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What started as a simple inquiry about a potential profile developed into a beautiful correspondence between two longtime wheelchair users about life on the ranch. TIM GILMER and HENRY POLING wax poetic about everything from what kind of moms cows make to being stranded 17 miles from home to surviving a cold winter and much more.

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BULLY PULPIT

By Ian Ruder

ANNUAL REVIEW

A wise man once said, “Life moves pretty fast. If you don’t stop and look around once in a while, you could miss it.”

Between the never-ending crunch of trying to put out a magazine every month and the realities of adjusting to a new role, “fast” seems like an understatement to describe the 12 months since I took over as the editor of *NEW MOBILITY*.

Taking a second to look back on the year reveals a period defined by continual change and, I would argue, a consistent commitment to bringing you fresh, interesting and helpful content. Here’s a reminder in case you missed anything:

- We added Posts, a new bimonthly look at colorful stories from around the wheelchair world; Everyday Ethics, an insightful examination of everyday dilemmas; and Ask Us, a help column where our knowledgeable staff answer your questions.

- We replaced our Contributors page with Behind the Stories to give you more insight into the people who shaped that issue.
- Wheelchair Confidential debuted alongside Please Remain Seated to form Last Word, our new back page.
- Teal Sherer started as a new columnist, offering her unique insider perspective on all things media.

- Additionally, nine new contributors penned features for us, as did a number of excellent new bloggers.

If you extend the look back a little further to January of 2018, we’ve updated 14 of our departments with new looks, writers or entirely new content. That’s a whole lot of change, but I’m hoping that it went as smoothly for all of you as it did for us.

If so, all the credit goes to the awesome team we have putting together *NEW MOBILITY*. People always seem surprised when I tell them there are only five of us

who work full time on the magazine, but it’s true. Getting to know each of them better and work with them to solve the inevitable day-to-day issues that come up with an undertaking of this magnitude has been a great experience.

I know many of you were worried Tim Gilmer had sailed off into the sunset of

“People always seem surprised when I tell them there are only five of us who work full time on the magazine.”

retirement and taken his insight and prose with him, but now you must know that couldn’t be further from the truth. If anything, he’s written more content in the last 12 months than he has during any similar timeframe. His excellent series on doctors and nurses stands out among the many highlights of the year.

So what’s next?

We’ve got a great slate of stories lined up for the second half of 2019 and, after a year of working together, our team has a better understanding of what we need to do to keep *NEW MOBILITY* trending in the right direction.

As always, we are counting on your feedback and suggestions, and we genuinely want to hear what you’d like to see us cover and how you think we’re doing. If you read online, please take the time to comment, share or message us through our website or social media pages. If you read in print, please email me at iruder@unitedspinal.org. I’m excited for the future and I hope you are too.



BEHIND THE STORIES

With Ian Ruder



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 KARY WRIGHT

When Tim Gilmer shared his correspondence with Wyoming rancher **Henry Poling**, we knew we had something special. While we had initially been drawn to the unique nature of Poling's story, the back-and-forths between the two overflowed with candor, insight and compassion. They told a story that is quintessentially what we like to call "a NEW MOBILITY story" and did so in a simple yet elegant way. For anyone wondering what "a NEW MOBILITY story" looks like, I'll leave it to Poling: "This story, unlike others that have focused on me, actually reaches a target group that can truly relate to life in a chair and all the challenges that come with it," he says. "My hope from it is that it might lend some encouragement to others trying to recapture some of their prior life and realize that, though there are definite adjustments, you can stay on the path that you wanted to go down in life. Most people limit themselves far more in their mind than their physical limitations."



Photographer Kirk Williams meets rancher Henry Poling.

In the last year alone, photographer **Kirk Williams** has put over 25,000 miles on the camper van that doubles as his mobile home and studio. For the photos he shot for this month's cover feature, Williams only had to tack on a few hundred miles from his Boulder, Colorado, base of operations. They were well worth it. In addition to great photos, he came away with plenty of epic stories of survival and adaptation in an unforgiving environment. "I've met a lot of pretty hardcore wheelchair users, and I joked that Henry Poling is the Chuck Norris of all of them," says Williams.

We get more pitches for travel stories than almost any other type of article. Everyone wants to share their awesome adventures (and get paid for it!). Two of the things that set **Lilly Longshore's** pitches apart are her focus on affordability and her attention to detail. Life as a wheelchair user is rarely affordable, and travel can be cost prohibitive, but Longshore goes out of her way to provide budget-saving ideas to rein in costs. Some of that comes from her upbringing as one of 10 kids. "We learned to pinch pennies," she says. "Now, it feels good to be able to help others do the same when it comes to seeing the world." Read about her trip to Germany and Austria in this issue and her further travels at lillylongshore.com.



Please send queries, manuscripts or feedback to Ian Ruder: iruder@unitedspinal.org



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Nurses Rock

How lovely to get my copy of *NEW MOBILITY* and see Michelle Kephart on the cover (“Nurses on Wheels,” April 2019). The article on nursing is excellent. I was privileged to meet Michelle at the Women’s Camp in the Colorado mountains in 2011 or 2012. She is as extraordinarily kind as she is beautiful. I’m glad to have the cover photo of her as memory is so ... changeable.

Patty Lee
Newmobility.com

Struggles of Socialized Medicine

I suffered a spinal cord injury while living in Belgium, which has a single payer system like Bernie Sanders is proposing (“Is ‘Medicare for All’ Medicare for Us?,” April 2019). I want everyone to know that such a system would be the absolute worst scenario for people with spinal cord injuries. While in the Belgian hospital for two months, they did a number of things wrong, including giving me a hospital-borne lung infection. As soon as I was over the lung infection, the company I worked for found me a private spinal cord rehab hospital in Switzerland. I was moved there, and they had to correct all the mistakes made in Belgium. Because of the Belgian mistakes, it took another full seven months for me to get well enough to be released and manage on my own.

Socialized medicine may be great for annual physicals and people who have the flu, but for anything a little less common, there is no incentive for government to invest in the resources needed to treat less common injuries

“The article on nursing is excellent.”

or diseases. Please do not vote for anyone who says they want to move to Medicare for All. It will be a disaster for those of us with spinal cord injuries and for many others with less common injuries or diseases.

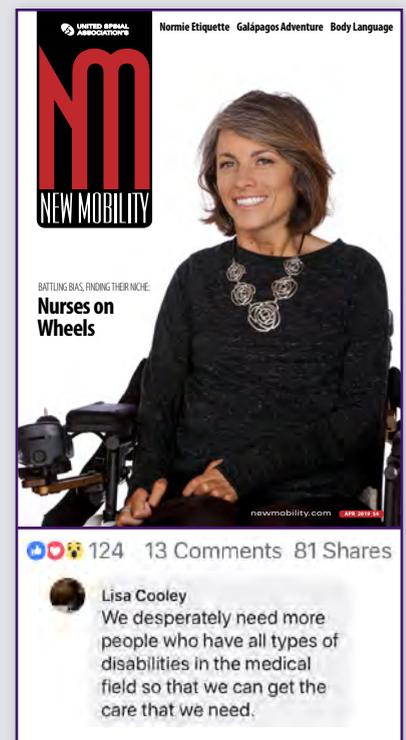
Jeff Yonker
Newmobility.com

Editor’s note: *Everyone in Switzerland is required to have private health care insurance, with those who work subsidizing the young, old and unemployed. Although Switzerland is ranked number one in Europe, Belgium’s government-run system is number five, trailing Netherlands, Norway and Denmark, according to a May 2019 article in Flanders Today. The United States trails behind both Switzerland and Belgium, placing 27th in the world, according to a study published by The Lancet in its Oct. 6, 2018 issue.*

Dr. Phil Inexcusable

One should not have to do an in-depth analysis to determine what was meant by a comment (“Why I Was Wrong About Dr. Phil’s Caregiver Episode,” Blog, Mar. 27, Newmobility.com). Insightfulness should not be a requirement to understand the meaning of a statement [about the role of caregiving in a relationship]. A doctor should also know to be very careful when giving absolutes! There are very few things in this world that can be 100%, 100% of the time. He would have to have data on EVERY single couple because even one success negates his statement. It was an unintelligent, and unprofessional, thing to say with the potential to cause way more harm than good.

John LeFebvre
Newmobility.com



Impossible Seems Possible

Your article made my day (“Exploring the Galápagos Islands,” April 2019). I’ve always wanted to go there and just figured it would be impossible in a chair. I’m going to start looking into it right away.

Michelle Steger
Newmobility.com

The Sting is Worth It

Wow, you are all amazing individuals who have gone through the stages of denial and acceptance and have adapted to what life has given you (“Living Through the Sting of Disability,” April 2019). A door is open to all who have the inner power to take back their lives. Once you embrace your new life, as if you had been reborn, you will find meaning to your life and realize that you can set new goals and accomplish anything you put your mind to. I was 21 when I became a T7 paraplegic. I was pregnant at the time and I am happy to say I’ve had an amazing 29 years. Regardless of my disability, I wouldn’t change the life I’ve had with my children.

Sylvia Luna
Newmobility.com

OUR QUEST TO PLANT TREES

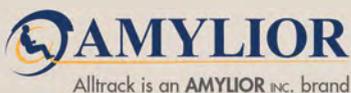
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By Tim Gilmer

TRUMP'S LETHAL SHELL GAME: WILL PRE-EXISTING CONDITIONS COVERAGE VANISH?

Amid all the media attention given to the controversy surrounding the Mueller Report, a critical piece of disability news was nearly crowded out: A March 25 Department of Justice letter sent to the U.S. Court of Appeals for the Fifth Circuit confirmed the DOJ's support of striking down the entirety of the Affordable Care Act. The letter stated bluntly: "The Department of Justice has determined that the district court's judgment should be affirmed."

The letter followed previous statements by President Trump that the ACA's guaranteed coverage of pre-existing conditions was "safe" and "in no danger." But if the ruling is eventually upheld by a majority-conservative Supreme Court that now includes two Trump appointees, guaranteed affordable coverage of pre-existing conditions would vanish.

Where would that leave those of us whose chronic disabilities demand continuous, consistent and timely health care coverage?

The National Council on Independent Living issued a fact sheet in January 2017 listing the harmful effects that repealing the Act would likely cause for those who have pre-existing conditions. Here is a general summary of the potential harmful effects as published in the NCIL's *Advocacy Monitor*:

- People with disabilities may lose coverage due to pre-existing conditions.
- People with disabilities may lose coverage due to plans being unaffordable.
- People with disabilities may lose their

ability to live in their homes and communities.

- People with disabilities may lose Medicaid coverage.
- Unemployment of people with disabilities may increase.

What few people are talking about, however, is the worst possible scenario: People with severe disabilities whose lives often depend on certain medications or treatments that must be administered regularly, often daily, could die.

It is no stretch to predict that thousands could lose their lives. A Jan. 23, 2017 *Chicago Tribune* article written by two public health experts from different universities claimed that nearly 44,000 lives would be lost as a result of repealing the Act. Similar claims by others who conducted statistical studies were published at about the same time. More recently, an Oct. 28, 2018 *Los Angeles Times* article pointed out that Trump bragged about supporting legislation to combat the opioid crisis at the same time his administration was pushing hard to eliminate healthcare coverage for those with pre-existing conditions, which "would effectively allow insurers to once again deny coverage to people seeking addiction treatment." The predictable result? More preventable deaths.

Will the ACA Be Repealed?

It is undeniable that repealing the ACA is one of the Trump administration's top priorities, as Republicans have been relentlessly pursuing that goal since it became law nine years ago. There



"Ordering government agencies to do the opposite of what he publicly claims he supports is akin to a high-stakes shell game. But it is not a game at all."

have been at least 70 Republican-led attempts to repeal, modify or otherwise curb the Affordable Care Act since its inception (*Newsweek*, July 29, 2017).

On Jan. 20, 2017, in his first day in office, President Trump signed an executive order to scale back as much of the ACA as possible without congressional action, a move that then-Press Secretary Sean Spicer said, "would ease the burden of Obamacare as we transition from repeal and replace."

Trump has promised to replace the ACA with an even better plan, but after two years in office neither he nor his party has yet to deliver. His



Illustration by Mark Weber

four-pronged attack on the ACA has included campaigning against it, issuing executive orders to weaken or gut it, promoting legislation to repeal it, and his latest — refusing to defend it in front of the Supreme Court.

A relatively recent timeline shows the Trump administration's actions:

2015-16: Trump promises to abolish the ACA.

2017: Trump-supported congressional attempt to gut the ACA fails.

2018: Texas Attorney General Ken Paxton, a Republican, brings a lawsuit to declare ACA unconstitutional. The lawsuit is joined by 17 other Republican state attorney generals and two Republican governors.

December 2018: Judge Reed O'Connor rules the ACA unconstitutional. O'Connor presides from the conservative United States District Court for the Northern District of Texas, often the court-of-choice for right-wing activists seeking to overturn laws they disagree with, such as the Americans with Disabilities Act and the ACA, as noted by the Dec. 19 *Texas Tribune* article, "By gutting Obamacare, Judge Reed

O'Connor handed Texas a win. It wasn't the first time."

Late 2018 through early 2019: Trump falsely claims his administration will protect pre-existing conditions, most notably during his Feb. 5 State of the Union Address.

March 2019: The Trump administration directed the DOJ to send a letter to the Appeals Court in support of O'Connor's ruling. According to a March 26 *Politico* article, both Attorney General William Barr and Health and Human Services Secretary Alex Azar opposed this letter.

April 2019: Following House Democrats' introduction of a bill to protect pre-existing conditions, Senate Republicans counter with a deliberately misnamed PROTECT Act. An April

12 *LA Times* editorial states: "All the PROTECT Act would do is encourage insurers to do something they did before the ACA: offer cheaper policies with thin coverage aimed at healthy customers, and considerably more expensive policies with comprehensive coverage for people who might actually need costly care."

May 1, 2019: The DOJ officially files a brief with the Fifth District Court of Appeals in support of declaring the ACA unconstitutional.

Trump's actions make his intentions clear despite his history of misleading and false statements, which have been publicly documented. His litany of hollow promises, incessant misdirection and ordering government agencies to do the opposite of what he publicly claims he supports are akin to a high-stakes shell game. But it is not a game at all. It is a lethal form of fraudulent misrepresentation.

Trump's Priorities

A 2017 report published by the Department of Health and Human Services' Office of the Assistant

Secretary for Planning and Evaluation states that up to 133 million people under the age of 65 in the United States have some form of pre-existing condition. This is the demographic within which people with chronic severe disabilities due to injury or disease are most likely to be found.

With these huge numbers, it is hard to understand why the Trump administration so aggressively pursues a national health care policy that would alienate all those voters. But he has not ever demonstrated a willingness to enact or support policies that are important to people with disabilities.

Even while running for president, his 2015-16 campaign's disability policy was notable for being simple and to the point: There was none.

Since his election, his administration has attempted to gut the Special Olympics as well as other programs benefiting people with disabilities, supported legislation to weaken the Americans with Disabilities Act and turned the DOJ from being the enforcer of the ADA to being its nemesis by nullifying rules and regulations and ignoring the need to issue guidelines, and more.

By his actions it is clear Trump does not consider the disability community's welfare as a viable concern of his or the nation's.

What Can Be Done to Save Our Health Care Coverage?

After Trump's election, many who did not vote for him decided to give him a chance, to see what kind of leader he would be. I, for one, held out the hope that the office would shape the man, as it often has throughout the history of our nation. Now we are well past the halfway mark of his four-year term. He has shown, again and again, that he is clearly not a friend of the disability community. It is critically important that people with disabilities, and others with pre-existing conditions, vigorously oppose his plan to abolish the ACA as a well-organized voting bloc — no matter what our party affiliation may be.

Not only is our quality of life at stake, our very lives are in danger.

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



NEWS FROM UNITED SPINAL

JANNE KOURI'S 'RIDE FOR PARALYSIS'

After over 2,900 miles and 66 days riding across America in his power wheelchair and electric trike, Janne Kouri, a C6 quad, rode into Georgetown University in Washington, D.C., on May 15 having raised almost \$350,000 for fitness and quality of life grants for individuals with paralysis.

Kouri, the founder of NextStep, one of the country's largest and most innovative functional rehabilitation networks for paralysis, set out from his Los Angeles home on March 10 to raise awareness and money via what he dubbed the Ride for Paralysis. The endeavor surpassed his expectations both as an adventure and a fundraiser. "It's such an adrenaline rush, being on the road every day and being able to do it with so many close friends — it's been amazing," said Kouri while on the road. "Seeing the United States from such a unique perspective is incredible, and the best part about it is all the different people we're meeting along the way. It's so inspiring and really wonderful."

Kouri founded NextStep in 2008 with the goal of improving access to secondary rehabilitation and fitness for people living with paralysis. There are currently seven NextStep paralysis recovery centers around the United States. Between his Permobil F5 wheelchair and a Bowhead Reach electric trike, Kouri averaged 60 miles a day. Along the way, the Ride for Paralysis team also awarded individuals with quality of life grants so they can afford memberships to NextStep rehab centers.

The team also donated medical equipment and hosted local events, often partnering with United Spinal Association and its VetsFirst division to help build support and awareness in the communities it visited. "The whole point of this trip has been to raise awareness about the lack of resources that people living with paralysis have across the country. The vast majority of communities and cities we're going through don't have anything like a NextStep," he says. "United Spinal has been amazing in getting the word out and helping us to, hopefully in the future, bring services to those communities."

Kouri will be speaking about his journey at this year's Roll on Capitol Hill. To learn more about the Ride for Paralysis, visit: rideforparalysis.pelicon.com



Janne Kouri and his team stopped at many iconic places on the cross-country Ride for Paralysis.

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HOW WE ROLL

VOLUNTEER/ATHLETE EXTRAORDINAIRE

Cruz Gutierrez



A chance encounter introduced Cruz Gutierrez to adaptive sports, and adaptive sports proved to be the key to his discovering how to embrace life after injury. Now Gutierrez is dedicated to ensuring others get the same chance he did.

From Hobby to Passion

When Cruz Gutierrez isn't out exploring the New Mexico desert on his handcycle or tearing up the basketball or tennis courts in his sport chairs, there's a good chance that he is volunteering at one of the local hospitals. He regularly speaks to physical therapy students at the University of Texas at El Paso, helps educate aspiring medical professionals at the local community college and also works with the U.S. Army's Warrior Transition Battalion at Fort Bliss.

No matter the makeup of his audience — be it professionals, wheelchair users or the general population — his message remains the same: not only does life go on after injury or disability, but it can still be exciting — and adaptive sports can play a huge role. "Adaptive sports changed my life to the point where I feel like I can do whatever I set my mind to," he says. "I want to show people that they can change their lives with adaptive sports. As wheelchair users, we don't have to just sit in our normal chairs all day — we have choices. We can have fun too."

Gutierrez credits El Paso wheelchair tennis great Reggie Espinoza with teaching him that lesson eight years ago. The two



Cruz visits a rehab unit after teaching transferring techniques to physical therapy students at Highlands Rehabilitation Hospital in El Paso, Texas.

met randomly at a local park and Espinoza convinced Gutierrez to try wheelchair tennis. After some initial misgivings while playing in his everyday chair, once Gutierrez started playing with the right equipment, he was hooked, and not only on tennis, but also basketball, handcycling and racing.

He plays wheelchair tennis competitively and has also competed in wheelchair basketball. He loves to race and is working on starting a handcycling team. He says tennis is his favorite, but it's clear all the sports hold a place in his heart.

Fueled by his appreciation for proper equipment, Gutierrez has amassed a collection of wheelchairs he loans out to people looking to try adaptive sports. He gets the chairs wherever he can, many of them secondhand, and has a room at his house dedicated solely to storing them.

Wanting to share his new passions and help others, Gutierrez started speaking at local medical facilities. Those conversations helped to strengthen his confidence even further.

"At the beginning, opening up and talking with people was difficult because I didn't know what I now know about myself," he says. "When they first invited me, they asked me to talk



CAN'T LIVE WITHOUT:

My Intrepid handcycle gives me the freedom to explore the desert around my house. I've only had it for three months, but I love it.



DREAM CYCLE: I

wish I was able to afford a Fat Explorer. It's a three-wheel off-road handcycle with an electric motor assist.



about my daily life and everything I did. They were asking me questions and I realized I did know the answers, because they were simply the realities of how I live my life.”

As he grew more comfortable with himself and with speaking, his volunteer work grew from a hobby into a passion.

“I realized that if I’m honest and I talk to them about who I am, what I do, what helps me and what can harm me, I can help them help people like me in the future,” he says. “Now, I love talking to the students and mentoring and teaching them whatever they need to know about living with a spinal cord injury.”

As surely as he has helped others, Gutierrez says he has been the biggest beneficiary from his volunteering. “Talking about my personal life to students has helped me gain my social life back,” he says.

Gutierrez, who has a bachelor’s degree in criminal justice, says he is considering taking his passion for volunteering and working with people in rehab to the next level by applying to get his master’s in rehabilitation counseling at the University of Arizona. In a true win-win, he could study what he loves and possibly play on the university’s wheelchair basketball team.

CONFIDENT AND COMFORTABLE

Man About Town

Gutierrez enjoys an active social life and doesn’t let a lack of access or a potentially awkward encounter keep him from doing anything he wants to do.

“Going out shouldn’t be a big deal. For me, I just feel normal. I’m glad that I’m still able to go out and I want to make the most of it. The key is that I understand my disability and I see myself for who I am, not what I am not. I don’t see my disability when I’m going out. I just enjoy myself.

One of the things I noticed when I first started going out was that people

don’t know how to approach you or what to talk about. My time volunteering and sharing my story with therapists and people with new injuries has helped make me confident that I can answer any question, no matter how awkward, and handle any situation.

If people see me out in the world, living my normal life, what

I want to transmit to them is that I don’t have issues. I go out just like they do. I hope that when they see that, they’re going to feel comfortable.



Out and about and testing the Omeo personal mobility device in Tucson, Arizona.



NEXT ON THE BUCKET LIST:

I can’t wait to go skydiving for the first time. There’s a place called Dropzone near me and it’s on my list.

WHY I JOINED UNITED SPINAL: When I was paralyzed, I was lucky to end up at a rehabilitation hospital where the El Paso chapter had a strong presence. They helped me out a lot, and I started volunteering regularly and never stopped.



LIVE WELL

By Josie Byzek



POWERLIFTER GARRISON REDD'S HEART IS HIS STRONGEST MUSCLE

As strong as powerlifter Garrison Redd's arm and core muscles are, his heart may be stronger.

"I was at work one day and had an epiphany," says Redd, a T12 para living in New York City. "I worked for the IRS, and one day I thought I was not doing enough to help others with dis-

abilities and that I need to do more to connect them with resources. I started growing a social media presence and getting messages from people around the world asking about my bowel routine, UTIs and keeping a healthy bladder. I realized there weren't many people they could turn to. I wanted to connect them with society."

Realizing he would be most effective focusing on fitness, he started

The Garrison Redd Project, which offers adaptive sports programs. Additionally he moderates a powerlifting group for the Christopher and Dana Reeve Foundation where he shares fitness tips and workouts. He's also rustling up sponsorships while training for this summer's world championship in Kazakhstan and next year's Paralympics in Tokyo.

How does he keep centered with everything he's got going on in his life?

"For a couple of minutes every day I do breathing exercises and just think, 'What am I doing today?' I try to make a plan for the week or next day or the month," he says. "That keeps me calm and healthy mentally. If you're healthy mentally, you'll be healthy physically as well."

Redd's website is thegarrisonreddproject.org and he can be found at Reeve Connect, community.christopherreeve.org/group/16-spinal-cord-weightlifting. Also look him up on YouTube, Instagram and Facebook.



HIKING APPS

The weather's warm, the sun is shining and it's time to get outdoors. Why not take a hike? Here are a couple of resources to get you on your way:

Trail Link, trailink.com/activity/wheelchair-accessible-trails/#state. If using your phone, click "wheelchair accessible" in the filter. Or on your laptop, click a state and then click a trail. On either platform it tells you where the trail is located and what material it's paved with, and also includes helpful reviews.

National Park Service Apps, iTunes or Google Play. Many national parks now have apps you can download. To test one, we downloaded Shenandoah and tapped "Trailheads." The ADA accessible Limberlost is first on the list, and the app gives you a location, directions and details such as that there are benches and wheelchair pullouts available along the trail.

VOLUNTEERS NEEDED FOR ONLINE WELLNESS STUDY

The Center for Research on Women with Disabilities is looking for women who have had a spinal cord injury for at least a year and have access to a high-speed internet connection to participate in a 10-week study on wellness.

Topics will include self-care, dealing with negative thoughts, building healthy relationships and sexuality.

And here's the twist: The study will take place virtually via the Second Life online role-playing world. "Second Life gives a feeling of embodied interaction," says lead researcher Margaret Nosek, Ph.D., a quad who uses a vent. Her research team has used this platform for years, since it allows people who can't meet in person to create an avatar and meet virtually in a pleasing online setting. "It's interesting to watch how they choose to create their avatars — if they use a wheelchair or how close it is to their real-life body. In most cases it's very different. I know mine is."

Enrollment takes place through August. For more info, email Zest@Memorialhermann.org or call 713/797-7570. A small payment is offered for participation.



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2019 PREVIEW: UNITED SPINAL'S ROLL ON CAPITOL HILL

BY AARON BROVERMAN

From June 23-26, 2019, United Spinal Association members from around the country will be descending on Washington, D.C., for the eighth annual Roll on Capitol Hill. Roll on Capitol Hill is the organization's yearly legislative advocacy event where people from the SCI community take over our nation's capital to educate

legislators on the issues that affect them and advocate for policies to help them.

NEW MOBILITY caught up with two Roll on Capitol Hill veterans and two newbies who will be making their first trip this June to find out what they are looking to achieve and what they hope to tell their members of Congress when they get behind closed doors.

COMMUNITY EMPOWERED

Shannon Minnick, 48, Silver Spring, Maryland

For Shannon Minnick, life as a C6-7 quadriplegic occasionally felt lonely and isolating, like she was navigating the haze of life with a spinal cord injury alone and in silence. But being among the many wheelchair users who attended the Roll on Capitol Hill in 2018 reminded her that she's part of a larger

historical tapestry — one with a booming collective voice.

Minnick is the former Miss Wheelchair Maryland 2010 and current director of Independent Living Services at Independence Now, a center for independent living in Silver Spring, Maryland. She is returning to Roll on Capitol Hill in 2019 to emphasize the importance of preserving programs like Maryland's Employed Individuals with Disabilities, which allows working people with disabilities to qualify for Medicaid.

"Sometimes I think people with disabilities aren't considered people who work and have families and children. I live my life independently, so just to be in a room with so many individuals who knew my story was powerful right there," says Minnick. "Then to go out on Capitol Hill and talk about our issues and the things that are important to us — it's overwhelming, it's scary, but it's also powerful."

Being with fellow SCI community members gave Minnick the strength to speak to members of Congress directly. She believes the unity of the group made its message even more powerful. "You go into these things and sometimes you're shy because of who you're talking to, but when you go in as a group, it's awesome because someone always steps in if you leave something out," she says. "We all need to come together because the things that I need are also things that someone with cerebral palsy needs. They need catheters, they need personal care attendants, they need wheelchairs, so we should all be harmonizing together toward the same goals."

The 2018 Roll on Capitol Hill gave Minnick a sense of

Shannon Minnick is passionate about employment rights.

community that stayed with her long after leaving the event. Seeing what her new advocate friends were doing on social media sustained her when times were tough and inspired her to continue her own efforts throughout the year. “[The Roll on Capitol Hill] gives me hope,” she says. “It tells me that the work I do every day at our independent living center is not in vain. People are living, people are striving — and that’s important to me.”

Now as she prepares to return, Minnick hopes her participation will inspire more people with disabilities in her community to take action. “If you want something to change, you have to be a part of the process,” she says. “I can’t complain that I need Medicaid and they won’t give it to me because I only make a certain amount a year and then sit at home and do nothing. I have to get out there and fight for that and say, ‘this is why I need it.’”

FIGHTING TO KEEP MOVING FORWARD

Adam Lane, 46, Oklahoma City, Oklahoma

Despite being relatively healthy with a good job and great insurance benefits, Adam Lane finds his access to complex rehab technology dwindling and the cost of managing his own healthcare as a T10-11 paraplegic rising. “Catheters have been a big expense. Sometimes they’re covered by my private insurance and sometimes they’re not. I have a baclofen pump for my spasticity and it’s very expensive to refill every year. Every time you see a doctor there’s a co-pay, so I can spend \$1,000 or \$2,000 for my annual follow-up visits,” says Lane.

This is one of the reasons the former paramedic and current mobility specialist is returning to the Roll on Capitol Hill. He also has concerns regarding access to the built environment. He lived in Kansas City, Missouri, and says it was quite accessible, “but it’s been eye-opening moving to Oklahoma and seeing the lack of accessibility in public spaces. Even new projects aren’t entirely accessible. They just opened a new streetcar track in Oklahoma City and only 16 of the 20 streetcars meet ADA compliance.”

Tired of being an afterthought, Lane hopes to talk to his representatives about the importance of including those with disabilities when it comes to infrastructure planning. He believes many of the accessibility issues in Oklahoma City could have been easily rectified if decision makers had put more thought into them or just included wheelchair users in finding creative

Cole and Charisma use their popular YouTube channel to amplify their advocacy.



Adam Lane, who advocates for better insurance coverage and access, talks with Lindsey Elliott, United Spinal’s director of member initiatives, at the 2012 Roll on Capitol Hill.

solutions. “People think we are being overly sensitive when all we want is to use the public facilities that are available to us. We need to be able to be there, on the ground, so we’re not looked at as some whiny people looking to create causes and hurt small businesses. We just want to go where everyone else goes — it’s vitally important,” says Lane.

Though he has seen an ebb and flow of positive legislation around disability issues since he last attended the Roll on Capitol Hill, he still believes in the importance of direct political action. “The whole reason I got involved with United Spinal Association is because I had a very supportive network and very good insurance prior to my injury and I realize not everybody has that, so I believe it’s my responsibility to ensure others get the kind of benefits and support that I’ve been able to reap.”

FROM YOUTUBE TO D.C.

Cole Sydnor, 24, Richmond, Virginia

If you’re one of their 322,000 subscribers, you’ve probably already heard of Cole Sydnor and his girlfriend Charisma from the *Roll with Cole and Charisma* YouTube channel. The C5-6 complete quadriplegic and his partner use their videos to document political activism within the disability community as well as to provide an ongoing warts-and-all look at their own interabled and interracial relationship. It’s



all part of their effort to lift the veil on life with a disability. “The Roll on Capitol Hill is a great opportunity to raise awareness about disability issues, show people how many of us are out there and demonstrate how we really do care about our rights,” says Sydnor.

In addition to giving their viewers an inside look at Roll on Capitol Hill, Sydnor hopes to help the Sheltering Arms Foundation raise money for what will be the only hospital in the Richmond, Virginia, area offering expert therapies for SCI. “When I first got injured I had to go down to Atlanta, Georgia, and I was really far away from my support system,” says Sydnor. “I don’t want anyone to go through that at such a critical time.”

RAISING AWARENESS
Joe Gavic, 47, Dallas, Texas

When Joe Gavic lived in Milwaukee, he knew where all the SCI resources were and how to take advantage of them. Then he moved to Dallas and found himself in unfamiliar territory, where finding



Joe Gavic, who founded a United Spinal chapter last year, looks forward to networking at the Roll on Capitol Hill.

and connecting with needed resources was not easy.

To start addressing that problem, he founded the North Texas Chapter of United Spinal Association in 2018. Its primary role is to connect those with SCI to the little-known services that are available to them. “We’re publicizing all sorts of things — anything from recreation, to lifestyle, to education, to awareness, advocacy and arts,” says Gavic.

“All of those things are available to our consumers. Yet, not all our consumers know about them.”

For him, the Roll on Capitol Hill is a networking and awareness opportunity that cannot be missed. “Our immediate goals for Roll on Capitol Hill are to go and get exposure and to let our legislators know that there’s an organization that is new, that is out there and looking to promote greater advocacy and greater awareness for the consumers in our area,” says Gavic.

NH

For more information about the Roll on Capitol Hill, or to find out how to get involved, visit unitedspinal.org/events/roll-on-capitol-hill

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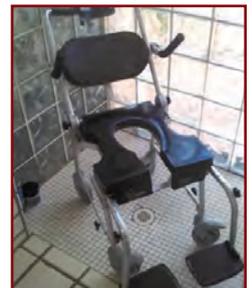


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A DIY GUIDE TO AFFORDABLE ACCESSIBLE TRAVEL: Germany and Austria on a Budget

By Lilly Longshore

Planning your dream accessible vacation on a budget is not easy.

It is always tempting to leave the details to a travel agency that knows what is and isn't accessible and, hopefully, where to save money. There are some seasoned agencies with great reputations, but it always pays to be careful. After a bad experience on an agency-planned trip, I went back to planning most everything myself. Aside from enjoying being able to tailor everything to my taste, I became more aware of the huge savings possible if you're willing to do all the wheelwork.

For example, excluding airfare, a prominent agency is charging \$504 per day for a trip to Ireland, whereas I paid only \$124 per day to go there last year. Or consider that it cost me \$103 per day to visit Germany and Austria last September, when a comparable European trip through an agency started at \$599 per person per day. My costs include hotel, all meals, tickets to attractions, transportation and more — that's more inclusive than some agencies.

Here are some helpful strategies I used to save while planning that trip to Germany and Austria that you can use when you plan your next getaway.

Start Big and Narrow Down

I start planning at least eight months in advance and I look to travel off-season, like May or October, because there are cheaper fares. Before I settle on a destination, I do an internet search of the place, say "accessible Germany." Then I try "barrier-free" and "wheelchair accessible" and even "handicap" as key terms connected to that place. For my trip to Germany and Austria, I scoured the internet for "barrier-free Germany" (Germany's preferred term). The results are detailed and immensely helpful — down to how many centimeters wide the narrowest opening is in a palace — and should give you a sense of what is feasible.

I read up on other wheelers' blogs

or their Facebook posts. What did they successfully see and do? Is the terrain reasonable? Did others have problems I can avoid? If my research shows the country to be a terrain I can manage in my manual chair with reasonable sidewalks/curb cuts, and a general culture and tourist climate that strike my fancy, I narrow my focus, in this case from country to city, homing in on specific sites to see.

Tourism bureaus and municipalities, in Europe especially, are putting out great wheelchair accessibility information. Berlin has an "Access Berlin" app and Munich, Frankfurt and Vienna all have detailed websites and downloadable PDF files about their accessible sights.

If I am still unsure about a town, like I was about Salzburg, Austria, I post somewhere like the Spinal Cord Peer Support USA/Worldwide Facebook group and ask the over 10,000 members for first-hand experiences. I had read that Salzburg was cobblestoned and hilly, so I was concerned until someone

from the SCI group who had visited told me, “Bring your FreeWheel. You’ll be fine.” I did and I was.

Once I have my potential cities, I narrow down which ones to visit by their proximity to each other and the number of accessible tourist sights. Google Maps is a great help for routing. I plug in “distance between Frankfurt and Munich,” for example, and check out the map, travel time, distance, towns of interest along the way and transportation choices.

I chose to start and end in Frankfurt because it has a major airport and it is close to the Rhine River. I also considered driving from Frankfurt to Vienna and flying out of Vienna, but the car rental would more than triple what it would cost to return the vehicle to Frankfurt. Instead, I chose a route south and east of Frankfurt through Munich to Vienna, selecting different towns for overnights.

In planning my route, I base the number of overnights in each town on



Thanks to a FreeWheel, cobblestones like these in Salzburg were no problem.

desirable accessible attractions, some of which offer discounts for disabled visitors. Also, there are many — such as the Schönbrunn and Hofburg Palaces in Vienna, the Documentation Center Nazi Party Rally Grounds in Nuremberg and Dachau Concentration Camp Memorial Site in Dachau, Germany — that do not charge entry for the companion traveler of a disabled visitor.

I factor driving times, lunch and bathroom breaks into my schedule. If there are a lot of sights in a town, I stay three nights or more before moving on. Hotels often discount multiple overnight stays. I also prefer less hopping around, as I find this more relaxing.

Booking It

Once you’ve got your plan, it’s time to maximize your savings with diligent booking. Travelocity and Kayak work well for flight cost comparisons. Big airports have the best deals, possibly making it worthwhile to drive a few hours to save \$500. Flying and purchasing tickets costs less if done mid-week, like on Tuesdays.

As far as ground transportation, it’s always good to have a backup means of getting around. I can transfer into the passenger seat of a regular rental car, and I have also found European trains to be a convenient, no-transfer option. If you need something different, early planning lets you seek out and lock down your options.

Once I lock in my route and schedule, I book accommodations. I’ve had

good luck with Booking.com and Travelocity in finding hotels with wheelchair access since they have a filter for this. If no accessible rooms are available on a booking site for a specific affordable hotel, I call that hotel directly. Often, hotels have accessible rooms that are not advertised on booking sites.

I have successfully used both Airbnb and HomeAway/VRBO. Regardless of how I book, I always call or email specific questions to the owner/manager to ensure the accommodations suit my needs. Is the unit step-free? How wide are the entry, bedroom and bathroom door openings? Are there grab bars in the bathroom? Can they send me photos of the bathroom layout? I ask whatever is important for my decision. I know my needs best and email is easy, so I prefer booking rooms myself, since I suffer if it’s done poorly.

Roll with the Punches, Go with the Flow

Things don’t always go as planned. It’s a given. For medical needs, it helps to have insurance that covers worldwide emergencies [see resources]. My Medicare Advantage plan came in handy when I fell off a tram lift in Vienna and broke my nose. I received great help from the Park Inn Hotel in Frankfurt when my manual chair was damaged by the airlines. The hotel maintenance man fixed it for the weekend, and the front desk person connected me to a





Photo courtesy of #ivisfrankfurt / Holger Ullmann

Connect, Save and Enjoy

Thanks to the internet, it is easier than ever to plan your own affordable, accessible trip. Between government sites, travel agency sites and travel blogs, the internet is filled with information you can use to help plan your trip, but the real asset for the cost-conscious traveler is the opportunity to easily connect with other savvy travelers with disabilities. Think of it as having hundreds of “wheels on the ground” scouting out the missing details or answers you need to ensure the best trip and the best deals.

When planning for Ireland, I found Earle the Service Dog’s website. I messaged Chris, Earle’s person, for more details and learned Neptune Hostel in Killarney has a wheelchair accessible room. I stayed there for 30 Euros a night.

wheelchair repair shop on Monday. Beyond that, I don’t plan for emergencies, which most tour companies do.

For tour details, all the calls in the world cannot guarantee that I’ve received flawless, accurate information; flexibility is a must. I missed part of a scheduled cruise down the Rhine because I didn’t know there was more than one boarding port named Rudesheim. A travel agent would have known this and saved us some hassle, but it wasn’t a big deal.

To get back on track, I drove to Boppard, the next port, along a scenic highway with some of the most spectacular views of castles and terrace farming that I have ever seen. I eventually learned that despite my efforts, our original boat wasn’t wheelchair accessible. The ticket vendor said, “If I let you board this boat, you’ll say, ‘That man is crazy!’ Wait for the sunset boat,” he advised, “It’s beautiful and perfect for wheelchair users.”

I traded my ticket for a roundtrip sunset ride from Boppard to Koblenz. The scenery was magnificent, with more castles and charming villages along the banks. Most passengers disembarked in Koblenz. With only a handful of us still onboard, I was treated like royalty, and was served coffee and dessert on the upper, open-air deck.

Weather is another wild card. I was disappointed more than once by a downpour on my proverbial parade. Between Frankfurt and Munich,

Rothenburg ob der Tauber was the next stop on our route — yes, there are other Rothenburgs so you need all the words for your GPS. This lovely medieval city, untouched by World War II, is still enclosed by an intact, ancient wall. The Bavarian-style homes and old stone buildings line hilly cobblestone streets and plazas. It rained the day I was there, and I had a very hard time navigating cobblestoned hills with slippery gloves.

It rained the next day, too. Outside of Munich, Neuschwanstein Castle, the most visited castle in Germany and the model for Disney’s Sleeping Beauty castle, was top on my list of day trips. It poured on my reserved day, and the whole enormous edifice was cloaked in a dense, gray cloud.

My manual chair has a rigid frame, which caused a carriage driver to charge six times the rate because he said it took up too much room. Had I known about the buses at the top side of the grounds, I would have used them to and from the castle. They were much easier for my wheelchair and cost only one Euro each way instead of the 42 Euro total we paid for the one-way carriage ride. The steep uphill roll from the horse-and-carriage drop-off point was too hard for me to do myself, especially when everything was wet and slick. Out of nowhere, three Japanese ladies started helping me up the slippery slope. “Arigato,” I told them, meaning “thank you,” the only word I know in Japanese.

Ya Gotta Eat

Food is an essential part of the culture of every country but dining out can eat up a lot of money. Unless you are there specifically for the food, try eating out only once per day. You can save a great deal by hitting the grocery store when you come into town.

Typically, I get fruit, nuts, sliced cheeses and meats and pre-made salads. Most hotels have ice buckets that double as little refrigerators. For 15 Euros, two of us ate for three days in Austria, supplemented by one nice meal at a café, restaurant or street vendor each day.

Through the Spinal Cord Peer Support USA/Worldwide Facebook group, I've met several wonderful travelers. I Skyped with a knowledgeable Slovenian traveler who connected me with a resort on the Adriatic Sea owned by Slovenia's Paraplegic Association. I booked a room for three nights at 60 Euros a night. My room had a permanent Hoyer lift installed in the ceiling, and I had the pleasure of meeting her for dinner at the edge of the sea in Koper. It was fabulous!

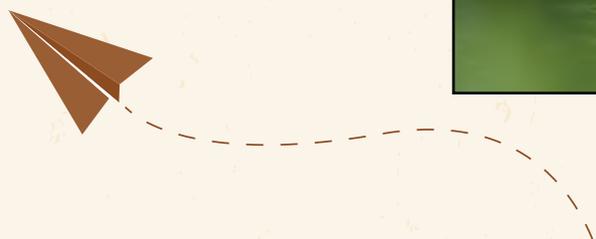
Of course, there are disadvantages to eschewing a travel agent and planning everything yourself. A knowledgeable agent could have saved me the 240 Euros I had to pay for a fine I received for not buying an 8 Euro toll pass for the highways. And I'm sure there are other hiccups that I could have avoided, but all in all, everything went smoothly.

By starting with the big picture, narrowing down to details and being ever-vigilant about where you can save, planning a successful accessible trip becomes very manageable. Seeing the world is more affordable and more accessible than you may think. MI



Resources

- "The Best and Worst Travel Insurance Companies," www.forbes.com/sites/christopherelliott/2018/08/18/the-best-and-worst-travel-insurance-companies/#3ed459944fc2
- Spinal Cord Peer Support USA, www.facebook.com/groups/SCPSUSA/



No trip to Vienna would be complete without a visit to Schönbrunn Palace.



Photo courtesy of Vienna Tourist Board

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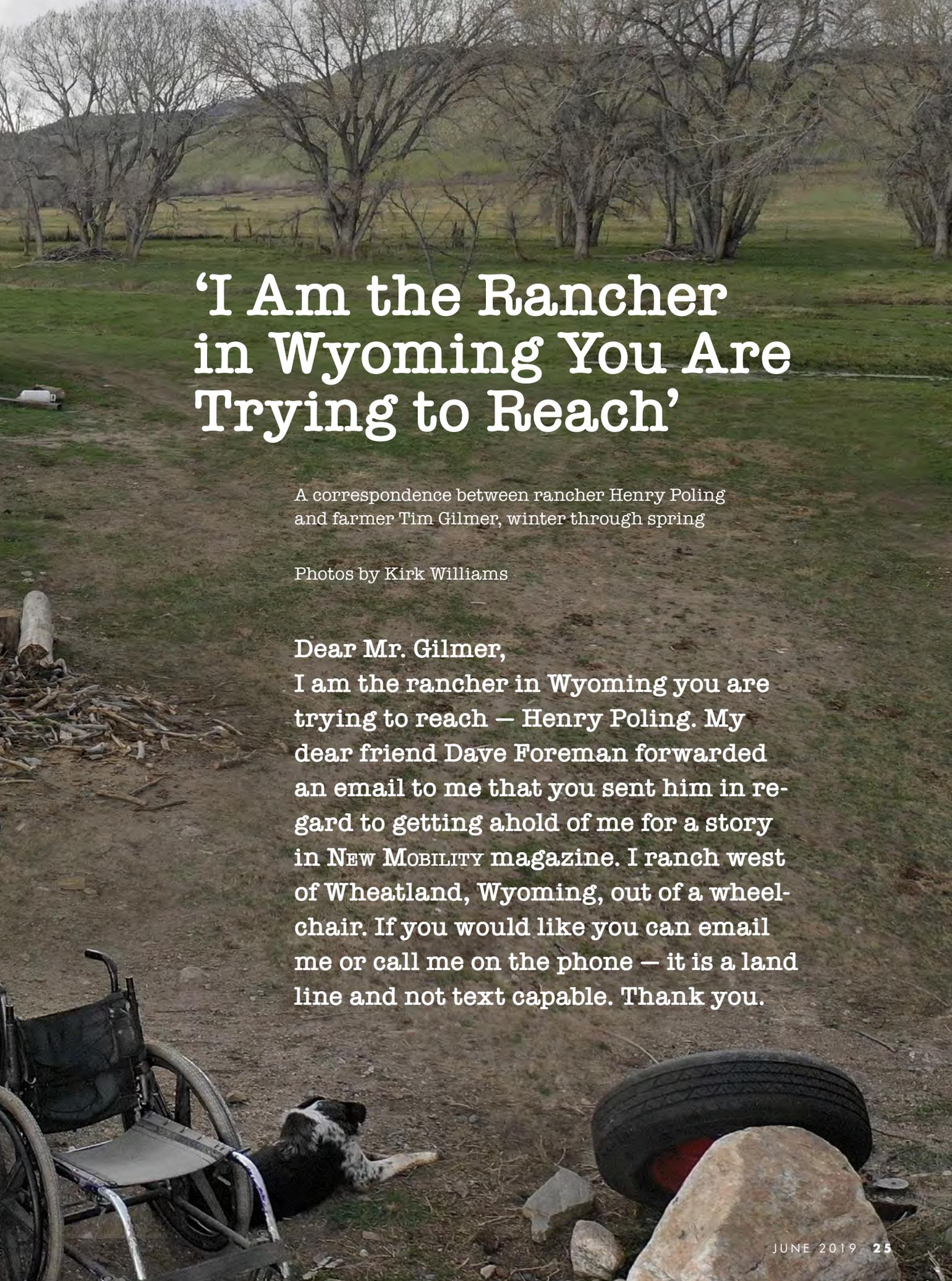


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'I Am the Rancher in Wyoming You Are Trying to Reach'

A correspondence between rancher Henry Poling
and farmer Tim Gilmer, winter through spring

Photos by Kirk Williams

Dear Mr. Gilmer,
I am the rancher in Wyoming you are
trying to reach — Henry Poling. My
dear friend Dave Foreman forwarded
an email to me that you sent him in re-
gard to getting ahold of me for a story
in *NEW MOBILITY* magazine. I ranch west
of Wheatland, Wyoming, out of a wheel-
chair. If you would like you can email
me or call me on the phone — it is a land
line and not text capable. Thank you.



In a unique email relationship, Tim Gilmer and Henry Poling, fellow paraplegics, discovered they are kindred souls who love the land, cattle ranching and farming — and what it means to persevere through difficult times.

Tim Gilmer: Henry, I would love to get acquainted. I feel we are kindred souls. I am a farmer-writer, paraplegic since 1965, semi-retired after editing *NEW MOBILITY* for 18 years. My wife and I and a small crew of workers grew organic veggies on our farm and sold them to restaurants and markets in Portland for about 30 years. We also had a small herd of cattle for 20 of those years. I think our readers would benefit greatly from getting a glimpse of your lifestyle — and your connection with land, livestock and people.

HP: Good Morning, Tim. It is clear and cold here in Wyoming with a northeast breeze. My cows are getting close to calving, should start in a couple weeks. I have a little over 100 head of mother cows to calve. I normally try to run about 150 but had a bad drought that made me sell off a lot, and build-back has been slow.

As I tell everyone, I really do not see much interesting in what I do. After my accident, I continued to ranch for two reasons: first and foremost because it is the only thing I ever really wanted to do in life, from the time I was very small, and secondly it was the only thing I know how to do to make a living, and poverty is a great motivator.

I have come to realize that many people, when put in adverse situations, do not respond the same. I was fortunate in some unusual ways. First I did not end up being able to qualify for any disability assistance, neither SSI nor SS Disability. I really was not interested in a monthly check, as I always intended to support myself, but the medical benefits would have been useful.

One of the other big things that was extremely helpful to me were the friends and family who helped me after I got out of the hospital. They did not treat me as handicapped and insisted that I go about my daily life as much as possible. I think

this, along with my own desire, helped me to adjust to my life in a chair and devise my plan to continue on the path that I had chosen in life.

If you like you can read a story about me that was in *Range Magazine* in the Summer of 2017. I think you can access it online. It was written by a very good friend of mine, Ray Hunkins, an attorney and two-time candidate for governor of Wyoming. He is retired now, but a truly remarkable man in his own right.

TG: Henry, wow! One hundred head of cows are a lot to take care of. I read Ray Hunkins' story of your remarkable journey scooting on your butt for miles across rangeland after high-centering your 4-wheeler. Did you come out of that ordeal without skin damage or a pressure sore?

HP: I didn't end up with any major sores from my crawl home but have had several over the years. Had a bone infection that required surgery from rolling a 4-wheeler, have had a lot of 4-wheeler wrecks over the years. Last wreck I had was in 2014 trailing cows to the mountains for summer. I lost my temper cutting a yearling heifer of the neighbor's out of the herd and flipped my 4-wheeler on the pavement, landed on my head luckily, road-rashed my hand and cracked my pelvis.

A friend that was helping trail wanted to take me to the emergency room, but we had nine more miles to go up over the mountains and I told him it was OK to leave me dying by the side of the road, as when we start out with cattle somewhere, we don't stop to go to the doctor. So I had them set my 4-wheeler on its feet and put me back on, I stuffed some paper towel in my hat to slow the blood from running down my head, and we went on. I made it the rest of the day, but the adrenaline was wearing off on the ride home in the back

seat of the pickup, and I got packed to the house. Laid on the bed for a while and then got help to get in the shower to wash some of the blood off.

The next day I was going to finish taking the cows the rest of the way to the pasture where they were to go but got overruled and ended up staying home. Had a friend do chores for a couple of days as I was moving pretty slow, but I was back milking and doing chores in two days.

TG: How many acres do you own, and how many acres do you run your herd on, either owned or leased? Your talking of drought makes me think that the pastures are not irrigated.

And I'm wondering how you market your cattle. Sell them as calves or pairs, feed them up to weaning or yearling size and ship them off to auction? Do buyers come to the ranch? I assume you make more on the cattle than on selling pies and jellies and eggs or whatever you can sell in Wheatland (I saw a video of you talking about that). Just curious, but are you still paying on your property or do you own it outright?

HP: My home place is 1,200 acres, which is fairly small for here. I bought it after I got hurt and still struggle along making the payments on it annually. Not too many years left to go though. I have a typical cow/calf operation where I maintain a cow herd and sell my calves in the fall, usually on Labor Day, at the local sale barn about 60 miles away. I usually sell all my calves at one sale, but sometimes I hold some younger ones back for a month or two and sell them later. This past fall, I pre-conditioned the late calves that I held back with vaccines for diseases as well as with a pour-on for parasites. This usually helps them to bring a little better price at the sale. My cow herd is mostly Angus based. They tend to bring a better price and are a lot hardier in this climate.

My cows graze on non-irrigated pasture, short grass prairie — excellent weight gains, but it takes quite a bit of land. I use the home place primarily to winter on and normally go to the mountains to summer the cows. I usually trail them back and forth, and for the last few years had a ranch leased from Ray Hunkins. It is normally a long day trailing up in the spring and a day trailing back in the fall.

For many years I had another place in the mountains about 55 miles from here, or 45 miles cross-country. I would truck the cows and calves up there at the end of May — 130 miles as they couldn't cut through the mountains on the road like we could with a pickup — and had to go around by the highway to Rock River, and from there 50 miles of dirt road across the Laramie Plains. In the fall we would trail them back home using horses and 4-wheelers, covering 45 miles in three days.

The bulk of my income comes from my cattle. I started doing jams and jellies and stuff in 2002 to make extra income due to drought and having to cut my herd from around 150 down to about 85. The sideline income has helped me to pay most of my

“A friend that was helping trail wanted to take me to the emergency room, but we had nine more miles to go up over the mountains and I told him it was OK to leave me dying by the side of the road, as when we start out with cattle somewhere, we don't stop to go to the doctor.”



Photos courtesy of Henry Poling

Twice a year Henry and other ranchers trail, or follow, their herd to different grazing grounds. It makes for a long day.

living expenses and put cattle income into the ranch.

During the 2000s we had drought about every other year, so it was hard just to maintain the herd, but I did have it back up to almost 150 again by 2011, just in time for another big sell off, cutting it again in half for the drought in 2012-13. Since

then it has been a struggle to grow numbers again but am finally back up over 100 mother cows and slowly working back up to a goal of 150.

TG: It sounds like a demanding life, dealing with harsh winters and drought and moving cattle long distances. What are your living conditions like?

HP: My home place sits at the base of the mountains. The previous owners had put an old trailer house on it and that was it. It had no corrals, sheds or anything, just an old trailer house. I was already in a chair of course, had never lived in a trailer, looked at the one here and thought, “Do I fix it up or burn it down?” Well I fixed it up, moved in, and in the meantime built corrals, calving shed, storage shed/shop, chicken coop and a milking barn. I cleaned ditches, picked rocks and sticks off the meadows, worked to improve them. I had help from friends and family, too.

I had to buy equipment to hay with. The first few years I traded work with a good friend for use of his equipment to put up my hay and every year I tried to add another piece or two until I had what I needed to do it on my own. Of course none of it was new, quite the opposite.

In 2008, I built my new house, after 10 ½ years in the trailer that was literally falling apart from the wind. I designed it, acted as general contractor — a pole barn building, but with 2-foot eaves. I did go with metal siding and roof because of the wind and threat of fire in summer and the fact I do not live close to a fire station. The building is 6-by-6-foot posts set 4 foot in the ground in concrete. My walls are 8 inches thick, stuffed full of insulation. Attic has 18 inches of blown-in insulation — warm in the winter and cool in the summer.

A pole barn/house has no load bearing internal walls, so I could lay it out any way I wanted. It is small by today’s standards, 1,680 square feet, but is more than adequate for me.



I would not have built a house this big except that my mom was living with me for a while as she went through cancer surgery and treatments, so I needed more space. It has three bedrooms, two baths with an office, a huge kitchen with a breakfast nook and a nice-sized living/dining room.

I heat totally with wood cut from along my creek. I designed the house to keep all of the water on the east end of it and can shut French doors between the kitchen and dining area to shut off the west end of the house in the winter so I don’t have to heat it if I don’t want to. The east end of the house has the bathrooms, my master bedroom and kitchen and breakfast nook. There are no halls. Being in a chair you can appreciate how much easier that makes life. Doors are all 36 inches wide. I spent all that time in the trailer house learning all of the things I did not want in a house! It amazed me how much easier my life became after I moved in here.



TG: I can’t imagine living in a trailer for that long. Glad you made it into Henry’s Hilton. Must have been quite a construction project, not to mention all the other improvements you made.

I also heat with wood and love it. For decades I had a Mexican worker who came to Oregon and lived in a small trailer on my property from April to November, then went back to Vera Cruz and his family and returned again the next year. 2018 was the first year José did not return, after 30 years of loyalty. He is now 67. He would cut wood down by the creek, drag it in sections to higher ground with a tractor, then to the flat land where my 1913 two-story farmhouse is. There is also an 1880s barn built from hand-hewn timber, Douglas fir, that blew down in a huge storm around 1880.

A friend and I converted an old pig barn into a greenhouse with roll-under benches, where I started all my seedlings before planting them out. As for the wood, I did a little chain saw work but not that much. I did hand-split a lot of wood, but



later went to a hydraulic splitter and José did most of the work.

Did you handle cutting and hauling and splitting and stacking all that wood by yourself?

HP: Good Morning, Tim. Chilly morning here, 7 degrees when I got up. We had a small covering of snow, about an inch is all.

I normally have some help with getting wood. One winter I got all of my wood alone. I dragged smaller downed trees to the house and cut them with my electric chainsaw, then stacked them. I have a hydraulic log splitter for the tractor that we split a lot of wood with and also have a three-point buzzsaw that I cut anything under 6 inches diameter with. I love the buzzsaw and usually am the one running it. I have someone pack small trees and limbs to me to cut.

I do reasonably well in snow. If it is a big snow I sometimes have to shovel my way around. I keep my 4-wheeler at the end of my ramp, so I don't have to go far to get on it and go. We can have big snows, especially in the spring. Obviously it is tough to get around in a couple of feet of wet snow.

One winter I had a couple of feet of snow when I was feeding. The snow came down off the metal roof and stacked up on everything. The first day was not bad, but it started to warm and snow came sliding off my roof and piled up in front of my door where I go out to the 4-wheeler. I had forgotten to bring the scoop shovel inside so I could dig my way out, so I resorted to a stainless steel mixing bowl and dug my way to the wood on the concrete pad outside the door.

When I went to feed, I had to leave my chair in my hole outside the door that I had dug and slide on a plastic tote lid down to the 4-wheeler. Then took it up to the stackyard to open the gate, then came back down and parked next to my 8N Ford tractor and crawled over onto it to go feed. When I got done feeding, I went in reverse of the earlier steps, crawled onto the 4-wheeler, went up and closed the stackyard and came back and crawled with my tote lid back up the drift to my chair so I could come in. It was not too bad. Often times if things get too bad for too long with weather, I have neighbors and friends who will help out.

TG: Henry, it seems like you are on your own for much of the time. I'm wondering what effect being around cows and other animals for so much of your life has had on your personality, disposition and way of thinking over the years. It seems to me that we humans have much to learn from them.





HP: Good Morning Tim, I apologize for taking so long to get back to you. We had some subzero temps and snow. We were on the edge of the incredible weather that hit Nebraska and much of the Midwest. The storm came with a mighty wind, bringing snow that piled in drifts and made it tough to get around. It did have a lot of moisture in it, which we were in desperate need of, so it was welcome. I got by with no death loss in calves, which is great. Others here were not so fortunate, and of course the tragedy felt by our fellow ag producers to the east is beyond imagining. My heart goes out to those poor farmers and ranchers and what they will continue to face in coming months and even years as they struggle on to recover financially and emotionally from this.

Often times those of us in animal agriculture are viewed



as heartless, soulless money grubbers, whose only feeling for the animals we raise is the money we gain from their sale. This is not true for the most part. I live in an area that is primarily family operated farms and ranches. Yes, we do have a couple of corporate operations in the area, but mainly it is people working hard to do their best to make a living for themselves and provide a healthy source of food for other Americans. I have known first-hand the sadness and disappointment of losing calves and even grown cattle to blizzards, having to wait until the snowdrifts melt to count the dead ones. I have struggled in the cold, wind and snow to bring in half frozen calves to thaw out in the house and feed them colostrum so that they'd hopefully make it.

The first concern in my mind and many others in this industry is not the money we may lose but saving this animal that is dependent on us and unable to make it on its own.

It is interesting to note how well many calves mind their mothers. I have had cows in the past that are quite adept at

hiding their calves for a few days when they are first born and they seem to be able to order that calf to lie down in a certain place, usually somewhat camouflaged and the little fellow will be perfectly still even when you are right next to him. They have a pretty good ability to communicate.

I think spending my life around livestock has taught me many things. I have learned patience, especially as I get older. The old saying, "The only way to move cattle fast is slowly," is true. I have trailed cows to pasture and home a lot over the years. The key to trailing cattle a long ways is to rest frequently. They don't sweat and overheat easily, so it is best to rest them for a little while every few hours.

We trailed 17 miles in one day every spring to summer pasture with cow/calf pairs, up and over the mountains to the other side. People who had trailed a lot would ask me how we could make it that far in a day with young pairs. It is because I never let the cows get tired. We trailed a few miles and rested them, on water if possible, then trailed a few more miles and rested, usually 45 minutes to an hour, but enough for them to lay down, get a drink if possible and cool off.

I have also learned compassion. Having a gentle cow take you to her calf that is in need of help, and somehow she knows you are able to assist her, is a humbling thing. Struggling to save a calf dehydrated from the scours [severe diarrhea], knowing that every few hours you have to get more electrolytes down him or he will be gone is more than just a financial consideration. It is saving a life that would not make it without the assistance from a person.

Like people, cattle have a hierarchy and it changes at times, as when an old "boss" cow is no longer able to maintain her position, a younger cow fights to gain position. They definitely have personalities and sometimes I find myself just sitting and watching them eat after I have put hay out, enjoying the contented sound of cows chewing hay, watching them mill a bit, finding the choice grasses or clovers. No concerns of the world of humans, of taxes, political wars, bills or even concerns of where the hay for tomorrow is coming from. They trust it will be there.

TG: Henry, thanks for sending the photo of you feeding round bales to your herd. How many round bales do you feed at a time? Also, I have always assumed that you use your 4-wheeler for moving your herd, but then I keep wondering if you are still able to ride and move animals on horseback as well.

HP: I usually feed two round bales a day (each bale weighs about 500 pounds). If the weather is bad I sometimes feed three. I have not ridden for a while, mostly due to a pressure sore, but I still do ride some. Most of the time the 4-wheeler is just faster and easier for me to get things done, but I still love to ride.

TG: Lately I've been thinking about the "big picture" of your



story — not so much the raw details and anecdotes, but the overall effect of your story. Do you have any final thoughts you want to share?

HP: I think one of the things I have learned in my life of ranching is the forgiveness of seasons. Especially spring.

We ranchers tend to talk more about seasons in a different context — calving season, haying season, shipping, and so on. I have faced some tough calving seasons, terrible storms. But the seasons also have a way of giving back as well. A mild winter followed by a wet spring that grows grass and assures plenty of irrigating water. An abundant hay crop to get cattle through the coming winter storms.

Calving season has always been my favorite — life renewed watching a calf just a few minutes old struggle to its feet to get its first suck. Watching the calves run and play while their mothers graze, watchful, but not dominating. Cattle have taught me a lot over the years. Enjoy a sunny day, a good meal and friendship. Yes, cattle do have friends, it is not unusual to find certain cows together a lot of the time.

I have also learned the lesson of moving on, even when tragic things happen. I have watched a cow stay by her calf for a few days after it has died, obviously saddened by the loss, but I see how they eventually go back to the herd, reintegrate and go on living. This has probably been one of the best lessons for me in dealing with life in a chair. Mourn for a bit, because the loss deserves it, then move

“I have learned the lesson of moving on, even when tragic things happen. I have watched a cow stay by her calf for a few days after it has died, obviously saddened by the loss, but I see how they eventually go back to the herd, reintegrate and go on living. This has probably been one of the best lessons for me in dealing with life in a chair. Mourn for a bit, because the loss deserves it, then move on and make the most of the rest of your life.”



Photo courtesy of Henry Poling

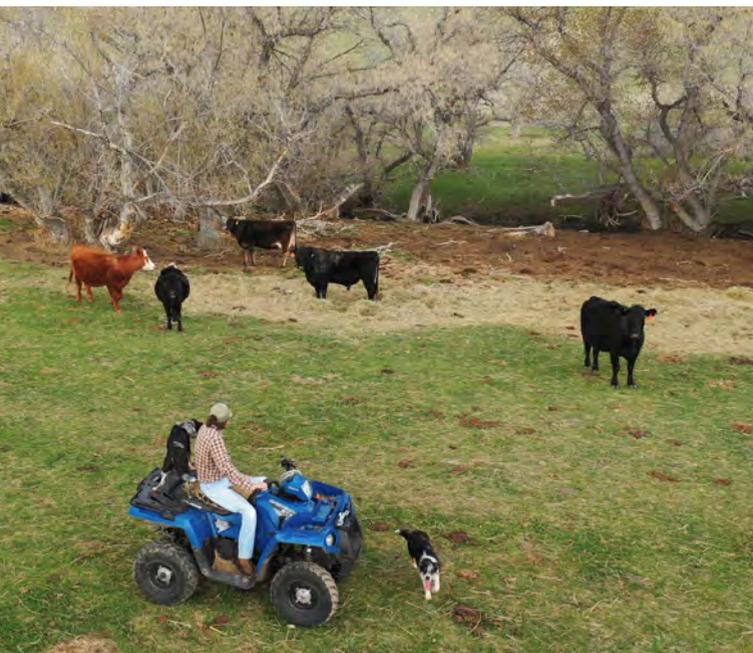
on and make the most of the rest of your life.

Too many times significant changes tend to throw us a curve and we want to stall out and lose momentum. It is OK to do that for a little bit, regroup, but then it is time to move on. Life still has to be lived and deserves to be lived.

We are going through a bit of a rough patch in our country. Uncertain politics, leaders of our political parties focusing more on parlor games and theatrics than attending to the business of making our country safe and economically sound for its citizens. As ag producers and land-

owners we see our own situation somewhat threatened, often times by uninformed people with no concept of the incredible task of feeding millions of people.

It is a fairly thankless job being a food producer. Most of us in the business do it because we love what we do. We love the freedom of being self-employed, the satisfaction of growing a plant or animal that will provide life-sustaining nourishment for others. Money plays a role in it, as it does with any job, but given the hours involved in oftentimes bad weather, it is far from the primary motivation. **MM**



Get Off Your Duff: **POLITICAL VOLUNTEERING WITH A DISABILITY**

BY ABE MUNDER

The 24-hour cable news stations won't stop babbling about it. Your Facebook friends won't stop raging about it. And pols won't stop tweeting about it. These days, there's no escaping it — and you know exactly what it is: politics.

Tired of feeling frustrated, I wanted to get involved. There's big stuff going on — 23 candidates in the Democratic primary race and more each time I edit this article — and I didn't want it all to pass me by. I began poking around my rural area 70 miles north of Houston, looking for ways a quadriplegic with multiple sclerosis could participate from a wheelchair. Hopefully my journey will give you ideas for how to get involved where you live.

THE EASIEST STEP

Linda Cohn, president of the League of Women Voters of the Houston Area, said everything starts with getting registered. "You have to be registered if you want to vote," she says, "and voting is the most important way to participate in the system that determines everyday life. When you're driving to work in the morning and you're in a traffic jam, maybe the system can be tweaked to improve the traffic, and the people who make these decisions will be the ones who will be voted for in November."

Cohn timed it and said the Texas registration form takes 29 seconds to fill out. "The voter registration form is so easy, trust me," she says. "It is the easiest government form you will fill out." Find the registration form you need through your state's website.

This simple act could bring massive results. In 2016 Hillary Clinton and Donald Trump each

notched just over 27% of all voting-age Americans' votes. Now compare that to the 43% who didn't register. It's President Not-Registered, by a landslide!

Additionally, voters with disabilities are among those at risk for losing their rights to the restrictive voting policies being passed in states like mine. In Louisiana, officials in one parish — that's what they call counties — closed 21 polling places by claiming they could not be made accessible. It pays to be vigilant.

FROM HUMBLE ORIGINS

Registering to vote may seem like a minor step, but everything has to start somewhere. "You might get bitten by the bug and find yourself organizing more and more," says Cohn. "Start small, start with a little piece of your day, don't try to take on the world in one fell swoop. Do something as part of something you're already doing."

James Van Winkle of Conroe, Texas, can testify to Cohn's comment. Van Winkle, 62, felt his back up against the wall before getting involved. When an auto injury left him quadriplegic, Van Winkle suffered severe depression. His big step forward was volunteering at a local mental health organization, doing what he knew how to: teaching computers and finding used equipment in the community. His work snowballed into advocacy. Now coordinator of Conroe/Houston ADAPT, a direct action group, Van Winkle meets with local leaders and legislators at the capitol in Austin. He even lobbied Texas Governor Greg Abbott by purchasing a copy of Abbott's book and waiting in the autograph line — doubly interesting because Abbott is himself a wheelchair user.

“People look at you like you should be grateful for what you have and that you should not expect what everybody else has. That’s wrong,” Van Winkle says. “You’ve got a mind, you can think, you can do stuff.”

“Go and volunteer at your local groups. Let yourself be known. Let people see you, that you’re a part of the community. Don’t hide in your house. Get out in public and let people see who you are. And then it can grow from there. You don’t have to get radical, you don’t have to throw a fit. You just have to be there.”

SOMETHING FOR EVERYONE

Being there can take on a variety of forms, from nuts-and-bolts needs such as canvassing, serving on organizing committees and distributing materials like political signs, to things you may not have considered. “There are a lot of activities behind the scenes without going around canvassing a neighborhood and ringing doorbells,” says Richard Yawn, vice-chairman of the Walker County Republican Party.

This is one thing all political parties can agree on: “There’s a role for everybody,” says Bernard Sampson, coordinator of the Houston Organizers for Bernie Sanders. “We need people who will raise or collect money, or who will host watch parties, get-togethers, things like that.”

Sampson says there’s a role for anyone with any amount of time to spare: knocking on doors or making phone calls; serving on outreach committees to labor, LGBTQ or people of color; or helping organize watch parties of campaign events. There are even roles for those who are shy.

“You just have to get over your fear or apprehension and just do it. Getting out of your box is really uncomfortable, but it’s so worth it,” says Iowa advocate Jenn Wolff. Wolff, a 48-year-old T10 paraplegic and board member of United Spinal Association Iowa Chapter, has notched years of advocacy and outreach. “There are so many different ways that you can advocate at your comfort level.”

Wolff’s advocacy was born of her own frustration when the wheelchair that therapists said she needed was denied by Medicare. In that moment of desperation, she spotted an ad for a scholarship to an event organized around preserving access to complex rehab technology in Washington, D.C. She took the leap and filled out the application and hasn’t looked back since.

Now years and many projects later, she continues organizing outreach programs, both in-person — her March event included 10 participants in chairs — and through online video-conferencing with the Zoom Meetings app that lets people participate from home, so valuable

in rural areas like hers in northeastern Iowa where transportation is an issue.

Many organizations and campaigns across the political spectrum are easily accessible online. Medicare 4All.org, Common Cause and Human Rights Watch are just a few of the groups welcoming those willing to write letters or call their reps. Many organizations enable phone banking from home: Obama for President 2008 featured internet phone banking that was smooth and simple. Running it with voice recognition was touchy but doable, and adding a mouthstick made it sail.

But no associations at all are needed to whip out the phone or pen and let federal, state and local officials know just what you expect out of government. Writing letters to the editor, attending meetings of local boards, volunteering at citizens groups around town, or even meeting with judges or police officials are all ways to exert influence — and much more effective than rage-watching cable news in your underwear.

“You can look into building relationships with your local or state legislators,” says Wolff. “You can just get signed up to be on action alerts so you can send an email or phone call. There are so many different avenues.”

MM

RESOURCES:

- Democratic National Committee, democrats.org
- Republican National Committee, GOP.com
- League of Women Voters, lwv.org
- United Spinal Association, unitedspinal.org

GET OUT THE VOTE

Running a one-person voter registration drive is a great way to dip your wheels into the political waters. And it’s easy, too, according to Linda Cohn, president of the League of Women Voters of the Houston Area. Registration forms can be found at public buildings like libraries or tax assessors’ offices. She suggests carrying around forms and leaving them Johnny Appleseed-style at work or other stops on the daily routine, such as block parties or other community events.

“You don’t have to devote huge amounts of time to develop and manage a vast voter registration campaign,” says Cohn. “For instance, if you have a Girl Scout troop or a Boy Scout troop, send them home with a form or two and ask them to pass them along to someone who might need it. Or at the doctor’s office, ask if you can leave a couple of voter registration forms on the counter for someone who might need it. Throw breadcrumbs in the pond sort of thing. Get them out there in the community.”

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HealthSouth East Valley Rehabilita-
tion Hospital, Mesa, AZ;
480/567-0350

Honor Health Rehabilitation Hospi-
tal, Scottsdale, AZ; 480/800-3900

CALIFORNIA

Dignity Health - Northridge Hospital
Medical Center, Center for Rehabil-
itation, Northridge, CA;
818/885-8500

Rady Children's Hospital San Diego
- Division of Pediatric Rehabilitation
Medicine, San Diego, CA;
858/576-1700

Santa Clara Valley Medical Center,
San Jose, CA; 408/885-5000

Sharp Rehabilitation Center, San
Diego, CA; 858/939-6709

Sutter Rehabilitation Institute,
Roseville, CA; 916/878-2588

COLORADO

Colorado Acute Specialty Hospital,
Denver, CO; 303/264-6900

Craig Hospital, Englewood, CO;
303/789-8800

CONNECTICUT

Gaylord Specialty Healthcare,
Wallingford, CT; 203/284-2800

Hospital for Special Care, New Brit-
ain, CT; 860/827-2761

Mount Sinai Rehabilitation Hospital
- a Trinity Health of New England,
Hartford, CT; 860/714-3500

DISTRICT OF COLUMBIA

Medstar National Rehabilitation
Hospital - SCI Program, Washington,
DC; 202/877-1000

FLORIDA

Brooks Rehabilitation Hospital,
Jacksonville, FL; 904/345-7600

Pinecrest Rehabilitation Hospital at
Delray Medical Center, Delray Beach,
FL; 561/498-4440

GEORGIA

Emory University Hospital Center for
Rehabilitation Medicine, Atlanta, GA;
404/712-7593

Rehabilitation Hospital Navicent
Health, Macon, GA; 478/201-6500

Shepherd Center - Southeastern
Regional SCI Model System, Atlanta,
GA; 404/350-7645

ILLINOIS

Marianjoy Rehabilitation Hospital,
Wheaton, IL; 800/462-2366

Schwab Rehabilitation Hospital,
Chicago, IL; 773/522-2010

Shirley Ryan Ability Lab,
Chicago, IL; 312/230-1000

The Spinal Cord Injury Program of
Marianjoy Rehabilitation Hospital,
part of Northwestern Medicine,
Springfield, IL; 217/788-3302

INDIANA

Parkview Rehabilitation Hospital,
Fort Wayne, IN; 260/373-4000

Rehabilitation Hospital of Indiana,
Indianapolis, IN; 317/329-2000

IOWA

Childserve, Johnston, IA;
515/727-8750

KANSAS

Mid America Rehabilitation Hospital,
Overland Park, KS; 913/491-2400

KENTUCKY

Cardinal Hill Rehabilitation Hospital,
Lexington, KY; 859/254-5701

Frazier Rehabilitation Institute, Louis-
ville, KY; 502/582-7490

Gateway Rehabilitation Hospital
Florence, KY; 859/426-2400

LOUISIANA

The Gilda Trautman Newman Reha-
bilitation Center, New Orleans, LA;
504/899-9511

Touro Rehabilitation Center, New
Orleans, LA; 504/897-8560

MASSACHUSETTS

Spaulding New England Regional
Spinal Cord Injury Center, Charles-
town, MA; 617/573-2770

MARYLAND

Adventist Rehabilitation Hospital of
Maryland, Rockville, MD;
240/864-6132

International Center for Spinal Cord
Injury at Kennedy Krieger Institute,
Baltimore, MD; 888/554-2080

Medstar Good Samaritan Hospital
Spinal Cord Rehabilitation Program,
Baltimore, MD; 443/444-8000

University of Maryland Rehabilitation
and Orthopaedic Institute, Baltimore,
MD; 410/448-2500

MICHIGAN

Mary Freebed Rehabilitation Hospi-
tal, Grand Rapids, MI; 800/528-8989

DMC Rehabilitation Institute of
Michigan, Detroit, MI; 313/745-1055

MINNESOTA

Essentia Health Miller-Dwan
Rehabilitation Services, Duluth, MN;
218/727-8762

MISSOURI

Ability KC, Kansas City, MO;
816/751-7812

MISSISSIPPI

Methodist Rehabilitation Center,
Jackson, MS; 601/981-2611

NORTH CAROLINA

Cone Health Inpatient Rehabilitation
Center, Greensboro, NC;
336/832-8153

Vidant Medical Center, Greenville,
NC; 252/975-4100

Wake Forest University Baptist
Inpatient Rehabilitation Program,
Winston-Salem, NC;
336/716-2011

WakeMed Rehab Hospital, Raleigh,
NC; 919/350-8861

NEBRASKA

Madonna Rehabilitation Hospital SCI
Rehabilitation Program, Lincoln, NE;
402/489-7102

QLI - Spinal Cord Injury Program,
Omaha, NE; 402/573-3700

NEW HAMPSHIRE

Northeast Rehabilitation Hospital
Network - Neuro Centers, Salem,
NH; 603/893-9478

NEW JERSEY

Bacharach Institute for Rehabilita-
tion, Pomona, NJ; 609/748-5480

Kessler Institute for Rehabilitation,
West Orange, NJ; 973/252-6367

NEVADA

Renown Rehabilitation Hospital
Reno, NV; 775/982-5000

NEW YORK

Helen Hayes Hospital, West
Haverstraw, NY; 845/786-4000

Mount Sinai Medical Center,
New York, NY; 212/241-6500

Orange Regional Medical Center,
Middletown, NY; 845/333-1000

Rusk Rehabilitation at NYU Langone
Medical Center, New York, NY;
212/263-6012

St. Charles Hospital Rehabilitation
Center, Port Jefferson, NY;
631/474-6011

St. Mary's Hospital for Children,
Bayside, NY; 718/281-8987

Strong Memorial Hospital of the
University of Rochester, Rochester,
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Sunnyview Rehabilitation Hospital,
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The Burke Rehabilitation Hospital
- Spinal Cord Injury Program, White
Plains, NY; 914/597-2500

OHIO

Metrohealth Rehabilitation Institute
of Ohio, Cleveland, OH;
216/778-3483

Ohio Health Outpatient Neurologi-
cal Rehabilitation, Columbus, OH;
614/484-9600

Summa Rehabilitation Hospital,
Akron, OH; 330/572-7300

OKLAHOMA

Integrus Jim Thorpe Rehabilitation Network, Oklahoma City, OK; 405/951-2277

Valir Rehabilitation Hospital, Oklahoma City, OK; 405/609-3600

OREGON

Legacy Rehabilitation Institute of Oregon, Portland, OR; 503/413-7151

PENNSYLVANIA

Allied Services Integrated Health System Spinal Cord Injury Program, Scranton, PA; 570/348-1360

HealthSouth Rehabilitation Hospital of Altoona, Altoona, PA; 814/944-3535

HealthSouth Reading Rehabilitation Hospital, Reading, PA; 610/796-6000

Moss Rehabilitation Hospital, Elkins Park, PA; 215/663-6000

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Spinal Cord Program at The Children's Institute, Pittsburgh, PA; 412/420-2400

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HealthSouth Rehabilitation Hospital of Charleston, Charleston, SC; 843/820-7777

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TENNESSEE

Patricia Neal Rehabilitation Center, Knoxville, TN; 865/541-3600

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Encompass Rehabilitation of San Antonio, San Antonio, TX; 210/691-0737

Houston Methodist Hospital, Houston, TX; 713/394-6000

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University of Texas Southwestern Medical Center - Rehabilitation Unit, Dallas, TX, 214/493-0597

UTAH

University of Utah Health Care Rehabilitation Center, Salt Lake City, UT; 801/585-2800

VIRGINIA

Inova Acute Rehabilitation Center at Inova Mount Vernon Hospital, Alexandria, VA; 703/664-7924

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Spinal Cord Injury at VCU Health, Richmond, VA; 804/828-0861

UVA - HealthSouth Rehabilitation Hospital, Charlottesville, VA; 434/924-0211

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University of Washington Harborview Medical Center: Northwest Regional Spinal Cord Injury System, Seattle, WA; 206/221-7390

WISCONSIN

The Spinal Cord Injury Center at Froedtert and The Medical College of Wisconsin, Milwaukee, WI; 414/805-3000

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Miami Physical Therapy Assoc., Inc. Miami, FL; 305/444-0074

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Sanford, FL; 407/571-9974

Project Walk - Boston
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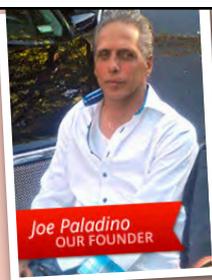
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OUTDOOR TRACKS

By Kary Wright

MINE, ALL MINE

"Here is the pièce de résistance!" says Dennis, our guide at Arizona's Hull Mine in Castle Dome City. "Follow me!"

"Sounds great, looking forward to this!" I reply.

Our group follows him down another mine shaft to where it opens up into a small room with a ceiling that is about 55 feet high. There is a narrow tunnel off to the left, and it's definitely not wheelchair accessible down there.

"Now put some goggles on as the light can hurt your eyes without them." Dennis tells us. "OK, now I'll turn on the lights."

First the cave is darkened by extinguishing the regular lights, then the ultraviolet lights are turned on. There are several pointed in different directions to illuminate the cathedral.

"Things should light up soon," Dennis assures us. "It'll take a few minutes to charge the rocks."

The Invite

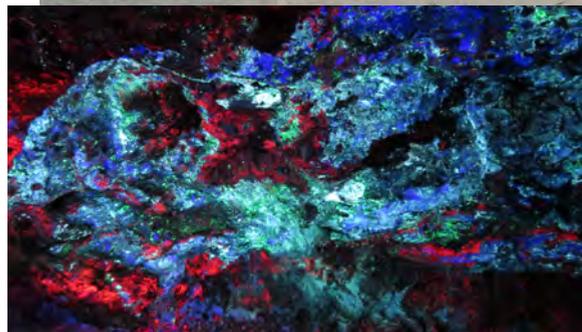
We are 100 feet below the surface in an abandoned silver mine that has been made safe for public viewing by shoring up the walls and pouring a concrete floor throughout most of it.

Our adventure started a few days ago when our wives went down into the mine on a tour. We were told it wasn't wheelchair accessible, so my friend Jim and I opted to take one for the team and enjoy the desert sun in the parking lot. While leaning back, doing our best impressions of a lizard, a gentleman rode up on his bicycle and stopped to chat.

"You boys enjoying the sun?"

"Yes, the rest of the crew is on the tour, we stayed here," Jim replied.

"If you could get to the entrance, we



Only 600 feet below the hot Arizona desert lies the stunning fluorescent mineral cave wall.

could probably get you down, it's paved all the way," he says. "Can you get transferred into an ATV?"

"Not easily, but if my van could get to the mine, I might be able to go down. What's the road like?"

"About the same as the last few miles of gravel that you came on. If you want, we'd let you drive to the mine sometime to see. The shaft is about a 16% grade — can your chair handle that?"

My inner voice is nattering, "Pshaw, my buddies and I have tested my chair on stuff way steeper," but my senior judgment auto-corrects my words before they hit my mouth (a relatively new skill): "We might just be able to make it."

"Do you work here?" I ask.

"Sort of," he says. "I own the place."

And so here we are, a few days later

on a private tour with Dennis, a volunteer guide at the mine. The trail to the mine was about a mile long, winding up and down desert gullies — nothing that the minivan couldn't handle.

Inside the Mine

"I can see the colors — the rocks are starting to glow," I say.

Under ultraviolet light, you can start to see reds, greens and blues from the walls of the cavern. Within a few minutes, the colors are so vivid it looks like there are lights inside the walls. I lean my chair back and discover the colors extend way up.

"What causes this?" I ask.

"The minerals in here are phosphorescent. They seem to charge up in the ultraviolet light and then emit these fantastic colors. This place is kind of an

anomaly, rocks that phosphoresce aren't that rare, but most stop glowing shortly after the light goes out. In here, they will emit light 20 minutes or more after the lights are turned off. We don't know of another place where this happens."

Once we are done taking pictures, Dennis extinguishes the ultraviolet lights. Sure enough, the walls continue to glow, and when we leave 20 minutes later the light from the walls is still visible.

On our tour we saw a cavern that was once used as a hideout for outlaws. Apparently, they were relatively safe in there, as lawmen had little interest in entering a cramped mine and being greeted by heavy fire-power. At one point a bat emerged from a tunnel and fluttered around before returning. There are hundreds of bats down that shaft, which we were told is about a half-mile long. It is normally closed off during tours. There was a silver vein plainly visible in the ceiling, and old artifacts found down in the mine such as tools, chisels and hammers — almost like the miners walked out after their shift and never returned. The

Frequently Asked Questions

How steep is the grade?

I heard it was 16%. With my Quickie 646 power chair I simply leaned back to move the center of gravity and wheeled slowly down into the mine with help hanging on behind. It is up to you and your crew to determine if it is passable for you in your situation. Personally, I have gone far worse places with this chair, but that doesn't guarantee that on some of my adventures sound judgment was always utilized ... or even available!

Where is the mine located?

It is between Yuma and Quartzsite, Arizona. You travel north of Yuma on Highway 95 to mile marker 55, then turn east for 10 miles. The last seven miles are gravel, but our minivan had no trouble. Just leave extra time so you're in no hurry.

How far down is it?

The journey down the tunnel is about 650 feet long and drops about 100 feet down. It was comfortably warm down there.

For more information, visit www.enchantedcavern.org.

museum even has a pair of Levi's jeans from the 1800s.

There was a "two-holer" rail-cart biffy held in place by a bar and chain under the wheels. The word is that when a new worker sat on it to relieve himself, a veteran would pull the chain to release the

cart down the track giving the new guy a fast pants-down run through the mine. Apparently, the term "Don't yank my chain!" came from these adventures.

It was well worth the fee to go down in an abandoned mine, especially in a power wheelchair.



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PARA/MEDIC

By Bob Vogel

POPULAR UTI ANTIBIOTICS AND TENDON RUPTURE

Q. *I'm 58 and in my 34th year as a T10 complete para. Over the years I've managed symptomatic UTIs with Cipro, and later with Levaquin, both of which wiped out the UTIs with no side effects. Fortunately, I haven't had a UTI in over a year.*

I've noticed a lot of buzz that suggests these antibiotics can cause tendon problems. I've seen articles, SCI forums and late-late-night TV ads asking variations on, "Have you taken a type of drug called fluoroquinolones and had a tendon rupture? If so, call 'so-and-so' attorneys at ..." This got me thinking. Like many of my peers who have had SCI for decades, I was recently diagnosed with rotator cuff tears in my shoulder. I'm wondering if there is a connection with these drugs? These antibiotics work great when I get a UTI. Are they dangerous to my tendons? And if so, for how long? Are the effects cumulative? And what are the options.

— Chris

Chris, this is a topic that is frequently in the news. The FDA has issued "black box" warnings on these drugs — the strictest precautions it puts on prescription labeling. You should take these very seriously and discuss the risks and benefits with your physician. Here is a look at how the warnings came to be, along with a look at the reports in perspective and options to help avoid UTIs.

Fluoroquinolones — which include ciprofloxacin (Cipro), levofloxacin (Levaquin), Proquin XR, Ofloxacin, Noroxin, Moxifloxacin and Gemifloxacin — are a class of broad-spectrum antibiotics that were introduced in the '80s and '90s. They are great for infections in the bladder and kidneys, and testicular infections like epididymitis, because they target gram-negative bacteria, which are the most com-

mon bacterial culprits, says Dr. Michael Kennelly, director of urology at Carolinas Rehabilitation in Charlotte, North Carolina.

Millions of people take fluoroquinolones each year, and most find them effective with few, if any, problems. It is important to note that all medications, even aspirin, have the potential for serious side effects and fluoroquinolones are no exception. A PubMed search brings up journal articles that associate fluoroquinolones with tendon damage starting in the mid-'90s, and reports have become more frequent in subsequent years. So far, there have been no clinical studies that prove a cause-effect link, only anecdotal evidence.

The FDA keeps tabs on reports of side effects of drugs, and when enough reports of a side effect happen, they take action. In the case of fluoroquinolones and tendon damage, by 2008 enough reports had been logged — plus a petition and lawsuit by Public Citizen, a nonprofit consumer rights organization — that the FDA decreed a "black box" warning be added to fluoroquinolone drug labels, prescribing information and treatment guides. In 2016, the FDA issued further caution with an advisory suggesting that fluoroquinolones should not be used to treat uncomplicated urinary tract infections — as well as acute sinusitis and acute bronchitis — due to association with tendon pain and damage.

In 2018 the FDA issued yet another warning on fluoroquinolones, this time about the risk of ruptures or tears in the aorta. However, with aortal side effects, the risk is specific to people with a history of blockages or aneurysms of the aorta or other blood vessels, high blood pressure or certain genetic disorders that affect blood vessels and the elderly.

Since these reports of tendon

injury weren't made under controlled trials, there is no way to know if they are directly related to the drug, says Kennelly. "The FDA is saying, 'even though we don't know fluoroquinolones are a direct cause, there is enough substantial evidence in the reports of side effects that we need to look at this.'"

Risks, Rewards and Alternatives

For perspective on the risks, Dr. Jerome Stenehjem, medical director at Sharp Rehabilitation Center, searched on the medical site UpToDate.com and found the incidence of tendon pain associated with use of fluoroquinolones is about one per every 200 treatments. Tendon rupture is about one per 800 treatments. According to a 2012 study, fluoroquinolone-associated tendinitis "is more pronounced among elderly persons, non-obese persons, and individuals with concurrent use of glucocorticoids." The Achilles tendon is what is injured in the majority of cases — and this is associated with running and jumping — but other tendons, including the rotator cuff can be affected.

Reports associate increased risk of tendon injury immediately following antibiotic use for up to five months, but Stenehjem thinks the risk drops off sharply after two months and decreases over time. A 2017 article in *Infectious Diseases Consultant* states that symptoms have an average onset of just nine to 13 days after the start of drug therapy.

Stenehjem also says that if you do need to take a course of a fluoroquinolone and notice pain in a tendon or joint, you should stop taking it and talk with your doctor right away, so you can be switched to a non-fluoroquinolone anti-

biotic. Then, take it easy so you don't turn tendonitis into a rupture.

This brings us to ways to help avoid taking fluoroquinolones, starting with the basics of trying to avoid UTIs: drink plenty of water — enough to keep your urine in the clear-to-straw-color range — and make sure your bladder management system is fully draining your bladder.

People also report success in UTI avoidance by taking D-mannose capsules, which fight E. coli by "lubricating" the bladder walls, making them slippery so the bacteria can't gain a stronghold. Cranberry capsules may help, but keep in mind that cranberry juice isn't strong enough and can contain harmful sugar. The capsules decrease urine pH, making it more acidic, which creates a hostile environment for certain bacteria. Vitamin C also makes the urine acidic.

Another option for preventing recurring UTIs is to ask your doctor about using an antibiotic irrigant solution in your bladder. It's also important to get a yearly urology check-up for kidney and bladder stones, which can cause recurrent UTI.

If you do get a UTI, it is important to use an antibiotic that targets the specific bacteria you have rather than a fluoroquinolone. This is done by submitting a urine sample to a lab at the first sign of infection. An option to have this done quicker is to see if your physician will supply you with some urine collection cups and a standing order at a lab for a urine culture so you can bring it in immediately. Unfortunately, it takes 48-72 hours to get results from a urine culture and sensitivity report to pinpoint the most direct and effective antibiotic.

While you wait for the results of your culture, you can get started on the antibiotic most likely to target the bacteria you have by asking your doctor to check the antibiogram for your area, which has data on bacteria susceptibility and resistance in a specific area the size of a clinic, hospital, or even a region, says Kennelly. Bacteria develop different resistances in different areas, and recent information from an antibiogram can stack the antibiotic deck in your favor.

"These days I think if physicians have their choice, they will say 'Well, there has been enough bad press about fluoroquinolones that if we have an option, let's try and steer away to something different if we can,'" says Kennelly. "However, for patients

of mine that have a UTI and have used Cipro and it has worked and they've not had any problems, it is still a good option. But with the information that is out there, fluoroquinolones are no longer our reflex go-to antibiotics like they were 20 years ago when I was in training."

Resources

- Bladder Irrigant Solutions for UTI Reduction, newmobility.com/2015/12/bladder-irrigant-solutions/

- FDA warning on fluoroquinolone and aorta damage, fda.gov/Drugs/DrugSafety/ucm628753.htm
- Minimizing the Risk of Tendon Injury With Fluoroquinolone Use, consultant360.com/articles/minimizing-risk-tendon-injury-associated-fluoroquinolone-use
- WebMD: FDA Warning: Cipro May Rupture Tendons, webmd.com//osteoarthritis/news/20080708/fda-warning-cipro-may-rupture-tendons

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ERVIN

By Mike Ervin

CRIP GENERATION GAP

I have a question for everybody out there who was once a criplet. When you played with your favorite childhood dolls, did you ever wish those dolls were crippled like you?

My doll of choice when I was a criplet in the 1960s was G.I. Joe. I had several that I played elaborate war games with, although if you called G.I. Joe a doll to my face back then, I would've spit fire back at you. G.I. Joe wasn't a doll, dammit! Girls played with dolls! He was an action figure! G.I. Joe was a soldier, or a sailor, or an Air Force guy, depending on how you dressed him that day. He wasn't some wimpy-ass Ken! G.I. Joe was buff and rugged. Some G.I. Joes had beards. No Kens had beards. Ken was a scrawny, preppy, spoiled-brat-son-of-a-millionaire draft dodger! The only thing G.I. Joe and Ken had in common was that neither had genitals. At least G.I. Joe had an excuse. In his case, it could have been a war wound.

Anyway, I asked the above question because the Mattel toy company, famous creator of Barbie dolls, recently revealed that later this year it will come out with a wheelchair Barbie. She is the latest addition to the Fashionista line of Barbies, which has a wide variety of different body types, skin tones and hair textures.

It's kind of funny because Mattel already introduced a wheelchair Barbie in 1997. She had the cutesy name of Share-a-Smile Becky. And

then a few years ago, Mattel quietly killed her off. They stopped making her. But the Mattel spokeswoman who announced the coming of the new crippled Barbie said the demand among young girls to create a new wheelchair Fashionista Barbie was high.

But I didn't want my G.I. Joes to be just like me. I wanted to be just like them, except for the part about not having any genitals. It didn't once cross my mind that it would be cool if my G.I. Joe was in a wheelchair. If I wanted a crippled G.I. Joe, it was easily done. All I had to do was yank off one of their limbs. I did have some G.I. Joes who became amputees through wear and tear. It was traumatic for me when that happened. In my war games, they were always relegated to the lowly role of wounded guys.

Maybe that's the difference between today's criplets and the criplet of my vintage. When I was a criplet, the whole point of dolls like Barbie and G.I. Joe was that they didn't look like you. When we played with dolls, we were pretending. And you don't pretend to be what you already are. A princess doesn't pretend to be a princess. If there's some weird planet out there where all the females look like Barbie dolls, I bet nobody there buys Barbie dolls.

But today's criplets pretend differently than we used to. They (and their parents) are cocky enough to

“Maybe that's the difference between today's criplets and the criplet of my vintage. When I was a criplet, the whole point of dolls like Barbie and G.I. Joe was that they didn't look like you.”

believe that they can be a princess or a badass like G.I. Joe and still be in wheelchair, too.

In addition to a wheelchair Barbie, Mattel also added that the Fashionista line will include a new Barbie with a prosthetic leg. And in the interest of realistically depicting living with a disability, the leg will be detachable.

I think that's a good thing. No human has their prosthetic limb permanently attached, so why should dolls? It would be like having wheelchair Barbie molded into her wheelchair.

But when it comes to realism, Mattel is only ready to go so far with wheelchair Barbie. Her accessories do not include catheters and suppositories. Maybe someday criplets will be cocky enough to demand that.

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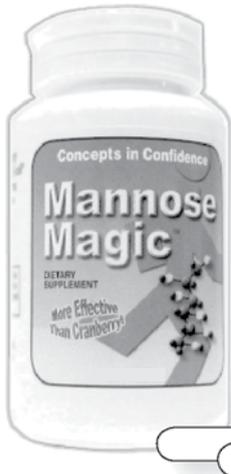


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WHEELCHAIR CONFIDENTIAL

THE GETAWAY CHAIR

While getting out of my van one evening, my wheelchair got away from me and rolled across the parking lot, down a driveway and across Route 20, a four-lane highway. Luckily, no vehicles hit the chair, and it settled in a ditch. A confused motorist pulled over and retrieved my chair for me. Seems like a happy ending, right?

Well, four or five days later I went to pay some bills and couldn't find my checkbook anywhere. After thoroughly searching the office and all around my house, I was at a loss. No activity on the account meant it was likely not stolen. Thinking back, the last time I remem-

bered seeing it, was in the pouch under my wheelchair the night of the incident. It took some convincing, but I eventually got my wife to go back to the scene to look for it. Sure enough, in less than five minutes she found my checkbook. Somehow that was the only item that had fallen from the pouch despite my generally not keeping it zipped closed.

Xavier Cash

BOTTOMS UP

I was in a party mood one evening and after one too many drinks, I made my way to the restroom. While pulling up my leggings, I stumbled and fell and there was no way I was getting up from the floor without help.

So there I was, naked from the waist down, my pants pooled around my ankles, and I didn't even have my cell phone to discreetly call for help! To make matters worse, the door was unlocked and I was terrified someone would walk in and see me like that. As luck would have it, my husband knocked on the door to ask if I was OK. He sensed something was wrong and came in right away when I said I needed help.

After he picked me up off the floor we both turned around to discover that I'd knocked a hole the size of a football in the sheetrock with my head! Fortunately, our hosts understood when we explained what happened, and we took care of the damages.

I always carry my phone to the bathroom now.

Tipsy-Turvy



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