needed a self-dissolving shunt to drain.

“I was kind of complacent about the surgery, probably because I’d had a number of surgeries,” he says. “I thought I could handle it without a problem. I tell you, the surgery kicked my ass. I woke up in a lot of pain and extreme disorientation. I think the drugs were still affecting my state of mind. The nurse told me the next day, laughing, ‘you were pretty certain you were going to die.’”

Today, two years following his untethering surgery, he’s glad he went through with it. “Smart thing I took care of this,” he says. “I totally trust the people at Craig.”

Prior to the surgery he also had pain in his left arm and hand. There has been little change in pain since then, but he’s OK with it. “The good news is I have recovered the strength I lost. In fact, I’m stronger now than I’ve ever been since the accident. The main thing I was afraid of was loss of function. From that standpoint, the operation was a complete success.”

Loss of Sensation

While snow sledding in 2005, Dave Denniston, an NCAA champion swimmer who just missed out on the 2004 U. S. Olympic team, hit a tree and sustained a T10-11 SCI. Two years later he started having pain and numbness. “It started in late 2006, pain when I sneezed or coughed. A sharp pain followed by momentary numbness. Seemed like every time I did this, I felt the pain go a little higher on my left side.” At the time, he had made the transition to Paralympic swimming and was in training for the 2008 games in Beijing, so his main concern was that motor loss might follow the pain and loss of sensation.

“I went to a neurosurgeon. He thought it might be cancer in my cord and wanted to take a biopsy from my neck. I said I’ll pass and began looking for a second opinion.” He found Dr. Ulrich Batzdorf at UCLA, a well-known neurosurgeon, who diagnosed it as syringomyelia.

Batzdorf supervised the surgery in August of 2007. “They did some untethering, drained the cyst and reinforced the cord with GORE-TEX sheathing for protection. Whatever they did, it must not have been enough. Also, I might have pulled a bonehead stunt by pushing myself more than I should have when I returned to training. Too much exertion might have been a factor.” In late 2007 symptoms returned — pain and numbness on his left side. Fluid was still finding a way to get trapped in the center of the cord.

“I was afraid I might lose all sensation on my left side and end up like a stroke victim, so I went to Dr. Scott Falci at Craig. He said the cyst had moved from T10 all the way up to C4. It was frightening. I saw the images myself,” says Denniston. “It went all that way and was about the diameter of a pencil before it was drained and released.”
In April 2008, Falci did a second untethering surgery and inserted a shunt to keep the CSF flowing. "After the surgery I was in a lot of pain, a kind of radiating ache in my body. It maybe lasted about a week." After the pain subsided, Denniston was able to return to training, and over the next two months Falci did two follow-ups and another MRI. "It all looked OK. I had some muscle tightness in my back but worked it out with massage and exercise."

It took about four months for Denniston to recover. He competed in the Beijing Paralympic Games in September 2008. "Now I'm great, pretty much normal, lost just a little bit of sensation on my left side. I have to be careful when I grab stuff with my left hand out of the microwave, that kind of thing. But no usage problems. I lost a little in my stabilizer muscles on my left side, so it affects my posture and stability in a minor way. What I feel most is fatigue there sooner than other places. No one would ever notice it, just something that I feel. I've been pain-free for more than a decade now."

Now Denniston is head coach of the men’s swim team at the University of Wyoming. He and his wife live in Laramie, Wyoming, not far from the site of his sledding accident. He has been pain-free for over a decade, thanks to untethering surgery.

"The cyst had moved from T10 all the way up to C4. It was frightening. I saw the images myself."

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has learned to stress the importance of recovery time for his swimmers. “Allow time to let your body recover. I preach that a lot.” He still swims regularly.

Breathing Problems and Pain

A year after Ali Ingersoll sustained a C6 SCI from a shallow diving accident in the Bahamas, an MRI showed a syrinx near the injury in her spinal cord. If the fluid-filled syrinx moved higher, say to C4, it could result in breathing problems. If that happened, would she ever be able to regain what she was likely to lose?

Concerned about losing function, she spoke with multiple surgeons, including the Miami Project’s Dr. Barth Green, a leading expert, but didn’t find any who thought she was in immediate danger. Because of the high risk of the surgery, no one wanted to surgically intervene.

Ingersoll and her family disagreed and began searching for alternatives. Her father, with a background in science and ever the diligent detective, met Dr. Wise Young of Rutgers University, a global leader in the field, who facilitated a trip to China to observe a spinal surgery. The neurosurgeon was Dr. Lansheng Liu, who Young enthusiastically endorsed.

Ingersoll and her family moved to China to begin planning the removal of her syrinx at Tongren Hospital in Kunming, where Liu was the lead neurosurgeon. As an added benefit, Tongren Hospital was one of the sites conducting an experimental locomotor-based walking program, and Ingersoll would be able to participate after her surgery. Ingersoll also hoped the surgery would relieve her moderate to severe neuropathic pain.

When they got settled in Kunming, her symptoms got worse. “Within about two or three weeks of our arrival, I was on oxygen for most of the day and afraid it could get worse,” says Ingersoll.

The surgical team, led by Liu, had to perform a triple laminectomy.
nectomy just to gain access to the problem area. It isn't unusual for untethering/syrinx surgeries to take up to 10 or 12 hours, but the highly experienced Chinese team completed the operation in less than half that time.

After recovering from her surgery, she began the walking program, but on the first day of standing in a walker, aided by helpers, she experienced severe autonomic dysreflexia. Tests discovered fractures in her femur and tibia — her walking program was over before it got started.

The good news is she is happy with the results of the untethering surgery, calling it "a net-net success." No more breathing problems. On the pain front, however, more disappointment. "No change in neuropathic pain," she says, "plus I ended up with persistent chronic pain in my neck." (For more on Ingersoll's experience, see her story on page 34.)

McCall, Petersen, Denniston and Ingersoll each had different symptoms — a drooping eyelid, stiffness in the back and neck, increase in spasticity, loss of strength, loss of sensation, breathing problems and pain — which can diminish, linger or sometimes increase following surgery. Their combined stories serve as an example of how confronting worrisome symptoms, rather than downplaying or ignoring them, is a smart course of action. No one wants to lose more function than they lost at the time of injury.

Since we are entering a time of greater understanding of how the spinal cord can regenerate and damage can be reversed, syringomyelia may soon be a problem of the past. And there is even more reason for hope. Recent research has shown that untethering — when no syrinx has formed — may actually help restore some functions that were lost at the time of injury.

Opening Up New Possibilities

When untethering was included in clinical trials at Tongren Hospital in Kunming, China, where Ali Ingersoll had her surgery, surprising results occurred. The trials, organized by Young (results published in 2016), combined implantation of umbilical cord blood mononuclear cells followed by intensive locomotor training. This resulted in return of limited walking function for some. Surprisingly, some participants also regained bladder and bowel function. Moreover, a sub-group that included untethering surgery showed an even greater percentage of participants who regained bowel and bladder function.

A more recent follow-up trial in Kunming, as-yet unpublished, focused on untethering surgery and locomotor training with no cell implantation. The official data for this latest study is not yet available, but Young has told New Mobility that 80% of the untethered subjects regained bladder and bowel function, and many of them now no longer use catheters. "Bowel and bladder recovery appear to be a result of locomotor training increasing the excitability of the lum-
bosacral spinal cord,” says Young. “Untethering surgery appears to help increase the incidence of bowel and bladder recovery. This is, to my knowledge, the first study to show that untethering surgery will restore bowel and bladder function if it is accompanied by intensive locomotor training. The untethering surgery is actually more than just removing adhesions. All causes of compression and adhesions were removed. The goal of the surgery was to restore pulsatile cerebrospinal fluid flow in the spinal cord.”

Up to this point, Young’s research has concentrated on umbilical cord blood mononuclear cells. It is notable that Young is no longer characterizing cell transplantation as necessary to recover function. He has now become an advocate for intensive locomotor training — six hours a day, six days a week, for six months. He refers to this as the 6-6-6 program.

From a practical perspective, however, intensive LT requires a substantial investment of time, energy and total commitment, as well as funding. Outside of clinical studies and their limited number of participants, programs that offer this are not widely available. And those private programs that are open to the paying public would cost a great deal of money and time as well. Many SCI survivors have jobs, families and other commitments. Clearly, as promising as it may be, intensive LT, at least at this time, will work for only a relatively small percentage of chronic SCI survivors.

Young knows this, and he is doing his best to get trials going in the United States as well as China and India. He is also planning U.S. trials for quads involving restoration of arm and hand function based on the principle of LT, in 2020.  

More Readily Achievable Restoration of Bowel and Bladder Function

The research of Reggie Edgerton, Susan Harkema, Wise Young and others has shown that epidural stimulation in combination with locomotor training can lead to restoration of a number of important functions, including bowel, bladder, sexual function, temperature regulation and more. Electrical stimulation is also an excitatory stimulus. It follows that another logical possibility for further research is to explore the potential of epidural stimulation by itself.

The obvious upside of epidural stimulation by itself is that it would appeal to a much larger percentage of chronic SCI survivors, who would benefit more or less immediately. Those who want to follow up with locomotor training could then do so at the pace and commitment level that is most practical for their individual lifestyle.

Unite to Fight Paralysis advocates for more inclusive research that focuses on more readily achievable, partial recovery of function. Matthew Rodreick, executive director of U2FP, is working with the research community to include the priorities of the SCI community in clinical trials. “It seems the scientific community has been obsessively focused on walking in most of their SCI trials. Most of the studies have paired locomotor training with other ‘tools’ to gain recovery in walking. But a number of studies have now shown that bowel and bladder and other important functions are being regained, mainly as a kind of side effect. Why can’t that now be the major aim of studies?”

Rodreick has organized a quarterly conference call attended by a dozen or so major researchers so they can share information. He sees a change happening where more studies are focusing on priorities other than walking (see Research Matters, page 42, for more on this topic). He has also been instrumental in advocating for funding for specific projects. One such project is a clinical trial still in progress, conducted by Dr. David Darrow, a Minneapolis neurosurgeon.

The study involves 12 chronic SCI survivors, female and male, that focuses on restoring bladder and bowel function using epidural stimulation. So far 10 subjects have been fitted with stimulators, and the results are impressive. The design of the trial is structured to make restoration of function less onerous. Stimulators are implanted in a day surgery, and participants are sent home to try various pre-programmed stimulator settings that are activated by an innovative smart phone app that Darrow and a colleague have created. In this way, optimum results can be achieved from the participants’ homes. The range of testing also allows data not previously targeted to be collected, like heart rate, blood pressure, and other information important to overall health.

So what’s next? More trials involving greater numbers. Perhaps further research in separate trials could also combine epidural stimulation with untethering surgery, which has already been shown to increase the incidence of bladder and bowel restoration in the Kunming trials.
Q&A with Dr. David Darrow

Tim Gilmer: Why focus on epidural in your study — with no locomotor training?

David Darrow: We already know the importance of the central pattern generator and intensive rehab/LT, but we don’t know what is the primary stimulus that activates the restoration of movement. We are targeting the entire lumbar-sacral area with a single 16-contact “paddle” and tracking outcomes of various settings.

TG: What if there’s damage to cord in that area?

DD: Interesting question. So far, people have to have an MRI that shows they don’t have damage in that area. But it’s hard to predict outcomes. We are concentrating on subjects with primarily thoracic injuries, C7-T10. So far we have implanted people up to 17 years post-injury, some 50 or 60 years old. In the future I see no reason why people with damage in the T11-L2 area couldn’t be implanted. You never know what is possible until you try it.

TG: What about higher cervical injuries?

DD: We are excited and looking forward to including quads in another trial. We are funded and may be enrolling, hopefully, by the end of the year. It will be more difficult. We’ll have to build on what we are learning and it will require more electrode paddles placed in different locations, perhaps two or three. We want to learn what works best for a range of quad issues.

TG: How do you track and collect data from the different settings?

DD: With an app that we created. We had to write our own app in order to monitor not only the best settings for bowel and bladder, but also other factors that are affected by SCI, like cardio, spasticity, autonomic dysreflexia and BP, etc. And the purpose of collecting the data is so we can learn what settings work best for different uses. We need different programs for different outcomes, so patients’ treatment can be individualized. The results can be transmitted to us wirelessly.

“Our approach is to target people who don’t have the time, money or ability to dedicate themselves to months and months of intensive rehab, but who might benefit more or less immediately and be able to do this in their homes. We are seeing a range of beneficial results converge in three to six months — bowel, bladder, sexual function and more. We want to facilitate it so people in rural areas can do this and maybe improve strength and bone building for later specialized locomotor training, if they have the opportunity. We want to minimize the burden on the person with SCI. We don’t think our approach is better or that LT is not needed, we are just hopeful that our work complements what everyone else is doing.

TG. Wise Young has talked about the need for SCI research scientists to not only do clinical trials, but to design them in such a way that the treatments can be applied in an affordable and practical way for as many people as possible. Sounds like that is a philosophy the two of you share.

DD: Absolutely. I’m not a scientist per se, I’m a surgeon. I work with patients all the time and I want to help them get better. So far the biggest gains, according to the patients’ own responses, are with bowel management and spasticity. One hundred percent have seen benefits with spasticity. And spending less time in the bathroom is a big deal for SCI survivors. We are finding out how important working with patients is and getting to know them as individuals.
little over a year after I became a C6 quadriplegic in a diving accident, one of my MRIs came back with a troubling finding in my spinal cord: a syrinx. In my case, if the syrinx moved up to C4-5, it could result in permanent breathing impairment.

After speaking with a number of leading U.S. neurosurgeons, two things became clear, neither of them good. First, my particular syrinx was on the back side of the spinal cord and thus particularly challenging — and dangerous — to reach surgically. Second, we learned that pressure from insurance companies and lawyers often helped dissuade U.S. neurosurgeons from doing the surgery I needed, a triple laminectomy followed by reaching around inside my spinal cord and removing the syrinx, unless it was deemed urgent. Exasperated, my father asked Dr. Wise Young what he would do if I was his daughter. The succinct response: I’d take her to China. Young went on to explain that thanks to the nation’s massive population and a variety of other factors, more Chinese surgeons do this surgery than American surgeons, and, they were very competent.

Since syrinx removal surgery wasn’t medically pressing yet, and neurosurgeons in the United States were not keen to operate on me, we chose not to accept the risk of waiting until we were in an actual crisis.

**Off We Go to China**

After careful deliberation, my family and I decided in March 2013 to move from Miami to Kunming, China, a city with over 7 million people in Yunnan Province. Fortunately, I had spent quite a lot of time studying and even working in China between the ages of 17 and 25, so I was already fluent in Mandarin and familiar with Chinese culture.

My family rented an accessible ground floor apartment near Tongren Hospital and I hired two lovely live-in Chinese caregivers. My particular case was a big deal for Tongren Hospital as I was its first foreigner to undergo this type of surgery, and I was treated like royalty by the entire hospital team.

Once settled in Kunming, we created a surgical plan to remove my syrinx. The chief Kunming surgeon also proposed spinal decompression surgery — untethering the spinal cord by removing scar tissue — to allow the cerebral spinal fluid to flow more freely. He assured me that spinal decompression would likely improve my chances of motor function recovery as well as reduce neuropathic pain.

My father, ever the skeptic, told me he would not put much stock into those assurances, as he could not find any medical evidence that spinal decompression reduced neuropathic pain or improved motor function. Nonetheless, I clung hopefully to the doctors’ words as we finally settled on a date for surgery.

**Showtime for Surgery**

As it turned out, surgery could not have come soon enough. I was already having trouble breathing. By the time of surgery, I was gasping for breath and on oxygen many hours a day.

My surgical team performed the triple laminectomy and then opened up the dura to access the actual nerve bundles making up the spinal cord. From there, they worked their way very carefully around to the ventral side, where they removed the syrinx and cut away some of the scar tissue to allow my cerebral spinal fluid to flow more freely.

I woke up intubated, alone, without my family in the ICU, completely disoriented, and with nothing more than a dose of Ibuprofen. Yes, you read that exactly right… only ibuprofen!
I had not thought to discuss post-op pain management protocol with my surgeons in advance. I had assumed that I would wake up pumped full of fentanyl or morphine, since I just had three vertebrae removed and my spinal cord laid open.

I was trying to scream through my intubation tube and flailing my arms about. The nurses seemed to think I was having some sort of panic attack. They responded by literally tying my arms to my hospital bed so I wouldn’t tear out the intubation tube!

Without speaking any Chinese, one of my brothers then intervened forcefully and literally cut me loose. The next thing I remember was waking up pumped full of morphine and hallucinating. The staff was not familiar with morphine dosing, so I ended up heading down the proverbial rabbit hole on a wild hallucinogenic trip. As a result of the excess morphine, my blood oxygen fell to 80, causing near panic in the hospital, and I was strapped into an oxygen mask for several days while they experimented with morphine dosage. (Since my stay, the Kunming Tongren Hospital has updated its practices and now has in place conventional international pain protocols.)

I later learned about cultural differences between East and West with respect to pain management. In China, people don’t typically complain about pain, especially the older generation, and have historically been taught to keep pain to themselves, seek some sort of alternative medicine such as acupuncture or tinctures and to stay brave through the agony.

I spent about a week recovering in the hospital and three weeks back in my bed at our apartment. While the hospital’s pain management philosophy may have left something to desire, nursing care was excellent. There was a nurse stationed in my private hospital room 24 hours a day, massaging my legs to make sure I didn’t get blood clots and checking my blood pressure manually every 15 minutes.

Once I fully recovered from surgery, I participated in the Kunming Walking Program, created by Young, five days a week for several hours a day. Unfortunately, I was unable to participate in the walking part of the program for most of my stay because of a broken bone in my leg. My

“I was a novelty because I was one of the few foreigners living in the city. When we wheeled half a mile to the gym every day, people would stop me on the side of the road to pet my blonde hair, touch my leg and ask me if I could feel it, or compliment me on the fact that I could understand what they were saying.”

In her blog, Ingersoll talks about how the hospital staff agreed to let her go ice skating if she would be the centerpiece for an ice show. “It was probably the most amusing thing I had done in Kunming,” she says.
life consisted of waking up in the morning, rolling over to the hospital, where the walking program was located, and participating in daily exercises that included stretching, lifting weights, cardio, and standing in a customized frame made by the hospital — for the entire two and half years I lived in Kunming.

When I was not exercising at the hospital I ventured out within Kunming. My family purchased a wheelchair accessible London taxi and I was able to explore parts of China I had never seen before. We took gondola rides up the sides of mountains, hopped around from town to town, tucking into little restaurants, gardens and the countryside. With a temperate climate that allows things to grow year-round, Kunming is one of the most beautiful cities I’ve visited.

Cultural Differences
Life in Kunming turned out to be pretty boring. However, boring seemed far better than being miserable and in pain. After the surgery my breathing immediately improved, albeit I was left with a persistent chronic neck pain likely due to nerve damage resulting from the surgery. Even with the chronic neck pain I still suffer from today, the surgery saved my life, which made the trip halfway around the world worth it in my eyes.

I was kind of indifferent toward life at that time, and I couldn’t find a good enough reason to move back to the United States. The cost of living is relatively cheap in China, and I had two fabulous caregivers whom I knew I simply would not be able to replace once I moved. So, in my mind, I was surviving fine and would stay put until I could figure out my next move in life.

The disability community in China is practically nonexistent, and there are few accessible buildings. Most seriously disabled folks in China are simply forgotten about. I spoke with many Chinese people with SCI who were so happy to participate in the Kunming Walking Program simply because they had nothing else in their life, and the hospital was a safe

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place for them to feel connected to folks in similar situations. The Kunming Walking Program offered “community” to disabled Chinese … no mean accomplishment, I came to think.

Naturally, I was a novelty because I was one of the few foreigners living in the city. When we wheeled half a mile to the gym every day, people would stop me on the side of the road to pet my blonde hair, touch my leg and ask me if I could feel it, or compliment me on the fact that I could understand what they were saying. I almost felt like a zoo animal, and that’s not meant in a derogatory way, because the Chinese were just so curious about who I was and why I was there that they were always trying to inject themselves into my life in some happy way or another.

After two and a half years living in China, I decided to move to Raleigh, North Carolina, to be closer to family.

**Conclusion**

I moved to China for surgery to remove the syrinx that I viewed as life-threatening. I do not question for a moment the technical competency of my Kunming surgeons, who successfully completed a difficult and dangerous surgical procedure, but I would be remiss not to point out they gave me high expectations for a reduction in neuropathic pain and none occurred.

Not only did my neuropathic pain fail to improve, I ended up with additional persistent chronic pain in my neck. To this day, I cannot sit in my chair for more than eight hours a day without feeling as though a knife is constantly running up and down the scar on my neck. Furthermore, spinal decompression did not result in improved motor function of any kind.

I don’t regret moving to China. It offered me an opportunity to head off a critical medical problem, and memories of my Kunming caregivers are some of my happiest since my injury. But as for others who may be tempted to try what I did, I’d say this: if you do not have strong command of the Chinese language, do not have a support system to help you in a foreign country, don’t need immediate lifesaving surgery, and if you do not know how to train your physical therapists to handle you safely, then I cannot in good faith recommend following the path I took.

Read Ingersoll’s full account of her stay in China at chinaquaddiaries.org.

“Even with the chronic neck pain I still suffer from today, the surgery saved my life, which made the trip halfway around the world worth it in my eyes.”

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Excitement builds as I extend the leather glove and call “Enkidu! Enkidu!” From the far side of the circle, Enkidu, an Aplomado falcon, spreads his wings, takes flight and deftly lands on my glove. I’m in awe of this beautiful bird of prey. It is surreal, thinking about his ethereal abilities — speed, flight, keen eyesight — it is like having a small superhero perched on my hand. Enkidu’s beak grabs a tiny piece of ground quail off the glove, his reward for flying to me, and makes a happy chirping sound as he affectionately walks up my arm, rests on my shoulder and looks me in the eye. It is amazing!

I’m at Squaw Valley, California, for an introduction to falconry class, one of the many offerings at No Barriers Summit, an annual three-day adaptive event featuring speakers, workshops, outdoor sports and adventures aimed at “unleashing your potential.” The class was conducted by West Coast Falconry, one of only 13 falconry organizations in the U.S. that are licensed to allow non-falconers to have these birds land on their gloved hands. Although the sport is called falconry, it also employs hawks, eagles and owls, and originated as a means of hunting, with the earliest references to the practice dating back many millennia.

The class was taught by Jana Barkley, a master falconer, who explained West Coast Falconry carefully chooses birds that have a unique acceptance of people other than their own falconer — birds of prey usually imprint on their falconer alone and eschew other humans — and then socialize their birds to be even more comfortable with other people, including wheelchair users. The birds are also trained to work with people who do not have arm movement, by either perching on a gloved hand or a wheelchair arm rest. Enkidu is trained to land on a non-moving arm or a wheelchair arm rest.

During the class, Barkley introduced us to three birds of prey and explained the unique features and abilities of each one. While holding Enkidu, she explained that another type of falcon, the peregrine, has the superpower of speed and is the fastest animal on the planet — they have been clocked diving at 242 miles an hour. “I’ve always enjoyed watching raptors in the wild. To get that close to them and have the experience of calling them, receiving them and then flying them, it’s a once in a lifetime experience,” says Steve Dalton, 50, a T4 para from San Pablo, California.

After Enkidu made his rounds, we were introduced to Don Diego, a 12-year-old Harris’s hawk. Don Diego is so large that participants could feel the breeze as he flapped his wings to slow his landing and perch on their arm. “It’s a wonderful feeling,” says Shannon Coe, a former Miss Wheelchair California from Berkeley, California. “Today I learned that training raptors is similar to training service dogs — they are treat motivated, require consistency and it’s best to keep them a bit hungry.”

Barkley explained that birds of prey are known for their superior vision, hence the word “hawk-eye.” A hawk’s superpower is vision. They can spot prey the size of a rabbit from almost two miles away and can peer into the ultraviolet light spectrum to find warmer rising air for soaring or even urine trails of small critters like mice, which fortuitously can lead to dinner.

Last but not least we met Tigg’RR a great horned owl. “It was amazing holding the owl! A little intimidating looking at the long sharp beak, but amazing,” says Walter Delson, a T4 para from Berkeley. “It was a powerful
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Thanks to the generous support of our sponsors, New Mobility celebrated its 30th Anniversary with a wonderful wine tasting and fundraiser event in Portland, Oregon on August 1. The evening was marked by great food and wine and, more importantly, a tremendous sense of community as we toasted the progress made by active wheelchair users over the last three decades. Cheers!

Resources
• No Barriers Summit, 970/484-3633; nobarriersusa.org/2019-no-barriers-summit-home
• West Coast Falconry, 530/749-0839; westcoast-falconry.com

“It’s a powerful feeling,” says Shannon Coe about having a raptor perch on her glove.

experience.” Barkley explained that an owl’s eyes always look straight ahead, which is why they need to turn their head 270 degrees. Owls are able to do this because they have twice as many vertebrae in their necks as humans.

An owl’s superpower is hearing. They can move their ears like we move our eyes, and the front of an owl is shaped like a satellite dish to collect sound, which enables them to hunt at night by triangulating sound.

We all agreed this was an amazing experience and like many No Barriers experiences, one that provided cool information and rekindled a sense of awe and wonder. It is an experience I recommend if you have the chance.

West Coast Falconry offers a basic falconry class that is completely wheelchair accessible at their facility in Marysville, California.
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How does spinal cord injury research get paid for? It’s an issue I’ve been trying to understand for the better part of two decades.

Fourteen years ago, I went to a conference in Washington, D.C., that was advertised as a gathering of spinal cord injury research scientists and people living in chairs. I was at the conference, called Working2Walk, because I wanted to understand whether there was any chance of healing my husband who had been injured four years earlier — and more importantly, what I could do to help make it happen. It was a heady time. Just a few years earlier a team in Wisconsin had managed to isolate human stem cells for the first time, and the promise of cures seemed real.

One moment that stands out from that weekend is sitting in a breakout room filled with tables that were too low for people in chairs. Those of us who could had moved furniture around so that as many people as possible could squeeze in. Dr. Hans Keirstead had come from California to talk about his research. I remember him: fit, tanned and casual in blue jeans and an open-collared, untucked white shirt, describing his work with cells and mice, and how exactly that work would one day lead to better outcomes for people with spinal cord injuries.

My goal here is not to review what happened with those cells and that science. I want instead to focus on something else Keirstead discussed that day. I wrote it into my journal: “The research can only go as fast as the money comes in.”

This comment was in response to the question on everybody’s mind: If what you’re doing with these mice works, how long until we see it tested in people? How long until it gets to us?

In the years since, hundreds and hundreds of millions of dollars have been spent on the effort to restore function to people living with injuries. Regular readers of this column know that scientists are still testing cell therapies in mice and rats, but also in pigs, dogs and rhesus monkeys. There are even a few trials involving people with injuries, all in the very early stages and with results that range from mixed to promising. In spite of the early excitement over human embryonic stem cells, few if any of the current projects depend on those cells.

Where Research Dollars Come From

Figuring out how to restore function after a cord is damaged is a wildly expensive project, requiring a whole infrastructure of education, tools and peer support. It’s surprisingly hard to put an exact number on what’s getting spent on repairing the cord in the United States, but there are only a few major sources of dollars.

There’s the National Institutes of Health, which gives scientists about $80 million annually, but far from all $80 million ends up funding research. That’s because almost all the scientists applying for that money are working in labs at universities, and the schools that house the labs get a big chunk of the money — known as “indirect cost” — for their general budgets. If a grant of $200,000 is awarded, anywhere from $60,000 to $100,000 never makes it to the lab. What’s more, the amount each university takes varies by school, making it difficult to look at the NIH spending and say for sure what it means in terms of actual research.

The Department of Defense likewise has an annual doling out of tax dollars for SCI research, but these grants are also subject to the indirect cost process. The nominal DOD annual spending is in the neighborhood of $30 million.

Another major player is the Craig H. Neilsen Foundation, which has granted $168 million since it began funding projects in 2004. It’s complicated, though, to break out how much was spent directly on spinal cord repair. A lot went toward repair, but the portfo-
lio also includes many grants for things like scholarships and efforts to make living with injuries easier.

Finally, there’s another source of funding: states. Funding spinal cord injury research at the state level is doable. It’s effective. It can only happen with the involvement of local people who have skin in the game — people like us. At the state level, we’re not just tolerated or allowed to sit in and offer an opinion; we’re necessary. And our input as to what projects go forward can be built into the system in meaningful ways.

**Research is Not a Zero-Sum Game**

The success of advocates in Minnesota proves the viability of this approach. The Minnesota story started in 2011 when Matthew Rodreick — father of Gabe, then a teenager and C5-6 quad — decided to try to get his state to spend money on research. That year, he helped found Get Up Stand Up to Cure Paralysis to advocate for funding, made contact with an interested legislator and thought he was on his way. Nope. He quickly learned that there was an already-established group with secured money for traumatic brain injury research, and this group was not prepared to share in what it saw as a zero-sum-game. It heard about his plans, got to the legislator and blocked the money. (Disclosure: The author cohosts a podcast with Matthew Rodreick that is published by GUSU.)

In 2012, he went back and succeeded in getting a hearing at the committee that would have to approve funding. This time, a member of the community arrived in a chair. The man had been paralyzed for 50 years and had a C5-6 injury, just like Gabe. From his wheelchair, the man told the committee that they shouldn’t spend precious dollars on research that was going nowhere and called out Rodreick to his face as a father who needed to work out his grief some other way. The committee dropped the potential bill.

Rodreick called the man and asked for a meeting. Over the next few months they spoke several times at coffeeshops. This man had been a vocal and effective advocate for disability accommodations. To his mind, Rodreick’s research project was pie in the sky that would actually hurt people. It was a zero-sum-game, remember, and Rodreick was trying to take money away from much-needed projects.

Rodreick told the man about some of the recent scientific progress, which, not surprisingly, the man had not heard about. And then Rodreick asked, “Are you really telling me that if you didn’t have to cath anymore, or we could get rid of your nerve pain, or your spasticity, that wouldn’t be worth it? Wouldn’t you do that?”

The man softened to the idea. In his mind, he’d been insisting for most of his life that his community accept him as he was and accommodate him accordingly. But Rodreick was pointing out that supporting realistic research was just another way to take that approach. The scientific community was just another group that needed to be called to account when it came to doing research meaningful to people in chairs.

Rodreick and his partners got the money that year, but more than that, they got the right to sit on the panel that read and approved grant applications. One of the first things they funded was Dr. David Darrow’s epidural stimulation project, which I described in a column last year (“The Promise of Epidural Stimulation,” April 2018). It was a fairly spectacular success, and it only happened because a few interested people from Minnesota decided to not give up.

Minnesota is a cool place, but it’s not magic. Since its legislature approved funding for SCI research, legislatures in Pennsylvania and Ohio have followed suit. There’s also a bill under consideration in Wisconsin right now. All these state efforts have benefited from working with Rodreick; they’ve also enjoyed interest and support from members of United Spinal chapters. What matters most to me is knowing that every dime of that money will be spent as directed and approved by people in our community. We’re not crammed into a meeting room in D.C. waiting for a famous scientist to tease us with stories of cells and mice.

We’re at the table, pushing for progress.
When I was in college, way back in the Pleistocene, I signed up for a Marxism class. But I flunked out. Well, actually I dropped out after a week. I was revved up to learn all about Marx and Engels and those bearded, radical dudes, but you know how dense that Marxist stuff can be. Sometimes you need a machete to cut through to the point of it all ... the bourgeoisie this and the bourgeoisie that. And there are no laughs in it.

The bearded professor who taught the class seemed to think his job was to make the subject matter even more opaque. He was a glum sort who slunk in, mumbled off a dry lecture and slunk out. He never paused for questions or discussion. After two classes, I was hopelessly lost. It was obvious I needed to take Marxism for Dummies.

The same thing happened years later when I joined a Marxism discussion group. It was like commie Bible study. The guys who organized it batted back and forth references from Das Kapital like tennis pros. They never came up for air. Witnessing it all made me dizzy. So again, I quickly dropped out.

And yet I call myself a socialist. I can’t explain my socialist convictions by reciting chapter and verse from anyone’s manifesto. They aren’t drawn from ancient texts. They’re drawn from living 60-plus years as a cripple.

The best examples of socialism I see in the world around me are those situations in which we cut out the greedy pigs. For instance, how about parks and libraries? Their reason for being is not so some knucklehead can rake in money. Everyone can partake for free.

Another example is my pit crew. That’s what I call the people I hire to come to my home every day to get me out of bed, lift me onto the crapper, etc. Their wages are paid by a state program. It doesn’t cost me anything. I, and everybody else, pay for it all up front with our taxes. Nobody gets rich. It’s beautiful.

Socialism is what gets me out of bed every day. If getting me out of bed was left up to the greedy pigs, I’d have no choice but to check into one of the nursing home chains they own, without possibility of parole. They’d drain me of whatever money I had until I was poor enough to go on Social Security, and then they’d drain me of that. They’d drain me of whatever money I had until I was poor enough to go on Social Security, and then they’d drain me of that. They’d feed me just enough elbow macaroni, canned fruit cocktail and horse meat to keep me alive, so they could drain me some more.

You gotta keep a close eye on the greedy pigs because they’re sneaky like that. When they smell a potential profit center, they’re like a slobbering bloodhound locked in on a scent. They’ll horn in on socialism and defeat its whole purpose by twisting it into something designed to make them rich. They call it privatization. They’ll do something like set up a “managed care organization” to run state programs like the one that gets me out of bed. And they’ll hire a bunch of social workers to do the same damn stuff the social workers who work for the state used to do. Except the guy who runs the managed care organization gets a big juicy cut of the action.

I know cripples are screwed in socialist systems too. Marx and Engels and those dudes may have been visionary, but I bet they never pondered such weighty political challenges as how to get cripples out of bed. So maybe socialism isn’t precisely the right word for the political system I believe in, but it’s the best word I can come up with so far. So, I’ll take it for now.

Cutting out the greedy pigs is the first necessary step. But then we have to create a welcoming culture that hasn’t been created yet. Maybe someday somebody will spell out what that culture looks like better than I ever could in some sort of cripple manifesto. I hope there are lots of laughs in it.
EMPLOYMENT OPPORTUNITY

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

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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.

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Meet New Member Brian R. Smith

Age 54, from Arlington, Massachusetts C5-6 quad from spinal cord injury Community outreach worker, The Miami Project

Why I joined United Spinal: I wanted to be part of a community of people who are in my situation, something other than a Facebook group. United Spinal seemed like a great resource center.

Can’t live without: My rehabilitation experience changed my life. Only a tiny percentage of people with an injury like mine get to the level of independence I’ve achieved. I could not even move my arm for two years. I attended four different rehab centers weekly for years, the most notable being Journey Forward of Canton, Massachusetts, where the focus is life outside of the wheelchair. Now I am independent and don’t need an attendant.

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LAST WORD

WHEELCHAIR CONFIDENTIAL

THE MAGIC WORD
When I was first injured back in the mid-2000s, I did not have enough finger dexterity to dial my cell phone well. Instead, I used a Motorola phone that allowed me to make calls by saying "abracadabra." It was a lot like summoning Siri, only it kept mistakenly activating phone calls.

On therapy days, I made sure someone helped get my earbuds back in before I went outside to wait for a ride. One day, I ran into my physician on my way out and needed to give him an update. As I'm explaining, I hear my phone activate through my earbuds, "Calling [the name of an ex-boyfriend]," followed by ringing. My stomach dropped, and I froze for a minute, but I couldn't get to my phone. I was relieved when he didn't answer, but so embarrassed that my phone never hung up and I ended up leaving a message of everything my doctor said for someone I hadn't spoken to in years. I cleaned out my contacts that night.

Morticia Fried

LATHER DISTRESSED
For my 27th birthday, my girlfriend and I took a road trip to Los Angeles. We had a fun day exploring and went out for celebratory drinks after dinner. Our departure was the next morning and I decided to take a shower before bed. A little buzzed, I got undressed, rolled into the shower and transferred onto the fold-down shower bench. The water was spraying at a weird angle, so I called my girlfriend to come help fix the setting to get more power on the handheld. She got it going and I pulled her over for an appreciative kiss. Let's just say one thing led to another, and the shower got a little "steamy." We were having a great time until the shower bench crashed down under us. We ended up in a slippery, soap-covered pile on the shower floor. More was bruised that night than just our egos.

Calamity James

Send your Wheelchair Confidential stories to confessions@unitedspinal.org. Anonymity guaranteed!

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