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COVER STORY
SURVIVING MODERN REHAB

Edie Perkins and Ashton Fritz both survived traumatic spinal cord injuries in the last 18 months, but their journeys to and through rehab couldn't have been more different. SAM MADDOX shares their stories and writes about the tough decisions and often harsh realities facing the newest members of the SCI club.

FEATUERS

20 THE TRAIL KING
Ian Mackay has put thousands of miles on his sip-and-puff power chair, crisscrossing the Pacific Northwest to raise awareness of the need for accessible trails. KENNY SALVINI profiles the dreadlocked pioneer.

32 INVENTORS & THEIR INVENTIONS
ALEX GHENIS talks with inventors designing products for the wheelchair-using community to understand what makes them tick and how they turn their ideas into realities.

36 WHEN WOUNDS WON'T HEAL
TIM GIILMER investigates the underlying causes of the worst wounds and shares what you can do to heal when bedrest isn't enough.
By Ian Ruder

For anyone wagering on how long it would take for New Mobility to be in the hotseat under my tenure as editor, all bets are now off: It only took one month. August’s News Analysis, “The Curious Case of Charles Krauthammer,” ignited a lively debate both in the online comments section and in my inbox. From “cowardly” and “offensive” to “wonderfully written and balanced,” responses to Seth McBride’s article ran the gamut, all the way up to one reader suggesting we had anti-Semitic intentions (despite no reference to religion or ethnicity anywhere in the article).

In light of the passionate response, I thought it might be helpful to pull back the curtain on how the article came to be and what our nefarious—or really-not-so-nefarious—intentions were.

It all started with a simple email I sent to our staff on June 8, sharing a New York Times article reporting Krauthammer’s announcement that he only had a few weeks to live as he battled cancer:

It’s interesting reading the initial coverage of Charles Krauthammer’s passing how little mention there is of his SCI. This NYT piece has no mention. Could make for a news analysis piece …

As a fellow C5 quad, a history major and a journalist, I had followed Krauthammer’s career with a great deal of respect. I often used him as an example of what was possible, both for myself and in discussions with others.

We started the news analysis column to look at how the mainstream media covers disability. I knew that Krauthammer didn’t go out of his way to publicize his disability, but what I found interesting was the Times article’s lack of any mention of his quadriplegia or use of a wheelchair. How often have the accomplishments of a prominent wheelchair user been trivialized in media coverage that plays up the inspiring, against-all-odds clichés so often attached to disability? Those trends are even more prominent when the person with a disability is near death or dying.

But here we had a story that presented Krauthammer’s accomplishments without any wheelchair-related trivialization, and it didn’t even mention his disability. Why didn’t it? Was this an anomaly? How were other outlets covering this? I had many questions, but honestly, more than having a single, brilliant idea for a column, I saw a topic that seemed ripe for analysis.

When Krauthammer passed less than two weeks later, McBride took on the assignment. He eloquently addressed many of the questions I had in his drafts, while also raising new questions. He and I worked together on revisions. We discussed the article on our weekly editorial calls and debated whether to run a photo of Krauthammer in his wheelchair. We knew some might object to portraying him in a light he worked to avoid, but eventually agreed it was appropriate since his legacy is secured and his disability is, and will be, a part of it.

While some of the vitriol in the response caught us off guard, we expected a healthy back and forth. In these polarized political times, it is imperative that we have discussions like this, and I am proud that New Mobility is one of the venues where we can do that.

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beginning his career as a rock 'n' roll journalist, Sam Maddox founded a Village Voice style monthly called CakeEaters and later did a lot of magazine work covering the arts, politics and business. He taught magazine writing at the University of Colorado and narrowed his focus to neurotrauma after meeting two young wheelchair users who sparked the creation of Spinal Network, the book that begat New Mobility. Maddox, based in Los Angeles, now publishes an acute trauma resource called SCI: First 90 Days, scifirst90days.com.

Jane Wierbicky, RN, BSN, is a nurse information specialist with the United Spinal Association Resource Center. She provides guidance and information to individuals with spinal cord injuries and disorders, their family members and healthcare professionals, helping them navigate available resources to address their specific concerns. For over 30 years, Wierbicky has worked exclusively in the field of spinal cord injury/dysfunction. She has a particular interest in addressing issues related to access to healthcare for people with SCI/D.

Writer and advocate Kenny Salvini throws parties with other paralyzed folks under the ruse of a nonprofit called The Here and Now Project. When not writing about airports breaking his wheelchair on his blog, Typical Guy, Atypical Situation, he spends much of his time being ignored by his black lab, Hank, or getting beaten severely at Cribbage and other games by his beautiful wife, Claire, at their Sumner, Washington, home. Find out more at kennysalvini.com and hereandnowproject.org.

Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org
Parent Problems
It's not easy being a disabled parent! ("Explaining Disability to Our Kids," August 2018) My son was 4 when I got my spinal cord injury. Once after, he told me, “All my birthday wishes are me wishing you to walk again, Mommy.” Then once I had the ambulance come and pick me up because I fell, and he told me, “Hopefully they can fix you, Mommy.” The hardest thing I had to do was to look into his eyes when he was 7 to break his heart and tell him, “I am never going to walk, and just because I go in an ambulance doesn’t mean they can fix me. I am very lucky I am still here. Things could have been worse for me, I could have died, but I did not. I am so happy to be here with you today!” He still hopes and wishes me to walk like before my SCI, but he knows it won’t happen. I have big challenges, but with his love by my side, I can do anything for him!

Patty Paul
Newmobility.com

Great Solution
Wonderful article (“Year One of the Ewan Experience,” August 2018). I have got to get one of those Bumbo seats and rig it up to my power wheelchair to haul around my upcoming nephew. This would be a lot easier than just hooking him into my seat belt or using a baby carrier.

Jessie Gray
Newmobility.com

Costco’s Condescension
I think the “free pass for crips” is similar to the age thing (“The Costco Social Experiment, Ervin, August 2018). I get more damn overly-solicitous attention from clerks and card checkers now that I’m 81. What bugs me even more are the “honeys” and “darlings” that suggest I’m “cute” and not to be taken seriously. It always makes me want to respond with “f--- you.”

Rosemary Molloy
Newmobility.com

Ervin Love
The articles written by Mike Ervin bring me to tears with uncontrollable laughter. His writing style, with his sense of cynicism and not taking his disability too seriously, is a great read — and his approach to his articles is something I keep in mind as I go through my day.

Stephen C. Grams
St. Peter, Minnesota

The Sad Truth
So many of us have had our lives mangled by what we do to receive our care ("Jason DaSilva’s 'The Disability Trap' Is Beautiful and Infuriating," Blog, Aug. 20). So many of us couldn’t work for more than nine months without losing community personal attendant services, so it thwarted our careers and kept us in poverty. I am looking forward, sadly, to watching this video. The nursing home industry exploits us and takes away our freedom by paying off our politicians.

Nancy Becker Kennedy
Newmobility.com

A Better Way to Comment
Is there any way to comment on a story online without having a Facebook account? If not, that’s really disappointing.

Katja Stokley
Newmobility.com

Editor: There is a link at the top of every article on Newmobility.com that allows you to send a letter to the editor.

The Curious Case of Charles Krauthammer
Incites Debate
Seth McBride’s news analysis on “The Curious Case of Charles Krauthammer” (August 2018) sparked a lively and thoughtful discussion with passionate arguments on all sides. Here are some of the responses.

Thanks for the Full Picture
This was a great story, and I’m glad I learned the full picture of Charles Krauthammer’s life. I always liked him and I sensed a certain dignity and clarity in his mind, although I didn’t always agree with his ideas; now I like him a lot more and I find his example to be quite inspiring for me. I agree with Krauthammer about not wanting a disability to define my life experience or other people’s perception of me. The only thing I would criticize him for is not supporting universal health care and the expansion of disability insurance. I would say that Krauthammer was either elitist because of his wealthy background or he was somewhat a victim of his own persona and his own fear of letting other people see him as being in a wheelchair. Conservatism and self-reliance can be great human values — but human beings are also interdependent and having good health insurance can make a tremendous difference in one’s quality of life. Krauthammer had
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to toe a certain Republican conservative line, yet he must have known that, had he come from less fortunate circumstances, he would not have had the support he needed to ultimately achieve the kind of success he enjoyed.

James Ainsworth
Newmobility.com

Cheap Shots
I found the article about Charles Krauthammer to be inaccurate and offensive — that if somebody well-known doesn’t choose to beat the drum of disability issues, they are wrong. Charles lived the life he wanted to live and did not hide from being disabled, but he refused to let that fact define who he was. I posted on the blog under the article as myself:

“Charles did not want to lean on being disabled but rather on his intellect and skills as an author and commentator. He talked in front of many crowds and did not “hide” his disability. His chair was very visible. I knew he was in a chair in 1975 and admired how he led his life. He began as a Democrat and gradually became disenchanted with the party. He called the issues as he saw them. He spent his last 240 days with us at Shepherd Center, and I had the privilege of speaking with him several times a week. I found the tone and tenor of this article way off base. Cheap shots.”

James Shepherd
Atlanta, Georgia

Kudos
Bravo! A wonderfully written and balanced story.
Bob Samuels
Newmobility.com

Cowardly
How dare you? Whatever gave you the right or authority to attack a man of Charles Krauthammer’s repute and success? How much he chose to publicly discuss his quadriplegia was his business and his business alone. You cowardly waited until after his death to attack him. You could not have survived the response he would have delivered.

George Rector
Clermont, Florida

His True Legacy
Lest we forget there was, several years ago, a special program on Fox News about Krauthammer, the man, and that included an interview while he was driving his van. It talked about his past, including the accident and disability. For this Fox News special 30 or 60-minute program, he did not try to hide his disability. It is, in my opinion, a shame that this article ends on such a negative note about what he could have accomplished. Furthermore, I suggest that had he been a crusader for the disabled, he might very well have been taken less seriously as a news commentator. And this was his true legacy.

Daniel Kovnat
Braintree, Massachusetts

Sign of the Times
The comments here are fascinating and some deeply ableist. While it was impossible to hide his disability, Krauthammer sure did go out of his way to make it as least visible as humanly possible. And despite great privilege, he did absolutely nothing to advance disability rights. I am not sure how he justified this in his mind given the grim
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statistics associated with disability and poverty, unemployment, lack of housing and transportation, etc. Regardless, bravo to McBride who has sparked some heated words — a reflection of current social division fostered by the GOP and Trump.

Bill Peace
Newmobility.com

Worth Saluting
Krauthammer wanted to be recognized for his mind and intellect rather than his clearly dysfunctional body. Anyone who has lived with a similar disability for any length of time knows how difficult a goal that is. We are immediately judged based on how we look, and usually unsaid, that judgment is negative. We are considered "lesser-than," and it is an uphill battle to overcome those perceptions. It can be done, at least to some extent, and Krauthammer is proof of that. It is all too easy to play the pitiable victim role; he chose not to, and I salute him for that.

Pete Smith
Newmobility.com

Correction
On page 24 of Seth McBride’s August article, “Year One of the Ewan Experience,” the practical tip should read: "If you have adjustable center of gravity, move your axle backward to remove some tippiness from your chair before your baby gets strong enough to really wriggle and kick.”

Pete Smith
Newmobility.com

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Pete Smith
Newmobility.com
It’s not often that the governor’s race in South Dakota garners the attention of the national media. The entire state has a population of less than a million people, and by the time the contest gets to the general election, it’s usually a foregone conclusion—a Democrat hasn’t won since 1974. But then Billie Sutton, the 2018 Democratic Party nominee, came along.

Sutton is a media darling. The New York Times, Pacific Standard, CBS, ABC News and The Economist, among others, have already done stories on his candidacy, and the coverage looks unlikely to slow before November. There are a number of things that give Sutton’s story the kind of glow that invites headlines. Somewhat shockingly, that he has paraplegia and uses a wheelchair is not at the top of the list.

Instead of leading with his disability, headlines about Sutton read: “Billie Sutton Will Not Be Out-Cowboyed,” “Cowboy Turned Lawmaker Hopes to Be South Dakota Governor” and “The Right Democrat Can Win.”

For the majority of the nation’s media, the fact that Sutton broke his back when his horse flipped in the chute is not quite as salable as the fact that a gubernatorial candidate from the state of Deadwood and “Wild Bill” Hickok was an actual rodeo cowboy.

Sutton is not the first politician to use a wheelchair — with Sen. Tammy Duckworth, Gov. Greg Abbott and Rep. Jim Langevin as contemporary prominent examples. Sutton doesn’t champion disability issues like Duckworth, though he has led a thus-far unsuccessful drive for Medicaid expansion in South Dakota. His most obvious comparison is to Abbott, the Republican governor of Texas, who also has paraplegia and is prone to being photographed in a cowboy hat and toting a rifle.

Both Duckworth and Abbott have shown that, regardless of political leanings, being a visible and unapologetic wheelchair user can be a boon on the campaign trail. Or as The Economist put it, to have a chance as a Democrat in red-state South Dakota, “It helps to have a compelling back story.”

Like any good politician, Sutton knows how to use his life story to his advantage. The rodeo accident and resulting paralysis feature in his standard stump speech. He uses them as he does his growing up in a rural town, riding horses and going to church — as a way of connecting with the electorate. A “South Dakota story of perseverance,” is how candidate Sutton frames his accident. “I was faced with a choice: Take the easy way and give up, or live by the values I was raised with. Do it the cowboy way — never give up and never quit,” Sutton said at his campaign kickoff.

Much of the media coverage in respect to his disability takes a similar tack, with outlets like The Economist, Pacific Standard and the Associated Press mostly framing his disability in terms of its relevance to the campaign. Pacific Standard, in particular, deserves recognition for hitting a respectful tone when discussing the fact that Sutton uses a wheelchair — and the magazine as a whole has been producing thoughtful, relevant and well reported stories related to disability.

In “Billie Sutton Will Not Be Out-Cowboyed,” the initial mention of Sutton’s wheelchair is that he uses it to travel from his pickup truck to the hotel ballroom where a meeting he’s to campaign at is being held. There are none of the usual disability tropes. He is never cast as a victim, a hero or someone who overcame “despite his disability.” Here, Sutton is portrayed as a politician trying to win an election, and his wheelchair is what it is in this situation: a means of conveyance.

Sutton may have a disability, but during election season at least, most media seem to have gotten the message that paralysis is only part of his story and not the thing that all other parts of his life must be framed against.
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[Editor’s Note: We contacted Sutton’s campaign with an interview request for this story, hoping to hear his views on all the recent media coverage, but aides declined our request.]

Resources

THE ADA AS A TOOL OF VOTER SUPPRESSION?

The recent closure of polling locations for not complying with the ADA in Georgia’s predominantly black Randolph County has stirred up voting rights advocates who fear the landmark disability rights law is being used as a tool to suppress minority voter participation nationwide. Major disability rights organizations in the state also opposed the directive because it shut down existing voting options rather than remedying the compliance issues. The elimination of polling locations was recommended by an outside consultant hired by the office of Georgia’s Secretary of State Brian Kemp, the Republican candidate for governor in the upcoming election.

Kemp raised eyebrows with a number of voter-registration and election operation changes following the Supreme Court’s 2013 decision to overturn parts of the Voting Rights Act. As The New York Times reported in 2016, “Kemp, a Republican who has crusaded against what he called the threat of voter fraud, has investigated voter-registration drives by Asian American and predominantly black groups. A 2014 criminal inquiry into a group that had registered 85,000 new voters, many of them minorities, found problems with only 25 of the registrants, and no charges were filed.”

The immediate media furor over Randolph County’s plans was directed at the racial implications of shutting down seven of nine polling locations in a county with no public transportation and a population that is 61 percent African-American. Stories about the closures included quotes and perspective from the ACLU and Georgia-based organizations that fight for minority voting-rights, and rightly so. But perspective from the disability community was, and continues to be, lacking in the reporting on Randolph County. “[The media coverage] was a situation where something happened about us, without us,” says Sarah Blahovec, the disability vote organizer for the National Council on Independent Living.

ADAPT Georgia, ARC, Georgia Statewide Independent Living Council
and Rev Up Georgia — the latter of which is dedicated to increasing voter participation by people with disabilities — came out unequivocally against the closures or “consolidation,” as Kemp calls it. The organizations point out that closing polling places, even ones with access issues, in a county with no public transit system, effectively shuts out many voters with disabilities. The distance to the nearest alternate polling place "makes it difficult, and possibly impossible, for voters with disabilities in that area to access alternative polling locations," ADAPT Georgia said in a statement. "These polling place closures will disenfranchise voters with disabilities of color in particular."

The swift backlash over the proposed closures caused the Randolph County election officials to immediately back off and fire the consultant who recommended the closures. In a meeting to decide the fate of the plan, officials took less than a minute to vote against shuttering the locations. But some activists worry that the attempted closures in Randolph County are one instance of a larger issue, as the United States Department of Justice has recently stepped up enforcement against polling locations with ADA violations in other counties across the country.

"The ADA was being weaponized in a way that would not have helped people with disabilities. ... It really does set a dangerous precedent. What happens for all those other polling places that have accessibility impediments, and is this a tactic that's going to be used more widely?" asks Blahovec. She says that NCIL is trying to engage with local CILs to make sure that, "polling places aren't closed due to accessibility violations. That's not the way to deal with it, obviously. We need to make sure they're properly trying to address accessibility instead of relocating them."

There's no doubt that accessibility in polling locations is a major issue. The nonpartisan U.S. Government Accountability Office issued a report examining a selection of 178 polling locations during the 2016 election and found that close to two-thirds of locations had access impediments either inside or outside of the building (65 percent and 60 percent, respectively). There are tens of thousands of polling locations that could be charged with ADA violations, but hyper-selective enforcement makes it all too easy to question motives.

In Randolph County, as well as other locations that have recently had enforcement actions brought against them, no one can find record of public complaint. If user complaints aren’t triggering the enforcements, why are officials choosing the locations they are? It’s a valid question, one for which we don’t yet have reasonable answers. At the very least, if officials are finally going to enforce the ADA, they need to listen to the disability community: Don’t shut down polling places — fix the access issues.

**Resources**

- “The ADA is being used to disenfranchise minority voters,” ThinkProgress.org; thinkprogress.org/ada-voter-suppression-cd7031080bfd/

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**FROM UNITED SPINAL**

**INTRODUCING THE MSAC**

United Spinal Association’s Medical and Scientific Advisory Committee is an interdisciplinary committee consisting of healthcare professionals, scientists and researchers with expertise in the management of spinal cord injury/disorders. The committee was established to advise and inform United Spinal and the SCI/D community on scientific and clinical issues of relevance to the community. Specifically, the MSAC advises and assists United Spinal by providing information and guidance in healthcare related topics, identifying healthcare policy issues that impact the SCI/D community and informing the SCI/D community of the latest advancements in research relevant to its health and independence.

Dr. Christine Sang, director of the Translational Pain Research Program at Brigham and Women’s Hospital in Boston, has served as MSAC chairperson since 2013. Sang uses her knowledge, passion and vision to guide the group and appropriately vet medical information for United Spinal’s online and print content. It focuses on breaking technologies, research and products marketed to United Spinal members and other constituents. Sang’s own research focuses on the issue of central neuropathic pain, a critical concern for many people living with the effects of SCI/D.

Registered nurse Jane Wierbicky, United Spinal’s nurse information specialist, serves as liaison to the MSAC, and as such, seeks input related to specific clinical, research and policy-related matters. Examples of MSAC contributions include crucial input toward the Interagency Committee on Disability Research initiative to develop a comprehensive, government-wide strategic plan for disability and rehabilitation research. MSAC members provided feedback related to ongoing needs and gaps in medical rehabilitation research. Similarly, as a participating member of the Disability and Rehabilitation Research Coalition, United Spinal solicited MSAC insights and recommendations to inform discussions between the DRRC and the National Institute of Health, related to the NIH Medical Research Plan.

Through their dedicated professional support, MSAC members ensure that United Spinal can empower people living with SCI/D to make more informed decisions and effectively exercise their rights regarding healthcare matters. The MSAC is instrumental in United Spinal’s overarching goal of ensuring that people living with SCI/D have access to every opportunity that improves health and quality of life.

View MSAC members at: unitedspinal.org/united-spinal-medical-scientific-advisory-committee/

— Bill Fertig and Jane Wierbicky

**ORGANIZATIONAL NEWS**
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.

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MORE THAN MAN’S BEST FRIEND
For Edgar Jimenez, using a service dog is all about independence. “It’s right there in the name,” says Jimenez, 30, about Canine Companions for Independence, the organization that provides him with his four-legged staff. Jimenez’s dog, Chase, does three things for him. First up is convenience. “I’m always dropping stuff out of my lap — my keys, cell phone, credit card — and he can pick it up and put it in my lap like nothing happened,” says the IT project manager for VISA. Second is personal safety, as muscular dystrophy makes raising his voice impossible. “So when I get stranded without my phone, he can bark, a deep loud bark, and a barking dog gets someone’s attention,” says Jimenez, who lives in Austin, Texas. “The third aspect for me, and these are in no particular order, is he’s a great companion to have. When we’re out and about, he helps bridge that social gap, as a lot of people are unsure how to approach people in wheelchairs.”

Chase is Jimenez’ second dog through CCI, as his first, Rowdy, retired after a nine-year career. How hard was it to give up a loved companion after such a long time? “It wasn’t too bad, the transition plan we put in place worked very well,” says Jimenez. “CCI tells you retirement is at your discretion, you know your dog best, and I identified the right time to retire him.” Rowdy retired in style, as Jimenez gave the dog to his dad, who owns a few acres. “He has some land to run around on and a swimming pool. It’s nice because I see him about once a week or so.”

Service dogs aren’t for everyone, says Jimenez. “It’s a lot of work. As much as is put into the dog by CCI to train him, you have to keep up that training.” But if you think it’s for you, find Canine Companions for Independence at www.cci.org, on Facebook, Twitter, Instagram or Youtube.

FEEDING THE GOOD WOLF
“The Good Wolf” is a new film that shares Crossfit athlete and paraplegic Mino Solomon’s life since the 2015 weightlifting accident that paralyzed him. The 18-minute documentary draws its name from a Cherokee parable that tells of two wolves fighting inside each of us, one “bad” that is full of anger and negativity, and one “good” that is joyful and life-affirming. The wolf you feed is the one that lives.

Nondisabled people may watch the film and be “inspired” that Solomon remains so positive, but many disabled people will see themselves in Solomon’s ability to eventually accept the reality of disability — despite how hard he works out — and get on with the business of living. Watch it at vimeo.com/284710388.

GOFUNDME SUCCESS STORIES
Celia Torres raised $5,575 of her $5,555 goal toward a down payment on a new, ultralight wheelchair on GoFundMe. Alexandra Yount, Ms. Alabama 2015, is one of many state-level Ms. Wheelchair representatives who have used the platform to raise travel funds. And some users, like newly-injured Leanne Taylor, create campaigns to meet the costs of their changed life, such as home mods.

These three women are part of a trend, says GoFundMe spokesperson Katherine Cichy. “Recently, our team has seen a rise in women with disabilities creating campaigns to support them in their unique journeys of self-acceptance, body positivity and independence,” she says.

Since the site’s inception in 2010, over $5 billion has been raised to support a wide variety of people and projects. For those interested in setting up a campaign, Cichy recommends visiting goo.gl/6HG3CC.
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Megan Hammond

A former teacher turned research assistant who also blogs about wheelchair life and serves as president of the Northeast Ohio Chapter of United Spinal Association, Megan Hammond is dedicated to helping people find the resources they need after a spinal cord injury.

Hammond got involved with peer support through United Spinal right out of rehab, when she started attending the local chapter’s meetings. “My dad and I were making trips every month, and I met all kinds of people through those meetings,” she says. She enjoyed the community so much that she started helping at events. She eventually took on a leadership role in the chapter and now serves as president. “The more involved I got with that chapter, the more I realized that I had this passion for helping others with spinal cord injuries get out into the community,” she says.

Informing people about SCI, both the general public and those already living with paralysis, is a big part of the Northeast Ohio chapter’s mission. Every month the chapter has a different speaker come in, with recent topics ranging from SCI-specific dietary considerations to catheter options to resources for home modification. The educational focus isn’t surprising, given Hammond’s background.

She graduated with a bachelor’s degree in middle grades education in 2006, and worked as a long-term substitute teacher before going back to school for a master’s in special education. While in her master’s program, Hammond had a motorcycle accident that resulted in a T4 SCI. Within four months of her accident, she was back working part time. “I’ve never been the type to just sit around,” she says. “After two months I needed to do something. It gave me a way to get out of the house and kind of get back to normal.”

Today, Hammond’s passion for supporting people with SCI manifests in a variety of ways. She recently changed careers, and now works as a research assistant on the Spinal Cord Injury Model System grant at MetroHealth Medical Center in Cleveland, Ohio. She is focused on researching and developing systems across a variety of fields to better serve the needs of the SCI community. Her favorite part of the job is talking with other people with SCI, whether they’re new to their injuries or many years post injury, “just finding out the different stories and how different people have coped,” she says. The basics, like support, equipment, proper medical care and advice are essential for managing post SCI life, but Hammond says she also sees a common attitude among those who cope well with the challenges of

CAN’T LIVE WITHOUT: I always have coffee in the mornings, and I almost always have water with me during the day. I could not live without my cup holder.

CHAIR OF CHOICE: I’m on my second TiLite. My previous chair was another brand, but I decided to go back to a TiLite because it just seems a little bit more comfortable and functional.
living with paralysis, "It mostly has to do with a having a positive mindset."

The power of positivity is something Hammond firmly believes in. Her blog, The Wheel Life, originally started as a way of sharing practical tips and tricks for living with SCI, "everyday functional things," she says, "like how I get my big trash and recycle canisters to the curb." (Hint: the containers roll and maneuver better if you tilt them back and rest the handle on your knees, then you have both hands free to wheel them where you need.) But lately, the blog has expanded to also include topics like goal setting and using positivity for practical purposes. "Whether it's the battle of the bladder issues or people staring at you in public or talking down to you because they think you can't talk, it's all about developing how you react to it," she says. Instead of just getting upset, "you can turn somebody talking down to you into an educational opportunity for them. Because most of the time, it's coming from them just not being around someone with a disability before."

Megan Hammond promotes using positivity, as she believes "you can turn somebody talking down to you into an educational opportunity for them."

HEALTHY LIVING
A Transformational Journey

About four years ago, Hammond found herself in a serious funk. Depressed and overweight, everyday tasks such as transferring and showering were becoming increasingly difficult. Tired of straining through life, she decided to make a change.

"I started going to group exercise classes at my local gym. It wasn’t anything geared towards wheelchair users at all, but the instructors that I worked with have grown with me, and we have figured out what I can do and what I can push myself to try to do — how to get stronger with different exercises that helped me build muscle and lose weight."

"I love Zumba. Dancing and singing a few days a week is just fun. It's not like you’re really working out, but you’re still getting a great workout."

"I also started researching nutrition, learning about how carbs, proteins, and fats affect your body. I think that it’s helped me improve my mindset with nutrition. Emotional eating is so real and is a daily struggle. But knowing how things affect my body helped me change the way I ate and the way I looked at food. I’m still not where I want to be, but I know I’m working toward it."

"WHY I JOINED UNITED SPINAL: I started going to our meetings right out of rehab and wanted to know how I could make my new life work for me. I still learn those things, plus, now that I’m a chapter leader I get the sense of pride and fulfillment of helping others."

TIP FOR NEWBIES:
Stay positive and keep trying. Not everything will work, but if you try enough things then something will work.
It's late March and Ian Mackay heads out to continue his streak of consecutive days with at least one mile on the Olympic Discovery trail near his home in Port Angeles, Washington. He started back in October 2016. Today is day 508.

Mackay says it feels good to see the trail more populated by fellow outdoors enthusiasts. His presence is as much of a fixture as the iconic majestic views of the mountain peaks, rivers and lakes it's known for — nearly everyone he passes knows him by name or nods in recognition. To be fair, the 4.5-foot-long dreadlocks draped over each shoulder, hanging down past his knees in thick, sunbleached cords, make him pretty hard to miss.

Humble almost to a fault, Mackay sidesteps any talk of his local celebrity status and redirects the conversation toward signs of spring along the trail. “You see it in the crocuses and the daffodils, the swallows and the goldfinches coming back around,” he says. “When you see those you get a little pumped up because you know warmer weather is coming.”

The lifelong birder, botanist and beer connoisseur is a driving force behind two nonprofits, runs three peer support groups and has accumulated nearly 10,000 miles in his power chair over the last three and a half years. In doing so, he has built a platform as a leading advocate for accessible trails all over the country. It’s a testament to a unique spirit whose love of nature brought him full-circle after a traumatic life shift in his mid-20s.

IN SURVIVAL MODE

Prior to the bicycle injury that left him a C2 quad nearly a decade ago, the San Diego native was a firm believer that nature was the best medicine. A self-confessed extreme extrovert, Mackay loved being outdoors, tailoring his college studies specifically toward a career as a community college field biology teacher. He wanted to share his passion with others. “I wanted to take people out and show them these things that made me love being outside,” he says.
When he wasn’t scouring Southern California’s back-country terrain in hopes of photographing some of its more elusive flora and fauna or searching for the perfect soil to make Native American-style pottery, he could be found zigzagging the coast in his ’78 Volkswagen “Westy” camper van, serving as road support for friends doing bike tours. “It was often my job as road crew to swing through a brewery and grab some beers and get camp set up.”

That all changed in the summer of 2008 when the 26-year-old hit a loose patch of gravel while riding back from one of his classes at University of California, Santa Cruz, sending him headfirst into a tree, breaking his neck and rendering him a vent-dependent quadriplegic. The once fiercely independent outdoorsman was barely able to speak, and struggled mightily to adjust. “All of a sudden I lost my voice and I lost my body,” he says. “I became a totally different person. I wasn’t interested in being outside, I was in survival mode.”

Mackay relocated to the Pacific Northwest with his mother and stepfather immediately after being discharged from rehab, and spent much of that first year in self-imposed isolation as he worked his way off the ventilator. “I was trying to redefine myself, and I think that was a mistake,” he says. “Instead of cherishing those aspects that made me who I am, I was trying to figure out who I could be after my injury.”

“I was trying to redefine myself, and I think that was a mistake. Instead of cherishing those aspects that made me who I am, I was trying to figure out who I could be after my injury.”

POWEROUL PEER CONNECTIONS

A road trip to his old stomping grounds in Southern California for a friend’s wedding a year after his injury helped Mackay start to come out of his shell. He and his family stopped off to visit the therapists who helped him through rehab at Santa Clara Valley Medical Center. It was an emotional stroll down memory lane, but a trip up to the ICU to visit newly injured people put his situation and his progress in perspective.

“That was a turning point for me,” he says. “It allowed me to tell my story and see how far I’d come in a year.” It’s a pilgrimage he’s repeated at least once a year since, stopping off to see old friends and visit the newly injured. Kathy Kobayashi, one of his occupational therapists at Valley, says she’s been blessed to witness what she calls a total metamorphosis since those early days. “He’s taught us things that we still use today,” she says.

Recognizing the power of peer connections, Mackay didn’t want to limit those experiences to the occasional road trip, so he started a peer support meeting near his home with the help of a friend and caseworker. In the beginning, there were many meetings where it was just him, a caregiver and his family, but attendance slowly grew over the months and years that followed. While the meetings gave him an outlet, he was still looking for a larger impact moving forward.

It wasn’t long after he returned home from that first road trip back to Santa Clara Valley Medical Center that he met Todd Stabelfeldt [see “Tech Titan,” Oct. 2017], a database manager and C4 quad of more than 20 years who lived an hour away. Being someone Mackay’s age with so much paralysis experience made Stabelfeldt the perfect mentor. “To see someone with a similar injury who is happy, successful and independent made me realize that I had a future ahead of me,” says Mackay.

Stabelfeldt could sense something in his dreadlocked friend that ran much deeper than a funky hairstyle — a fire for independence roiling underneath the surface. “He is a very special individual,” says Stabelfeldt. “He’s hungry.”

I got to experience that fire firsthand when I met Mackay at a gathering of local quads for the 25th anniversary party of Stabelfeldt’s injury. When our first conversation bent toward how far behind I was with adaptive computing, he couldn’t contain his frustration with me. “You’re an idiot,”
he said with a playful jab. He made a point of sending me some adaptive equipment a week later, and I couldn’t help but agree that I hadn’t known what I was missing.

The connections made that day planted the seed that grew into The Here and Now Project, a paralysis support network in the Pacific Northwest with hundreds of members who share their hard-earned knowledge for the betterment of others. For Mackay, it’s all about seeing what’s out there, meeting cool people, doing cool things. “We are lucky to be where we are in western Washington, to have a group of people who want to live well, have as much independence as they can, and are willing to go out there, find it and share it,” he says.

It was at another Here and Now get-together a year later that he and Stabelfeldt were introduced to Switch Control, an accessibility feature buried deep inside Apple’s iOS7 update that allows complete access to the iPhone platform with as little as a single microswitch. Within weeks, Mackay was testing the limits of the technology. “He was the first dude and was out there demonstrating it from the start,” says Stabelfeldt.

RECONNECTING WITH NATURE

Having reliable access to a phone meant Mackay could test a level of independence that he never thought was possible post-injury. Mackay’s compromised breathing means he needs someone close by at all times for a cough assist or other help. But having access to locator apps like Find Friends enabled him to take extended trips by himself, calling in support from the road only when needed. “It was scary early on,” he says, “but as my competence with the system steadily increased, it gave me the confidence to go further and further.”

The increasing solitude of those rides unlocked the familiar healing power of nature that had been missing from his life. “I could see the migrating birds come through. I could see certain flowers blooming, and the seasons change. I was able to talk to people and be by myself, and do things I wanted to do. That’s where I found something that I loved.”

Mackay soon found himself pushing the gearless, brushless motors of his Invacare TDX to their limits, topping out at 30.1 miles in a single charge. That kind of range opened up a whole new world of possibilities. Because his family’s home was nestled smack in the middle of the 17 miles that separate the two port towns of Port Angeles and Sequim, they were both well within range for independent trips. “It allows me to go either direction, depending on what I’m looking for that day,” he says.

The first time he visited Barhop Brewery in Port Angeles by himself, he knew he would have to ask the waitress to help him with his beer. “You have to do that,” he says. “You have to reach outside your comfort zones if you want to be independent.” By the end of 2015, he had sufficiently stretched his comfort zones, accumulated nearly 2,000 miles on the trail and was setting his sights on much more ambitious goals for the following year.

IAN’S RIDE

Dubbed Ian’s Ride, McKay’s grandest plan yet was to start from his home in Port Angeles, take a ferry up to Victoria, British Columbia, and then, using just his wheelchair, work his way south in 30-mile chunks, stopping at breweries every night. The trip turned out to be a more ambitious undertaking than he first imagined. In total, he spent nearly 75 percent of the ride navigating inaccessible highways and main roads in between the occasional reprieve of groomed trails. It gave him plenty to talk about with the handful of local politicians who joined him for stints along the way.

“There was so much for me to learn about infrastructure and transportation, as well as the financial cost and the environmental impact of building new trails,” he says.

Mackay is quick to admit that the adventure wasn’t an entirely selfless pursuit. “I just wanted to explore new trails and drink good beer along the way,” he says. “I wanted to relive my heyday and rekindle that love of doing cross-state bike rides from my chair.”

He also met up with a handful of chair users like Joe Meyer, a C4 quad from Bothell, Washington, who joined up with Ian for a 17-mile trek down the Burke-Gilman Trail near his home. Being part of Mackay’s grand adventure motivated Meyer to push outside his comfort zones as well. “Ian inspired me to test the limits of my batteries and see how far I could go independently,” Meyer says. He
would later put the Washington public transportation system to the test by traveling 300 miles in a single day to visit Mackay at his home, taking 14 different buses, and a couple of ferry rides to complete the task.

For Mackay, the whole experience harkened back to his pre-injury days. Instead of taking students up an obscure path in the backcountry to find rare plants, he was introducing the beauty of paved trails to a different cross-section of his community. “It was those experiences that I have such amazing memories of,” he says, “and to be able to re-experience them in a different way was really special.”

In total, the trip covered 340 miles in 12 days and raised $5,000 for local charities. “Don’t forget 15 breweries and 107 unique beers,” Mackay adds. In recognition of his accomplishments and work on behalf of others, Gov. Jay Inslee crowned him Washingtonian of the Day, and Washington Bikes named him its Person of the Year and asked him to be the keynote speaker at its annual summit. “If you would’ve told me I would meet the governor and do all these cool things, I wouldn’t have believed it.”

ADVOCACY ONE MILE AT A TIME

Most people would take a break after such an arduous experience, but Ian’s Ride just fueled Mackay’s drive to push toward increasingly larger goals. In 2017, he easily surpassed his new goal of 3,000 miles, finishing the year with an astounding 4,700 total. That included two nearly successful attempts to “Ride the Hurricane,” an annual 18-mile bicycle race from sea level to the top of Hurricane Ridge at elevation 5,240 feet. He also led a group of chair users up Mount Rainier to highlight the need for accessible trails there.

Much of 2018 saw Mackay settling into his new custom-built home on his family’s property, taking on a more active role in the development of both The Here and Now Project and Ian’s Ride, which became a nonprofit earlier in the year. But it hasn’t been all desk jockey work, as his elevated platform compelled him to take his advocacy to the national stage, making the long trip to Washington, D.C., for United Spinal Association’s Roll on Capitol Hill. “Too many of us are stuck indoors,” he says. “The more access that’s available, the easier it is for those of us who have mobility impairments to enjoy what’s out there. My brothers and sisters in chairs across the nation should have those opportunities to get out there and see the world.”

Once home from the nation’s capital, he set his sights squarely on prep for another epic ride with friends across Washington State in August, this time from East to West starting in Coeur d’Alene, Idaho. Spanning nearly 500 miles and over 25,000 feet of culmulative elevation gain, Mackay overcame a streak of days hovering near triple digit temperatures and smoky air conditions from multiple forest fires within close proximity of his route, stretching his consecutive mile streak to 661 days. “Adding an extra set of lithium-ion batteries to my chair was a game changer,” says Mackay. “It helped on the larger inclines and gave me a higher average speed overall.”

Asked about future goals, Mackay points to the East Coast Greenway, a route that stretches from Florida to Maine that he found time to zip down a portion of while in D.C. “It has been on my radar for a while, and I hope to ride a bigger portion of it one day,” he says. Whether it’s down the Eastern Seaboard or across the more familiar trails back home, Mackay is sure to continue his trailblazing ways one day and one mile at a time.

RESOURCES

- Ian’s Ride, iansride.com
- Switch Control, apple.com/accessibility/iphone/physical-and-motor-skills/
- The Here and Now Project, hereandnowproject.org

“The reward.
Acute spinal cord injury is mostly the same as it’s always been — crazy mixed up confusion, anxiety, shock, grief, regret. Rehab is shorter than ever. Doctors still say “you’ll never walk again,” but not as often as they used to; most at least know that they just don’t know. Physical therapy is more active and less compensatory, a nod to more aggressive therapies that have helped many gain significant health benefits, and even motor function. The psych component remains woefully underserved.

It’s still really easy for anyone to join the SCI club. You can jump in, as Ashton Fritz did, or get slammed in, as Edie Perkins did. Of course, neither of these young Californians gave life-changing trauma a moment’s thought — until it showed up. But they’ll tell you now how real it got, and how fast. It’s the most expensive, annoying, unfair situation, and the least exclusive group ever.

We will follow Fritz and Perkins, both spinal cord injured in 2017, as they navigate total chaos toward manageable chaos. I don’t know if you’d say they’re rehabbed, but they are home and settled now, Perkins working and Fritz back with his family and in college.

To get where they are, both had to confront the limits of their health care insurance. They did so in very different ways, but in the end they both used the powers of a networked SCI community, peer support and the kindness of strangers to mostly get what they needed. Here’s how.
Edie Perkins’ Story

Perkins was toned and fit, a competitive marathon runner, a badass distance cyclist. She once rode from Oregon to New York, on a whim. She had recently located to the Los Angeles area from New York City, where she’d spent 20 years in children’s book publishing.

On the morning of April 20, 2017, Perkins had just begun a bike ride, heading out from her house in Eagle Rock toward the Angeles Crest Highway. A woman driving an SUV was blinded by the sun and ran head-on into her. She spent 10 days in the trauma unit at Huntington Hospital in Pasadena with 11 broken ribs, multiple spinal fractures and paralysis at T5.

Today Perkins is OK and continues to get stronger. She’s working, staying active, still figuring this new life out, but upbeat and grateful. Her story is about how getting no advice and no information led to poor rehab, the need for paying out of pocket for good rehab, and eventually getting great community support and a decent homecoming.

Wrong! There is a huge difference between good and mediocre rehab.

Perkins’ insurance was purchased on the Affordable Care Act marketplace, yes, Obamacare. She had a silver level Blue Cross HMO. Not the worst plan, but clearly not the best when it comes time to pay for trauma care, but of course nobody looks at the back-end coverage for such things as rehab days or durable medical equipment benefits. Blue Cross assigned Perkins to Allied Pacific, an independent doctors group that has contracts with a handful of area hospitals, none of which has an accredited inpatient SCI rehab unit, or a board certified SCI doctor. She ended up being designated to Garfield Hospital, 10 minutes south of Huntington.

In my Southern California edition of SCI: First 90 Days [see sidebar], I rank rehabs in the region, based on accreditation and volume of spinal cord injuries. Garfield is in the bottom tier — lowest volume, no accreditation. Garfield’s Yelp ratings, take ’em or leave ’em, are not even lukewarm. Moreover, Garfield’s care is rated poor by the California Office of the Patient Advocate. Would you send your best friend or your mother to this place? Not if you had a choice. But rarely will anyone tell you that you might have a choice. Most people are so freaked out in the trauma hospital setting that challenging an insurance company decision just doesn’t happen [see sidebar].

Perkins and her family, blinded by the enormity of her injuries and her doctors’ misleading advice, didn’t know about Garfield’s rankings, or about insurance in general. Could they have appealed? Yes. They could have made a strong case that Garfield lacked expertise to handle a complex injury and that Blue Cross was obligated by law to provide for proper medical attention, even if outside its network.

“The plan to send me to Garfield didn’t feel right,” says Perkins. “We asked about other places. My parents visited California Rehab Institute and Casa Colina, both nearby, and much more familiar with SCI. But it was ‘no no no’ from the insurance company.”

Not ‘So Basic’

Perkins wanted to stay at Huntington for rehab; it’s a nice place even though it lacks specialization in SCI care. There was talk about flying her to Spaulding Hospital in Boston, where she’d grown up, or to Craig in Colorado. Neither of those places, Perkins would learn, was in her insurance network. She was fitted with a halo brace due to her complex injuries, and that complicated travel. Her physicians advised her to stay local. Indeed, doctors at Huntington urged her to go where the insurance dictated. “They told me the first month was so basic — teaching transfers and building strength — that there was little difference in quality between rehabs.”

After an unnecessarily arduous rehab process, Edie Perkins is home.
ALONE AND IN THE DARK
At Garfield, Perkins was the only person on the unit with a spinal cord injury, and the only one in her age group. She had a private room, ate meals in her bed. There was little social contact with other residents, most of whom were elderly and had had strokes.

Some of Perkins’ nurses didn’t speak English. “The staff at Garfield, they cared, they wanted to help me. Even though they were nice, they didn’t seem to have experience with some basic things about SCI.”

You’d think a rehab hospital in a major metro area would have the rudiments of neurogenic bowel and bladder care down. Perkins said she was transferred to a commode, expected to urinate on her own, and to move her bowel unaided. “They thought I would just start pooping, like, ‘Here, sit on this commode every morning and try to get regular.’”

Perkins wondered if her urologist had any SCI-specific training. “He kept getting mad at me for having to pee so much at night. This required a nurse to cath me, which they often neglected to do. In the morning I would have 1,000-plus ccs of urine. The doctor told me not to drink so much water. I learned later that people with edema would retain a lot of fluid in lower extremities, and therefore urine output increases at night. Seemed strange that a urologist wouldn’t know that.”

The urologist also put Perkins on antibiotics in advance of her having any symptoms of infection. This made her nauseated and interfered with physical and occupation therapy.

Getting her full allotment of therapy time was another struggle. “Usually what would happen is the nurses would neglect to get me up and ready for PT/OT. They would leave that to the first therapist to appear,” says Perkins. “It would infuriate me. We’d waste a whole session with the PT changing my diaper, putting my pants on and getting me into the chair. So I made a stink. The administrators responded well enough to my pushiness. But it was still hard to get nursing to comply.”

Perkins’ HMO approved three weeks at Garfield, but because she was still sporting the halo, which limited much of her mobility and therapies, she got extended to six. When Garfield deemed her rehabilitated, she wasn’t close to being ready for home. The HMO approved Perkins to enter Casa Colina’s Transitional Living Center — not full rehab services, but good prep for getting back home.

PROGRESS, FINALLY
To get her ready for Casa Colina, Perkins and her family paid out-of-pocket for more acute rehab: two weeks at California Rehab Institute. It was quite expensive, but “definitely worth the money,” said Perkins. “I got a lot of attention there. My doctor gave me a half-hour lesson every day. I learned about autonomic dysreflexia for the first time, and about bowel care, and I learned about using a catheter myself.”

Besides having a board-certified SCI doctor she trusted, Perkins discovered another key thing at CRI: community. She was met there by peer mentors Andrew Skinner, from the Triumph Foundation.
A chapter of United Spinal Association, and Dean McCabe, who she would see again at Casa Colina’s peer support program. “It was so moving, so motivational to have these guys wheel into my room,” she says. “I always had a sort-of vision that I’d become independent. I hadn’t lost hope. But I had no idea what that looked like. These cool guys zipping around, they were the first people I’d met who looked comfortable and cool in a wheelchair.”

Skinner sees SCI newbies all the time. “There’s no denying it, these folks are devastated. But we are there for them,” says Skinner, who’s been helming Triumph for 10 years now. “We share our testimony: We’re married, have homes, jobs, we’ve got responsibilities and lots more things planned. We do what we can to exert positive energy.”

Perkins stayed in touch with Skinner and McCabe. She got valuable advice about the new lifestyle, and also about dealing with such things as spasticity and pain. “These guys were so much more helpful with some medical issues than the actual doctors were.”

EXPELLED INTO REALITY

Eventually, Perkins got rid of her halo as she learned key survival skills at Casa Colina. Then the day came for her to be “expelled from the rehab womb.” She didn’t feel quite ready — common to most people leaving the security of full-time rehab services. Her bathroom remodel at home wasn’t finished, but there was a ramp into the house and that was good enough for discharge, ready or not.

“The spinal cord injury vets warned me that rehab doesn’t get real until you’re home,” she says. “Umm, yes. What they say is true. I knew it would be. But I had no idea how true.”

The first few weeks back home: brutal. “I measured progress by length of time between meltdowns. At first, it was how long and hard it was to do the simplest tasks. Getting dressed, going to the bathroom, cooking and cleaning all took forever, and was so damned hard.”

Continuing medical care is a critical concern. “I’d been home from the hospital for a few weeks and was referred to four urologists. Two don’t deal with spinal cord injuries, one refused to take me because I’m part of an HMO, and the other wouldn’t return my calls. Same runaround for outpatient therapy. I spent three to five hours a day on the phone trying to get it sorted out ... and nothing. The doctors in my network are terrible.”

Things eventually got easier. Perkins cited some little victories along the way:

**Week two:** “Getting through my bathroom routine alone, including the scary transfers from chair to toilet and shower bench back to the chair.”

**Week four:** “Figuring out the right dosage of gabapentin to alleviate my evil and incredibly debilitating nerve pain.”

**Week eight:** “Using a public restroom for the first time — pulling down and up pants in my wheelchair and on a toilet. This freed me to go out on day-long excursions with friends. A real life-changer. Monumental.”

**Week 12:** “Falling out of my chair at home alone and doing my first floor-to-chair transfer, which I’d learned a few days earlier watching a YouTube video.”

**Week 16:** “Training for my first race using a handcycle. Very excited!”

At the time of this writing Perkins is training to ride from Los Angeles to San Diego for a fundraiser.
little over a year ago, on July 28, 2017, Ashton Fritz was at a church camp in San Diego. “I was hanging with friends and we stayed up late, not wanting the fun to end on our last night. Unfortunately, while attempting a backflip with a dorm mattress laying on the floor, I snapped my neck on the landing, causing an injury that left me paralyzed. That decision forever changed my life.” And not just his life.

Fritz is still too fresh to his disability to have much of a perspective. That’s OK, he will. His story is about a family tossed into the churn, discovering tools they didn’t know they had available. The survivor community reached out. The Fritzes grabbed on. Next time, they’ll be the ones throwing out the lifeline.

CONNECTING EARLY

Fritz’s parents, Kevin and Sarah, got the dreaded middle of the night call and immediately drove 12 hours straight from Folsom, California. “We didn’t know what we were driving to,” says Sarah. On the way down, a surgeon told the family they’d fused Fritz’s anterior spine and were maybe going to do the posterior the next day. They arrived at University of California San Diego Hospital to find Fritz with no function in his lower extremities and limited function in his upper. “We were so in the dark,” says Sarah.

“We knew enough that Ashton’s rehab would be abbreviated anyplace but Craig or Shepherd Center — four to six weeks versus two or three months.”

The first couple of weeks there’s not much anyone can do. Floundering, that’s the word Sarah uses. Ashton was moved from intensive care to a step-down unit at the trauma hospital. By now the family’s insurance company, Kaiser, had been engaged. UCSD is out of network so the company was very keen on “repatriating” their client to a Kaiser hospital. At the two-week mark, they made arrangements for him to be flown to a hospital in Sacramento.

Not so fast, said mom and dad. The Fritzes had gotten some basic training. They went online, they tapped social media, they got advice from total strangers, they got the news media onboard. Debbie Paylor, whose son Robert had been paralyzed during a college rugby match just three months earlier, found the Fritz family by way of a Facebook page. (Turns out the Paylors live in the town next to the Fritzes.) She urged them to get in touch with Bernadette Mauro, director of resource services for the Christopher & Dana Reeve Foundation Paralysis Resource Center. Mauro had helped the Paylor family navigate Robert’s new reality and was instrumental in his move from rehab in California to Craig Hospital in Denver.

Anyone in crisis mode looking on the internet for SCI information will
INSURANCE APPEALS

Under the Affordable Care Act, you have the right to appeal decisions made by health plans, regardless of the type of insurance you have or state you live in.

- You have the right to know why a claim or coverage has been denied.
- You also have the right to appeal to the insurance company. If the case is urgent, your insurance company must speed up the process.
- If you can't work things out through an internal appeals process, you have the right to take your appeal to an independent third party for review.

California, for example, has a Department of Managed Health Care and an Independent Medical Review and Complaint Process. It's often worth the effort: Chances are better than 60 percent that an applicant will prevail over the health plan in an independent review.

The key to an insurance appeal is medical necessity, so it's advisable to get your doctor onboard. Tenacity pays off; some people and families lawyer-up to battle the company. And since health plans don't like bad press, using the news media to sell your story can sometimes seal the deal for you. That's what the Fritz family did, and they got what they wanted.

Come across Craig in about the first three minutes. It's a specialized high-volume SCI and brain injury hospital with a well-deserved reputation for being one of the top two or three rehabs in the U.S. As the Fritz family began to understand that there are differences between inpatient rehabs, they wondered whether there might be choices for Ashton. Says Sarah, "We knew enough that Ashton's rehab would be abbreviated anywhere but Craig or Shepherd Center — four to six weeks versus two or three months. We also heard about the age appropriateness of the specialty centers. Did we want him sitting in Vallejo with a middle aged man who'd had a motorcycle accident, or with a grandma who'd tripped in her kitchen?"

Kaiser owns a rehab in Vallejo, California, not too far from Folsom. It’s accredited in the SCI systems of care specialty by CARF. There's another rehab up north in Roseville. The Fritzes’ thinking was, let's get Ashton into one of those places and then transfer to Craig.

Mauro and Sarah connected the day of the scheduled flight. “We were planning to fly to Sacramento,” says mom. “People back home, Ashton’s younger brothers and friends, were so excited. But the first thing Bernadette said was, ‘don’t get on that plane.’ She said we’d burn our one allowed flight and it would make it harder to get to a choice rehab.”

Says Mauro, “I simply told her if Ashton took that flight, Kaiser would never approve any other opportunities for transfer. I told her she had one bite at the apple and needed to choose carefully.”

Mauro’s advice: “Get yourselves to Craig Hospital.”

A FORTUITOUS DETOUR

Craig said Fritz was admissible, but they’re not in Kaiser’s network. Kaiser wanted Fritz to go to its place. A Kaiser case manager threatened the family that if they didn’t leave they’d be liable for costs staying at UCSD. “They hadn’t offered us an actual medical plan, didn’t know if there was actually a bed available in Sacramento, and so we dug in. We told them, ‘You’re not ready, we’re not ready,’” says Sarah.

The Fritzes were prepared to take the risk that they might have to self-pay, figuring they had a short window of time before Kaiser came looking for them.

Meanwhile, the Fritzes actively campaigned to pressure Kaiser. They created Team Fritz and used social media and later, TV news, to make their case. A local stranger who heard about the family’s situation on Facebook offered an unsolicited recommendation: Write a letter to the CEO of Kaiser, making the point that this is a 17-year-old boy who has his whole life ahead of him and therefore needs a top tier rehab, e.g. Craig. “Tell them he needs to thrive,” the writer said. The family followed the advice and informed the CEO they felt “coerced” into going to another hospital and would not get on a plane unless it was to Denver.

Sarah basically hid out for a few days. If she didn’t sign a release, there was no way they could send Ashton to Sacramento. Meanwhile, the Fritzes kept up the social media messaging. Another stranger came forward to inform them that his family got Kaiser to approve an out-of-network transfer to a better rehab. And they got 22,000 people to sign an online petition.

What really turned the tide was using the news media. Television stations in Sacramento and San Diego ran segments on Fritz, mentioning Kaiser by name, and noting that his future success depended on a referral to Craig.

Sarah was soon contacted by a different Kaiser case manager, who was no doubt dispatched by the CEO. By then they’d all seen the news and the wellspring of community support.
There was still some “tap dancing” with Kaiser, says Sarah, as the company put up some resistance. Eventually Kaiser agreed to the transfer to Colorado. Fritz and mom boarded a plane to Denver; he was assigned the exact same room Robert Paylor had, and the same medical team. Fritz stayed four and a half months at Craig — longer than planned due to a pressure sore acquired at UCSD.

**LOOKING FORWARD**

Today Fritz reports that he’s doing well and getting the hang of things. In addition to gaining more mobility and stamina, he has gotten more adept using his knuckles and thumbs to control his phone and computer and is able to feed himself.

He’s not sure he’s ready yet to live on his own. “I know it’s possible, though,” he says. “At Craig, we met a quad with a higher level injury than me; he drives a sip-and-puff with his mouth. He lives independently in his own apartment and hires his own attendants.”

Fritz has his own list of little victories, including returning to high school last winter and graduating with his class last spring. “This experience has enabled me to connect with new friends that I might have been scared to talk to previously. It’s matured me too, surprisingly. I’m more outgoing and want to get more connected in college.”

He’s well on his way, having already been elected a student senator at the local community college he attends. He plans to transfer to a four-year college and get a degree in business. “Real estate might be a good fit for me,” he says.

**THE VALUE OF SPECIALIZATION**

I suggest that the basic issues faced by Perkins and Fritz, and anyone in the trauma/rehab/back-to-home cycle is that the value of specialization is not fully appreciated. Hospitals that are accredited have expertise, but this does not appear to be a major factor in determining the amount or quality of rehab that insurance plans will cover. SCI is enormously complex and has been recognized as a medical specialty for over 70 years, institutionalized in the U.S. with the advent of the Model Systems SCI centers nearly 50 years ago. They showed data way back then and it’s true today: Early transfer of people with traumatic SCI to integrated multidisciplinary specialized centers decreases mortality, and reduces time-consuming, expensive complications.

Specialized SCI management also reduces overall costs for insurance carriers. This is well-known in the world of workers’ comp, wherein insurers cover catastrophic care as long as their client lives. That’s why you often see workers’ comp folks getting the best care and best equipment: Higher front-end spending is cost effective in the long term. That’s far from the case with most private health plan carriers, and it’s not the case with Medicaid, though it really should be since government payors have the same long-term obligations as workers’ comp.

Getting to a top rehab should not be a challenge. But six of every seven people with new spinal cord injuries do not get to a Model Systems center, and the majority of the rest are not getting the obvious benefit of specialized, accredited rehab. And there are many low-grade HMOs that allow you 21 days of rehab at the local community hospital, and adios, you’re on your own, not our problem.

Over the last 30-plus years, managed care plans have set the agenda for rehab length of stay and discharge. Restricted services in the least expensive setting is great for the bottom line, not always so good for consumers. It’s hard to avoid the fact that many medical and rehabilitation decisions are made by insurance claims processors and not physicians. Too many folks are processed through a minimal and perfunctory wheelchair bootcamp. And when coverage runs out, they’re discharged, nowhere close to being ready to come back home.

**A MATTER OF LIFE AND DEATH**

Does the lack of respect for SCI as a specialty make a real difference? Yes, it does, and along the continuum of care, from injury across the lifespan, it may be a matter of life and death. Short-term SCI survival has improved greatly over the past 50 years — there are more clinically incomplete injuries, attributed to better roadside and acute management. But after two years, life expectancy has not changed. In fact, according to the medical literature, mortality in spinal cord injury
has actually gone up. It was higher in the 2005 to 2012 period than in the 25 previous years.

How can that be? SCI survivors are dying less from cancer, heart disease, suicide, and urinary tract diseases, same as in the general population. These gains have been offset by increased mortality rates in the SCI community for diabetes, nutritional and metabolic diseases, accidents (including drug overdoses), mental disorders (including addiction), homicides, nervous system disorders, diseases of blood, and musculoskeletal disorders (e.g. osteomyelitis).

According to the research, the mortality rate for systemic infection — septicemia — has not changed in 40 years, and no change has been reported in the death rate for respiratory diseases like pneumonia. Per the study, “significant gains in life expectancy will therefore not occur until progress is made in reducing mortality in septicemia and respiratory diseases as well as reversing trends in diabetes and accidental deaths.”

To me that means better care over the lifespan will save lives; better care means providers are better trained and specialized.

### OUR TO-DO LIST

**What are we going to do about this?** Those newly injured and their families need help navigating this system; a lot of folks needlessly thrash around trying to figure things out on their own. When they don’t, they’re back in the hospital with a major infection or complication.

Every person with a new spinal cord injury deserves to get access to the best care. Most don’t know what that is, or where to find it.

Every person with a new spinal cord injury deserves to get access to the best care. Most don’t know what that is, or where to find it. 

Our to-do list:

- **Patient advocacy** is to some degree being addressed by information and peer support agencies, like United Spinal Association and the Reeve Foundation. But these nonprofits are not in the case management business independent of the trauma system.
- **Our network** is the goal.
- Find your peers, and join them.
- They helped get things organized with supplies, equipment and medications, lined up his high school accommodations, and even set up his local doctors’ appointments.
- “We understand what challenges people face when transitioning home,” says Candy Tefertiller, director of Physical Therapy at Craig, who helped develop the program. “Soft Landing helps us improve our rehabilitation program to ensure a successful transition to the individual’s home and community.”
- More than 50 percent of those served by Craig come from out of state, and many are sent home with very complex technology. Says Tefertiller, the equipment needs to arrive in good working order, and the person with SCI’s family or caregivers need to be confident with operating and maintaining it.
"IF I am experiencing this issue, then so are other wheelchair users." It’s a simple thought that crosses all of our minds at some point, and it’s also the root of many great innovations that have made the world more accessible.

For Adrian Hollis, that thought struck when his feet kept getting stuck in his wheelchair’s casters. For Jason Derrington, it hit during a near catastrophe in an airport bathroom. The frustration caused by his phone frequently falling to the ground did it for Josh Smith.

In each case, these three regular guys devised functional solutions that not only fixed their problem, but promised to help others in similar situations. But bringing a product to the masses isn’t as easy as simply thinking it up and willing it into existence. It’s a process that can be frustrating, laborious and often disappointing. Here are the stories of how they persevered to bring us the BIGPAW, the Easy Reach and Attracmount.

The BIGPAW
In 2005, Adrian Hollis was working as a foreman for a power-line construction company in Melbourne, Australia, and kept his creative side busy with a home workshop he used to make furniture as a hobby. A motorcycle accident left him with a T4 spinal cord injury and a wheelchair, giving him a new reason to use his workshop.

"With my first chair out of rehab, my feet were all over the place and getting caught up in the casters, so I made a basic metal plate with rolled sides and stuck on some grip tape, and it helped solve the problem," says Hollis. The invention even allowed him to go barefoot when he wanted. The curved-up metal sides kept his feet from shifting sideways into his front wheels and a strap around his ankles stopped them from falling off the front or the back. Hollis was happy with his handiwork, but for over a decade he didn’t think to expand the scope of his project beyond a personal solution.

A pressure sore in 2017 changed all that. Hollis spent almost four and a half months in bed, using what time he could while healing to try out a new wheelchair to help his skin integrity. Still, one thing was off — the standard footrest gave him the same problems his first chair’s did, and his feet kept slipping off, hitting the wheels. “So with all my available time, I set to work to make something for myself,” he says.

This time, he went beyond his own wheels, creating a template for a custom footplate to benefit other wheelchair users and present a business opportunity in the process.

With an actual company in mind, Hollis pursued patents and partnered with a manufacturer to create the innovative footplates for chair users who need them. He also gave the product a name — the BIGPAW. After a little nagging, some buddies tried out prototypes. “My first trial plates went to mates who put it on to shut me up, then they realized the benefit of having it fitted,” he says. He decided the BIGPAW would be custom cut using measurements from a printable online template. The finished product can be mounted to pretty much any wheelchair using heavy-duty two-sided tape or a set of bolts. Soon enough, he was getting rave reviews. Within the first year, Hollis sold more than 100 units in Australia, New Zealand and the United States, and he has more on the way.

Handizap and Attracmount
Once Josh Smith tasted success with his first invention, the Sixth Digit, there was little doubt he’d be back with more.
A Richmond, Virginia, resident, Smith graduated with a mechanical engineering degree from Virginia Tech, worked as a nuclear engineer at Norfolk Naval Shipyard, and then in March 2014 took a job at Old Dominion Insulation, where he still works. Five months later he dove into a sandbar and fractured his sixth cervical vertebrae.

During rehab at Atlanta’s Shepherd Center, he decided that using his knuckles and a plastic typing clip to work his phone and computer were not good enough. The engineer in him immediately woke up, and while still in rehab he designed a specialized stylus for quads: a ring that hooks around the pinky finger with an attached metal tip that can be used on cell phones and touch-screens. He named it the Sixth Digit and created a design and sales company called Handizap. “Handizap is how I flex the engineering part of my brain and solve the problems that people encounter in their daily lives,” he says.

After he got home from rehab, he raised $10,000 via a Kickstarter campaign and found a manufacturer. The whole process took under a year — design started in October 2014, crowdfunding in April 2015, and he and his business partner, Jared Rhodes, secured their first shipment of the Sixth Digit by June. “Since then, we’ve sold thousands in different countries and 40-plus states,” he says. He even secured a distributor in the United Kingdom for the European market.

Smith designed his next invention to keep his cell phone from falling off his lap while he rolled around. His solution, the Attracmount, features a strong magnet that straps around any tube on a wheelchair and a cell phone case with a similar magnet on the back. The creative design keeps a phone or key ring securely in place, but still provides enough flexibility for a quad to grab them easily. The Attracmount isn’t just for wheelchairs. “It’s versatile,” Smith says. “It can be used for strollers or bikes or anything else metal that you’d mount your phone on.”

Smith and Rhodes began another Kickstarter campaign for the Attracmount and expect to receive the first shipment any day now. Smith sees a bright future for his inventions. “Big picture, it would be great to balloon Handizap up and have more products,” he says. He has made it this far while maintaining his day job as a purchasing manager for Old Dominion Insulation and is happy to advise potential fellow inventors. He urges others to branch out and ask people outside their circle if they have a product idea. “Figure out what the consumer is currently using and find out how to make it better,” he suggests. As for his own work, it’s all about the impact. “As long as I can make a positive difference in people’s lives, that’s what matters.”

Easy Reach

Several years ago, Jason Derrington, a T10 para, found himself stuck in an airport bathroom in a crappy situation. He transferred from his wheelchair to the toilet, but when he finished doing his business, he was unable to wipe while sitting on the standard toilet seat. He had to transfer to the floor to clean himself up. The experience...
was demeaning, unsanitary and took so much time he was anxious that he’d miss his flight. But more importantly, it gave him an idea to prevent similar situations from happening to others: a raised toilet seat designed specifically for wheelchair users and people who need caregivers.

Derrington built a platform that bolts onto any existing oval toilet and places the seat 4 inches higher up. Two large open areas on the sides make it easier for people with disabilities or their caregivers to reach under the seat and wipe. The front pillar also serves as a splash guard to keep floors and clothing clean. It is designed to be used anywhere — at home, in medical facilities, nursing homes or the bathrooms of public areas such as malls or airports.

Going from concept to product required partners and patience, but eventually paid off. Derrington was living in Indiana when he came up with the idea and partnered with the University of Southern Indiana to do the full design and testing using advanced computer models. The university staff refined an injection-molded design that computers showed could hold 600 pounds (lab tests held a full 750 pounds of weight without breaking, and the product has been officially rated for 450 pounds). Derrington spent “a lot of time and energy” to secure the patent and was able to procure a first run of 144 units after contracting with a manufacturer overseas. He dubbed his creation the Easy Reach and was finally rolling on his business venture.

One year later, Derrington moved to Texas to live with his father and take the next step with the Easy Reach. “My ultimate goal was getting my product to market so that it may help others better their quality of life,” he says. Through savvy marketing and a great attitude, Derrington connected with new distributors interested in selling Easy Reach on television and online. The whole process has helped him better identify his target customers and market his product.

Derrington’s success is the result of a lot of hard work. “As the founder of Easy Reach, I have been responsible for product design, legal consultation, prototyping, stress testing, management, marketing and sales,” he says. He has also kept inventing, improving the existing design, modifying the Easy Reach to fit round toilets and working on a soft top seat for added comfort. With distribution deals wrapping up, he is set to sell hundreds of Easy Reach seats in the coming months.

While many business people are focused on profit, Derrington leans more toward independence: “I want to work myself off Social Security,” he says, “and help put my daughter through college.” Even more, he wants to use his own example to motivate other businesspeople who might be struggling. “This one product has given me tremendous unexpected value — becoming an organic leader by spreading positive influence and becoming a creative inspiration.” His message is clear: keep inventing, keep working, and use your ideas to improve the world around you.

Resources
• BIGPAW, bigpaw.com.au
• Easy Reach, 812/202-1892; easyreachtoiletseat.com
• Handizap, handizap.com
• Solar Mobility, 509/851-3611; solarmobilityinc.com
Inventors don't need to use wheelchairs to create new products for the folks who do. Kurt Schneider, founder and CEO of Solar Mobility, is trying to revolutionize the way we juice our power wheelchairs. A retired Navy vet who worked in the medical corps, he and his wife were running a food stand as a part-time gig in 2007 when they encountered a road-tripping chair user whose battery ran out midday. Luckily, the man was able to find a nearby power source, but Schneider was blown away that there weren’t options besides a wall outlet and charger.

Instead of standing around, Schneider decided to build a fix. His first solution was a solar panel array that sits on top of a wheelchair for rapid charging, the Solar Companion. “It’s a multitude of things,” says Schneider, noting that the canopy design gives users respite from the sun, has both lights and reflectors for visibility and, of course, helps keep batteries charged.

As Schneider was going through the lengthy process of refining, patenting and manufacturing the Solar Companion, he saw an opportunity to do more. His next goal was a solar-equipped wheelchair with additional unique features — especially an improved seating system. Schneider saw the dangers of skin breakdown from his time in the Navy, and realized the extent of the problem as he pushed the solar panels through FDA and insurance approval. His inspiration came from the long-haul trucking industry: His new chair is designed to help maintain skin integrity by adding “air ride suspension” between the seat and the frame to create built-in air circulation. “It was taking from two different industries and making a new product,” says Schneider.

The full process from design to approval to sales took nearly eight years and the resulting product is called the Liberator. Testing, securing patents and working to get the Liberator insurance approved was tedious and time consuming. “You must be persistent. If you’re not, you’ll fail,” says Schneider. The chair now has VA insurance approval and Schneider expects it to be available for Medicare and Medicaid recipients soon, and hopefully for private insurance as well.

The final product is manufactured almost exclusively in the United States and features a solar-charging system that also works with low ambient light. Schneider tells of a user who was running low on battery at night and was able to park under a streetlight to get enough charge to ride the extra couple blocks home.

Despite some setbacks and the time from design to sales, Schneider is happy that he took the innovator’s path. He believes the Liberator has the potential to save medical costs by staving off pressure sores, while also changing the way chairs are powered. Most of all, “it’s been a fun project,” he says, and he’s looking forward to the future.
What should you do when you have a chronic, non-healing wound? I was faced with this life-threatening dilemma recently and had to undergo three major surgeries and spend six months in bed to close the wound.

Most of us seek out wound care specialists or clinics when a wound won’t heal. Treatment usually begins with bed rest or offloading, as if pressure is the sole cause and relieving pressure is the only remedy. Specialists often focus on topical treatments rather than doing a complete health history, lab tests, imaging procedures and nutritional screening to get to the underlying causes of non-healing wounds associated with spinal cord injury. But another approach is to take responsibility for your own care.

This does not mean that you are qualified to act as a doctor simply because you have had wounds. It means you must read, study, question nurses and doctors, and talk to others with SCI who have had the same problems in order to understand the underlying factors involved in skin breakdown and healing. Then you must seek out qualified nurses, doctors and other healthcare specialists with experience in treating SCI-related wounds. A
comprehensive team approach is ideal.

Depending on severity, non-healing wounds sometimes require flap surgery — a range of reconstructive surgery options that require a plastic surgeon. While bed rest and offloading are critical to closing the wound, a more comprehensive protocol that ensures adequate blood supply, protein-rich nutrition, antibiotics, proper positioning, cleanliness, and a home support team is also required. The importance of all of these factors cannot be overstated, as evidenced by the relatively high failure rate of flap surgery.

**UNDERLYING CAUSES**

Sometimes flap surgeries fail due to untreated underlying causes, such as undiagnosed osteomyelitis, or bone infection. Dr. Bruce Ruben, who owns and operates Encompass Healthcare and Wound Medicine in West Bloomfield, Michigan, is known for finding and treating underlying causes, not just symptoms. Other doctors often refer their patients with non-healing wounds to his clinic, which is known for attention to comprehensive care and complete wheelchair accessibility (see resources). Ruben has seen more than his share of osteomyelitis cases, but does not perform flap surgery himself.

While initial wound appearance may occur without osteomyelitis, Ruben says serious wounds often return because of the real underlying problem — bone infection. “When infection in the underlying bone is active, your body seeks a way to protect your life,” he says. “A sinus will open and wall itself off to get rid of the threat. That small superficial sore becomes the drainage port, your body’s way of expelling the enemy. But a wound will not heal and stay healed over infected bone. This is why aggressive IV infusion for several weeks before, and sometimes after, flap surgery is critical.”

Ruben says that even after active infection leaves, bacteria can remain dormant in bone marrow for many years. When our immune system is overtaxed for whatever reason, the dormant bacteria can “flare up,” become active once again, and another wound will appear, often in the same area.

**A CLASSIC CASE**

Mike Franz, 33, who has lived with C6 quadriplegia since 2001, experienced his first pressure ulcer three years post injury. “It was maybe nickel or quarter-size, only a few millimeters deep. There was some drainage, but it would go away with whatever the doctor prescribed — Santyl and a dressing, usually. Maybe Prisma, a collagen-enhancing wafer. But it came back every two or three years, even though I used a ROHO cushion and forced myself to take occasional down time.”

In 2014, the wound reappeared again. Same place — the right ischium — and same size. “I went to my usual doc, he treated it the same way. By Christmas it got a little worse. I wasn’t too concerned but decided to go to a different wound care clinic in a local hospital [Pontiac, Michigan] for another opinion. After that doc examined me, he said the wound was way worse than I had been told. I wanted to try hyperbaric oxygen therapy, but he said I wasn’t a candidate.”

The doctor began debriding and cleaning the wound. Over the next couple of weeks, it grew larger and deeper, which often happens with surgical debridement. “Then it began to tunnel and eventually went all the way to the bone,” says Franz. A wound vac was ineffective. His doc said he could do flap surgery and it would take three to four weeks to recover. “That didn’t sound right to me,” says Franz. “I had read at least eight weeks.” He decided to get a third opinion.

He went to Ruben, who told him he most likely had an underlying bone infection. “He was the first to suggest the bone could be infected,” says Franz. “I eventually decided to get a fourth opinion, and ended up going to a doctor from the University of Michigan for a biopsy and debridement surgery in May 2015, and sure enough, the bone was infected.”

His latest doctor prescribed IV Vancomycin for about four weeks prior to flap surgery and several weeks after. The wound, much larger now,
required advancement flap surgery, where muscle and intact blood supply is slid from the back of the thigh and “advanced” to the ischial area to fill the open wound. After a week on a Clinitron sand bed in the hospital, Franz went home to spend another 10 weeks on an alternating air pressure mattress, with home health care nurse visits and help from his mother and brother. It has been about three years since the operation, and so far, no more problems.

“I learned my lesson,” says Franz. “You have to be super vigilant. If possible, get multiple opinions. My first doc wasn’t doing a good enough job. The second discovered it was much worse than we thought. The third, Dr. Ruben, said it was a bone infection. He was the only one to listen to me and my aides. The others would always say pressure, pressure, pressure. We knew something else was going on, too. Docs do make mistakes. You have to learn all you can and be an advocate for yourself. This is no minor procedure. It’s a big deal.”

RECURRING FLAP SURGERIES

Pete Smith, 67, a T4-5 para from the greater Dallas, Texas, area, has been a wheelchair user since he was injured in 1978, but he didn’t have a pressure sore until 2004. Since then, it has been one problem after another. “I’ve spent every summer in the hospital for the last seven years. I’m hoping to make it safely through this summer.”

With multiple flap surgeries under his belt, Smith finds it difficult to separate one from another, but they have one thing in common. With the exception of his first surgery in 2004, none of them lasted more than a couple of years. Complicating underlying causes included a broken leg, a broken foot and a fluid-filled hydrocele on his scrotum. Secondary complications from SCI often cause us to compensate while sitting. Altered posture can redistribute pressure and lead to a new pressure wound. And yes, Smith also had recurring osteomyelitis.

After discovering his first wound in 2004 — he noticed blood on his underwear — he went to a wound care clinic. “I didn’t even know I was sick or infected or had a wound on my right ischial area. It was an opening the size of a fingertip, but when the nurse probed it, she gasped, ‘Oh my God, I can put this in all the way to the bone.’ By the time they debrided it, I had a wound the size of my fist.”

They tried a PICC line for IV antibiotics, and a wound vac. “The seal on the wound vac kept coming off when I was on the toilet, so I had to have a colostomy just to keep it clean,” says Smith. According to Ruben, a wound vac rarely works on an area that is not static and unmovable and is also contraindicated when osteomyelitis is present.

Eventually, flap surgery was followed by weeks in a Clinitron bed for complete healing. “That first one in 2004 stayed healed until 2010,” says Smith. “Then it failed, and I had to have three surgeries from 2010 until 2011.” Since that time there have been more flap surgeries.

Why so many? Besides underlying complications, Smith has always been active and a hard worker. As a geologist, he would spend hours at his computer without moving, glued to his screen. “Once I spent 36 hours straight without sleeping until I got the work done. Another time, on vacation, I drove 24 hours straight through because my wife was anxious to get home. Let’s face it, I was stupid,” he says.

In his case, continuous pressure was a definite cause, since it drove vital oxygen-carrying blood out of the fleshy area over the bone, causing prolonged cell death. He tried a custom RIDE cushion, which is made of a molded, firm material to offload vulnerable areas, but it wasn’t comfortable for him as an active para. Sure enough, he got a sore in a new area. His therapists insisted he go to a power chair with tilt in space. He resisted but finally gave in.

Even with his history of recurring wounds and surgeries, Smith is grateful. “I love the idea of sharing all this,” he says, “if it can help others.”

WHEN THINGS GO RIGHT

Sometimes osteomyelitis is not a factor. Jenn Wolff, 47, of Waverly, Iowa, became a T7-L2 para from a spinal tumor and surgeries in 2003 and 2007. In August of 2017, she broke her right femur, which required a brace. Swelling and the weight of the brace changed her positioning, especially when transferring. In September, she noticed a wound on her right ischial area about 2 centimeters in diameter by 3 centimeters deep. “My wound doctor packed it with Aquacel antibiotic packing, we tried Medihoney, and a wound vac — but none of it was working.”

Since she had gone to the Mayo Clinic in Rochester, Minnesota, for her spinal tumor, she returned there in March 2018 for an MRI. No bone infection was detected, so she went home to Waverly and consulted with a plastic surgeon at the University of Iowa. “We talked about surgery, but we had really bad communication about how to care for the wound after surgery. I decided to go back to Mayo for a second opinion.”
Once at Mayo, things started going right. “Dr. Basel Sharaf and his staff were really good. They had me see a nutritionist, go to a wheelchair seating clinic, see a nurse specialist in SCI and get a colostomy for cleanliness. I chose a permanent one. The wound actually healed a little prior to surgery because of it,” she says.

She had surgery at Mayo in July. A wound culture at that time found E. coli, so they inserted antibiotic beads during surgery and followed up with IV antibiotics for a week while she was in a Dolphin bed (made by Joerns, see resources). Mayo has satellite clinics, so she was transferred to transitional care in New Prague, Minnesota, for another five weeks on a Dolphin bed. “The place itself did a fabulous job,” she says. When Wolff went home, to continue her healing she put an alternating pressure overlay on top of her memory-foam mattress. She is currently on a gradual return-to-sitting protocol.

“I learned that what worked for me was not spending so much time on the toilet [the colostomy helped reduce pressure and fecal bacteria]. Also, following the protocol — calculating protein needs, taking a nutritional supplement called Juven that’s specifically formulated to support wound healing, staying off the wound area and opting for flap surgery when it seemed the best option. Hopefully, I’m at the end of this. I’m healthier than I’ve been in a long time. I want to go back to work, but I want to take time for myself, too — take time to heal, go to physical therapy and regain strength.”

### ALTERNATE TREATMENTS

Laurie Rappl, 61, of Simpsonville, South Carolina, has been a T12 paraplegic for 38 years. Prior to her 1980 injury she got her doctorate in physical therapy and later became a certified wound specialist. She knows wound care clinics from the inside out. “They have little incentive to try alternate therapies,” she says. “They go with products they can get reimbursed for. But sometimes alternate treatments work.”

Having both personal and professional experience with wounds, Rappl is a proponent of not only certain alternate therapies, but also of alternating different therapies. The trick is knowing which therapies work best on different stages of a wound.

Like others in this story, she developed a pressure sore while fighting off complications. In 2017, breast cancer in July was followed by a broken femur in September and a large coccyx wound in November. “My body was weak from chemo, and lying on my back drove pressure to my coccyx. I never thought about it but always checked my ischials. Then I discovered the coccyx wound.”

Luckily, there was no bone infection. She had the wound surgically debrided, then went on home healthcare three times per week, with three weeks of wound vac, one week of platelet-rich plasma treatments and another three weeks of wound vac. “Eventually it got small, with minimal drainage, so we finished it off with collagen dressings, which works well for final healing, but sometimes takes longer than you would think. PRP is a gel (see resources). A nurse friend drew my blood, and I centrifuged it with home equipment, then coated the wound bed, filling up the cavity using a wide-mouth syringe.”

When she first noticed the wound, she said she was weaker than she had ever been. But she made wise choices and stuck to her protocol. “No way that wound should have healed in five months, but it did,” she says. Flap surgery was not needed.

PRP therapy is not currently reimbursable by Medicare, so only forward-thinking wound clinics might be willing to try it. As an experienced professional, Rappl directed her own care at home. “What worked for me was eating lots of protein and taking a nutritional supplement, offloading and alternating treatments — to keep the healing moving forward.”

### RESOURCES

- “Lessons Learned From My Wound Care Journey,” newmobility.com/2018/05/flap-surgery-journey/
- Clintron Bed, hill-rom.com/usa/Products/Category/Hospital-Beds/Clintron-RiteHite-Air-Fluidized-Beds
- Dolphin Bed, joerns.com/product/2457/Dolphin-FIS%C2%AE.aspx
- Encompass Healthcare, encompasshealthcare.com; 248/642-9800
- Flap Surgery, ncbi.nlm.nih.gov/pmc/articles/PMC4511039/
- Prisma (Collagen), woundsource.com/product/promogran-prisma-matrix
- Protein for Wound Healing, optiderma.com/articles/wound-healing-foods-supplements
- PRP and Wound Healing, ncbi.nlm.nih.gov/pubmed/25179658
- Santyl (ointment), santyl.com
I imagine there is some set of etiquette rules that cripples are supposed to follow when lining up for treatments and cures, eh?

I imagine the cripples that get to go to the front of the line are those who were the guinea pigs. They're the ones who gladly let themselves be beta tested. They dutifully spent hours and hours working out in physical therapy gyms, took part in drug tests and/or agreed to have experimental surgeries.

I guess if I were interested in checking out a treatment or cure, I would be considered a gate crasher. Because I'm about as far away from a guinea pig as one can be. I've always had a strong aversion to being part of any campaign to cure my crippledness for a lot of reasons. There's nothing I find more tedious than exercising and medical compliance. God, how I hate taking time out to take a shot, change a dressing or whatever. I don't want to fritter away precious hours of life being medically compliant unless I'll die if I don't. I feel the same way about exercising.

I also fear that if I come anywhere near a cure campaign, I'll get sucked in to being an ambassador. What a horrid thought that is! I'll be expected to become an eloquent spokesperson for why it sucks to be someone like me. That's how these cure campaigns work. But I don't want that kind of pressure. It's too high of a price to pay.

A cure ambassador can never behave like a jackass, or you might ruin everything for everybody else. Because an effective ambassador must be tragic, even if just subtly so. And in order to be tragic, one must be ironic. Thus, the more brave, plucky and inspiring you are, the more ironic/unjust/tragic it is that you are crippled. But deep down in our collective, charitable heart of hearts in America, nobody wants to cure a jackass. We won't admit it, but it's true. There's nothing unjust about a crippled jackass. So I'd rather stay the hell away from any cure campaign and leave myself the freedom to behave like a jackass, since I know I'm inevitably going to anyway, like everybody else.

I'm wondering about all this because the FDA approved what some call a promising drug for the treatment of spinal muscular atrophy. I think that's what I have. I don't know for sure because when I was a kid in the 1960s doctors just figured everybody like me had muscular dystrophy, which meant they all thought I would die by age 20. When I didn't die by age 20, the doctors felt betrayed. They didn't know what the hell I had. And I never cared much what my official diagnosis was. I claimed MD and moved on.

The drug is called Spinraza. They say it might at least stop or slow the progression of SMA. One of my buddies is trying it. He's older and less crippled than I am. First off, he says he had to fight his insurance company for a year to get them to pay for it. And the Spinraza, my buddy says, is administered through a series of spinal injections.

Yikes! First you spike your blood pressure through the roof screaming at your pig-headed insurance company, and for your reward you get a series of spinal injections. I don't know about all that. And besides, it says on the internet that the most common side effects of Spinraza include upper and lower respiratory tract infections, complete or partial collapse of a lung or lobe of a lung, constipation, headache, back pain and post-lumbar puncture syndrome. Post-lumbar puncture syndrome? That sounds spooky. I think I'll wait and see how my buddy does with the Spinraza. If his lungs don't collapse and he doesn't die from a respiratory tract infection or constipation, maybe I'll look into it. Maybe then it will be worth the risk.

But am I worthy? Have I earned it? If I try to get in line, will I be resented by those who sacrificed their bodies, their time and their freedom to behave like a jackass to get here? Will they call the bouncer to throw me out? "Go find your own cure, ya mooch!"

I guess, under the right circumstances, I wouldn't mind getting a bit of break from my crippledness. But I wouldn't want to be rude about it.
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During the two decades that I have been writing articles and columns about accessible collector cars for New Mobility magazine, two basic facts have become clear: There is no “cookie cutter” definition of exactly what a collector car is, nor is there one single reason why people choose to collect, restore, customize or drive them. The cars can be called many different things, including classics, antiques, muscle cars, exotics or hot rods.

The hobby of collecting them is big business, as evidenced by the multimillion-dollar companies that sell or auction them, provide parts to restore them or haul them around the world to auction sites, dealerships and new owners. While some rare and pristine vehicles can sell for several million dollars at elite auctions, it is not necessary to spend a fortune to enter the world of car collectors, and the returns can be more satisfying than any monetary investment. One enthusiast summed it up best when asked what advice he would give someone who wants to purchase a collectible car: “Find something you like and then just do it. The first step might seem like a big one, but the results are well worth it.”

Fulfilling the Dream
Steve “Wheels” Bucaro of Palmdale, California, found his dream car at age 12. It was actually a model of a 1970 Chevelle, which he assembled and painted purple. When old enough for a license, he was into riding motorcycles and bought a road bike as a graduation present for himself and totaled it three months later. The insurance payoff allowed him to purchase that dream car, which had already been set up for drag racing. Two years later he was working on the car’s engine but didn’t have the torque wrench that he needed to finish the job. While waiting for a mechanic, he went on a motorcycle ride and was struck by a car and paralyzed. The work on the dream Chevelle has continued — slowly — for the last 20 years, with other priorities pushing it to the back burner as he pursued off-road racing and the building of other classic vehicles for competitions at the SEMA show in Las Vegas. Thanks to the help of several friends, he hopes to fulfill his childhood dream and have the car on the road later this fall.

The Seven Year Itch
When Bob Shatney, a T12 para from Garden Grove, California, bought a used 1969 Camaro in 2007, he figured it would not take much work to return the popular classic car to its original condition. Unfortunately, that restoration turned into a seven year project that occupied most of the spare time he had available in retirement. After he bought it, he learned the engine needed rebuilding and the car was besieged by rust. Getting rid of that rust required replacement of the floor pan and most of the major sheet metal. Although it took more time, he did most of the work himself. Because of that effort, the project turned out exactly as he envisioned it would. Some setbacks with his health have kept him from getting behind the wheel for the past few months, but he anticipates cruising in it again very soon.

Sinister Style
One of the attractions for those who collect classic cars is that popular styling doesn’t fade away over time. The Camaro is a good example of that according to
Glen White plans to take his grandson Kai on a Route 66 adventure.

Sam Learn, a C5-6 incomplete quad from Clackamas, Oregon, who drives a 2014 Camaro. When the later model Camaros were reintroduced by Chevrolet a few years ago, they had a big advantage in horsepower over those built in the 1960s. It is not necessary to pay a premium for that horsepower, as the car’s styling turns heads no matter how fast it is driven. By changing the chrome wheels into blacked out versions, Learn says the car has a look about it that is almost sinister, since the rest of the car is dark gray. He drives with Monarch push-pull hand controls, and there is room to put his wheelchair in the passenger seat during his transfer.

Room for 10 (or More)
Some collector car owners who use hand controls are not satisfied with owning just one vehicle. Glen White of Lawrence, Kansas, is a paraplegic with a love for the types of vintage cars he helped his father work on in the family’s shop while growing up. His 10-car garage houses several of these sturdy classics, but recently he has put most effort into updating his 1966 Impala convertible. While this convertible is a frequent visitor to car shows throughout the Midwest, it will have a more important role very soon — White intends to take a top-down “nostalgia drive” with his grandson, Kai, following historic Route 66.

Father-Son Fun
Some people started their restoration projects while very young. Bryan King, a para from El Centro, California, started work on his 1968 Camaro when his dad gifted it to him at age 9. They worked on it together for years, and finished during his senior year of high school. In 2001, he was injured at work and has since outfitted the Camaro with hand controls. He has also converted several pickups with features like bed-mounted wheelchair lifts and a remote-controlled canopy. King and his father recently finished installing hand controls in a Polaris RZR ATV that he can race in the desert.

The Hel Camino
Vincent Lopresti, a C6-7 quad from Hurst, Texas, has a 1985 GMC Caballero Diablo with a Bruno Outrider wheelchair lift in the back. The Caballero is similar to the Chevrolet El Camino, so he named his vehicle the “Hel Camino.” With the help of a mechanic, he has been doing much of the work on the Caballero himself, using his standing power wheelchair and several adaptive tools, and plans to race it once the work is completed. A recent setback when someone stole the truck and ruined the engine has altered his timeframe, but the truck was recovered and he continues to get it race-ready.

Safety First
One of the most popular and longest-running collector cars is the Chevrolet Corvette. Jemal Mfundshi, a C6-7 quad from Portland, Oregon, owns a 1998 Corvette for his daily driver. This is not his first collector-quality vehicle, as its predecessor was a GMC Cyclone, a high-performance pickup truck. As a longtime employee of an accessible car dealership, he knows the ins and outs of adapting vehicles and making them safe for individuals who need hand controls to drive. His Corvette is equipped with Sure Grip hand controls, eliminating the need for one of the rods that extends to the accelerator. Another safety feature that he has installed is a four-point safety harness to replace the standard combination shoulder and lap belt. While being firmly secured in the seat is a must when driving a high horsepower vehicle like the Corvette, he recommends that method of securement for anyone with limited trunk muscles in order to be safe behind the wheel.

Rebounding from a Rough Start
Someone who would probably agree with the importance of proper securement is Barry Long, a para from Woodinville, Washington. Long drives a 1968 Mustang that he bought in 1994. The classic car has 370,000 miles on it so far and is still going strong, but his first day of driving it with hand controls started out a bit shakily.

As he explains, “The first time I drove the ‘Stang with the hand controls, I drove it out of the installation garage never having any type of training or practice. When I got to the first intersection, as I took a left, I pushed the knob with my right hand to turn the car to the left and fell over into the passenger seat. Luckily I was going slowly so I pushed the shifter into park and the car lurched to a stop.” After practicing driving in an empty parking lot for about 30 minutes, he drove the 200 miles home without further incident. It still looks great and is driven regularly.

Resources
• Barrett-Jackson collector car auctions, azure.barrett-jackson.com
• Gooding & Company auctions, goodingco.com
• Hemmings Motor News, hemmings.com/auctions
• Mecum Classic Car Auctions, mecum.com
• National Mobility Equipment Dealers Association, nmeda.com
• Russo and Steele auctions, russoandsteele.com
• Specialty Equipment Market Association, semashow.com
• Sure Grip Hand Controls, suregrip-hvl.com
Spring and summer have been humdinger seasons for news about repairing spinal cord injury — and not just because of the encouraging research about cord stimulation I reported in April and July. This month’s story involves giving the brain a chance to reconnect to the cord below the injury site in a different, and potentially more exciting, way. I’m talking about corticospinal regeneration — the holy grail of SCI research for as long as scientists have been trying to repair damaged cords. To be brief, corticospinal regeneration is the process by which damaged axons that are attached to healthy neuron cell bodies grow past the site of injury and restore lost connections with cells below that lesion.

A quick refresher might be useful. In a functioning central nervous system, there’s a group of brain cells called corticospinal neurons. They have three main physical parts: a cell body, a forest of dendrites and a single slender axon with exquisitely tiny nerve endings at the far end. The cell body holds the DNA and builds proteins as needed. The dendrites are message receivers, and the axon is the message sender.

Collections of these axons, in long, dense bundles commonly called spinal nerves, are the “white matter” of the spinal cord. These axon bundles are part of what has been damaged in a spinal cord injury. Their cell bodies and dendrites, safely tucked away up in the skull, are fine.

Axons famously don’t grow and reconnect after injury, for lots of reasons. One is that a newly damaged spinal cord isn’t anything like a cleanly broken bone; it’s more like a toxic waste site, where decay is ongoing. The cord is supposed to be permanently walled off from intrusion, and it sees trauma as an invasion. When the cord is breached by broken vertebrae, inflammation follows, which leads to cell death, which leads eventually to a glial scar — an impenetrable wall that growing axons can’t ever get through.

At least, that’s the conventional wisdom.

But on May 29, 2018, a new study from the lab of Dr. Xiaoguang Li in Beijing described a successful attempt to regenerate corticospinal axons in rhesus monkeys. There are two reasons why this information from the journal Proceedings of the National Academy of Sciences of the USA should startle you.

First, rhesus monkeys are primates, closely related to humans. They share 93 percent of our DNA, as compared to rats, which share only 80 percent. Interventions that work for these monkeys are far, far more likely to work in humans than procedures that work in rats. Second, successful regeneration of corticospinal axons means functional return of both muscles and sensation. And that’s what happened in Li’s study.

Decades of unsuccessful lab work all around the world show just how difficult it has been to coax those axons to grow across an injury site, even in rodents. It’s simply an enormous victory to have managed it with primates. How did Li’s team get it done?

First, they caused T8 SCIs in these animals by creating hemisections, removing a 1-centimeter-long section from half of the cord — a half-cylinder-shaped piece about as long as a pencil is wide. Then, with the animals still in the acute post-injury stage, they inserted a tubular scaffold at the lesion site that was made of biodegradable material, like those stitches that eventually dissolve. Most critically, this bridge was infused with a slow-release molecule long known to be an irresistible lure for the broken ends of axons.

The bridge was made of chitosan, a type of fiber derived from the hard, outer shells of crabs, crayfish and lobsters. Chitosan has been studied, and used, as an excellent vehicle for sustained-release drug delivery in humans for more than a decade. Not only is it biodegradable, it does not form tumors and is nontoxic. These same Beijing scientists had used chitosan back in 2015 to test whether rats with completely transected cords could recover. They could, which is why it made sense to take the next step and test nonhuman primates.

The growth-attracting molecule in the chitosan tubes is known as NT-3 (neurotrophin-3), and we’ve known since 1994
that growing axons love it. Way back when that discovery was new, it seemed like the path to functional recovery was clear. For lots of reasons, it hasn’t been that easy. Li’s study is the very first time NT-3 has been shown to restore function in nonhuman primates, 24 years after the original work was published.

**What Did the Recovery Look Like?**

There were 32 animals in this study, and all of them were given the exact same T8 hemisection injury. After that, 20 of them had the NT3-chitosan tube inserted, and the other 12 were cared for as controls. Here, directly quoted from the paper, are the key data points:

- **Over one year after the surgery, a neural cable-like “bridging” structure connecting the ... ends of the severed right side of the spinal cord appeared in the NT3-chitosan matrix, whereas only scar tissues were found in the lesion control group.**

- **In the lesion control group, animals dragged their right legs most of the time. In the NT3 group ... we selected the 12 clinically most relevant parameters and showed good walking recovery.**

- **Compared to the lesion control group, the NT3 group displayed evident restoration of temperature sensation.**

- **NT3-chitosan signiﬁcantly reduced the incidence of bedsore [yes, monkeys do get bed sores], with a 58.3 percent occurrence rate in the lesion control group reduced to 10.5 percent in the NT3-chitosan group.**

The data in this paper is well worth looking at, even if scientific papers make your eyes glaze over. It gives me hope for a number of reasons. One is the meticulous nature of the work. Another is that it’s published by one of the most reliable journals, meaning that it’s been very carefully and thoroughly vetted by experts.

And finally, the authors are already focused on the next step: testing this product and process on nonhuman primates with chronic injuries. This is from the conclusion of the paper:

“While this study is mainly focused on acute injury repair, we hypothesize that for treatment of chronic injury, removal or at least partial removal of glial scar tissue will be needed ... of course, studies using NT3-chitosan to repair chronic lesion models ... are currently ongoing [emphasis mine].”

They’re already working on a chronic injury model! Let’s allow ourselves to assume the best possible outcome: that the work Li is doing right now with chronic injuries on rhesus monkeys is successful. Let’s assume that he is able to safely remove enough of the glial scar to allow the axons to regenerate and the test animals to recover some function. It’s a big assumption and it would be fantastic, but it wouldn’t be the end.

We can all see what the next questions would be. Could this work on chronic injuries that more closely match what most of us are up against — not nice clean hemisections, but messy contusions? Could it work if there was damage not just at the level of a single vertebra, but in more complicated situations with several sections involved? How might it be combined with one of the stimulation interventions, or with gait training or with cell transplants? Is there some point where an injury is “too chronic” (meaning, too far in the past) for this to be effective? At what point does it become risk-free enough for testing in humans?

The day is coming when we’re going to find out all of that and a lot more. The only question is when.

**Resources**

- *Proceedings of the National Academy of Sciences of the USA*, May 29, 2018, pnas.org/content/115/24/E5595

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“Sometimes I use the photos on Twitter to ‘reply’ to people in other planning and transportation professions when they post on issues impacting bike riders, like separated bike lanes being blocked or not swept and kept clean. I post a shot on their Twitter with our ramps, curbs and sidewalks being blocked as if to say, ‘welcome to our world’.”

— Terri O’Hare, creator @Wheelchairrampsandaccessfromhell
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