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The Man

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COVER STORY

ERIC HOWK. THE MAN

Eric Howk just won a Grammy. His band, Portugal. The Man, has two of the biggest hits of the year. And he is living his dream touring the world and playing guitar. IAN RUDER sat down with Howk to find out what it's like being one of the most visible wheelchair-using musicians in the world, what life is like on the road and what went on behind the scenes at the Grammys.

Cover and Contents Photos by Maclay Heriot



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BULLY PULPIT

By Tim Gilmer

A NEW PATH FOR NEW MOBILITY

In 2000, I faced a life decision: whether to continue teaching community college writing courses or accept the editorship of *NEW MOBILITY* magazine. So I prayed — as I often do — that God would make my path clear. Many of us with disabilities, with our overriding need to live independently, reject the idea that God guides our lives. As for me, over the years I have grown to accept that much of my life path has, in ways beyond my understanding, been chosen for me.

The application process, trial editing and writing assignments went smoothly. I told myself that either path would be right since teaching and editing both centered around what I love doing most — writing. Then came a three-hour interview with Barry Corbet, Jean Dobbs and then-owner Jeff Leonard at Barry’s home in the Rockies. Afterward, I flew home to Oregon and awaited their decision. When Jean called and offered me the job, I realized how much I wanted it. I got emotional, choked up — and could not speak.

“Tim, are you there?” asked Jean.

“Yes, yes, of course,” I finally managed.

“I’m ... overwhelmed, and happy to accept.”

I’ve been extremely fortunate to serve as *NM*’s editor. Now, 211 monthly issues later, I have reached another fork in the path: At the end of June I will retire as editor. I hope to stay connected to the magazine, both in print and online, editing and writing in a part-time capacity.

NEW MOBILITY has made recent changes under Jean Dobbs’ leadership. The magazine, newly redesigned, has a bright future. Since 1991, Jean has risen from intern to managing editor to editorial director to publisher. Her multiple talents, dedication and unparalleled experience make her the best possible person to guide the magazine, and we are all the better for it.

Ian Ruder officially becomes our new editor on July 1. He has a fresh outlook and just the right leadership qualities — a wealth of personal experience with disability issues, nearly two decades of journalistic writing and editing experience, and a talent for shaping stories that resonate with our readers. He is also extremely well-connected with United Spinal chapter members and freelancers.

Josie Byzek, always committed and competent, takes on the newly created position of executive editor. She is our advocacy expert, champion of diversity and indefatigable voice of passion. And a damn good writer.

“I have been extremely fortunate to serve as *NM*’s editor.”

Most recently she has infused new energy into our online presence and social media platforms and eagerly steps up to meet any new challenge.

Seth McBride is our new associate editor, a gifted writer, exceptional athlete, world traveler (and new father), poised to grow and prosper with *NEW MOBILITY* — we all hope — for a long time.

Bob Vogel, with decades of *NM* writing and reporting experience, known for his insightful profiles, adventure, recreational and product expertise, anchors our freelancers. And our stellar lineup of columnists is a rich blend of talented veterans and new voices.

As bright as *NM*’s future is, we are nothing without you, our faithful readers. May your paths remain connected with ours — and may we continue to educate, encourage and support one another for years to come.



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Our Staff and Freelancers



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ELLEN STOHL

A little eccentric, a little wild and full of soul — that’s how Ellen Stohl, a NEW MOBILITY mainstay for many years, describes herself. She also teaches at California State University, Northridge, and is raising a beautiful 14-year-old daughter with her husband, David — roles she never thought possible 35 years ago when she took a dangerous curve on a wet freeway at breakneck speed, shattering her spine and, at the time, her dreams. Today she considers herself a self-actualized woman whose education, experience and life story have given her unique opportunities and insights into living life fully.



MIKE ERVIN

Mike Ervin is a playwright, author, activist and the one and only Smart Ass Cripple. In addition to writing for NM, he has been published in everything from *The New York Times* to *Warehouse Executive* magazine. He boasts of being arrested 20 times in ADAPT actions. He also blogs relentlessly at smartasscripple.blogspot.com, where he shamelessly promotes *Smart Ass Cripple’s Little Red Book*, which has a blue cover, *Smart Ass Cripple’s Little Yellow Book*, which has a red cover and *Smart Ass Cripple’s Little Chartreuse Book*, which has a black cover, all available at lulu.com.



TEAL SHERER

Teal Sherer is an actor and advocate for the inclusion of performers with disabilities in the entertainment industry. She created and starred in the online comedy series *My Gimp Life*, loosely based on her real-life adventures in Hollywood. Teal wrote her first article for NM in 2008, taking readers behind the scenes of the Emmy Award-winning film *Warm Springs*, which follows President Franklin Delano Roosevelt’s early battle with polio. She lives in Seattle with her husband and 3-year-old son. This summer, you can find her on the water with the adaptive rowing team Seize the Oar.



.....
 Want to contribute to NEW MOBILITY? Please send queries and manuscripts to Ian Ruder: iruder@unitedspinal.org



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“It is good to hear of these thoughtful innovations and thrusts.”

Smart Chair Innovations

Be encouraged! It is good to hear of these thoughtful innovations and thrusts that address the emotional and psychological health of chair users [“Meet the Smartchairs,” April 2018]. Thanks for sharing.

Michael Andrew Williams
Newmobility.com

More Diet Info Needed

I’ve been struggling with weight ever since I wasn’t able to swim frequently. It is so hard to find information about SCI and metabolism and diet [“Making Sense of Your Metabolism,” April 2018]. Thank you so much for writing this comprehensive article. More articles like these are needed.

Mary Keating
Newmobility.com

Wheelchair Vanity

Why shouldn’t we be vain about our wheelchairs? People are vain about the car they drive, and the wheelchair is really just another mode of transportation [“Dreaming of a Prettier Chair,” April 2018]. I want my chair to be very comfortable, to be cute (or pretty) and quite frankly to have people stop me not because they feel sorry about the fact that I am in a wheelchair, but because the chair is so “cool looking” that they want to know where I got it.

Idalia Ringwal
Newmobility.com

Unique Chair Deco

My Jazzy Select 14 served me well for nine years until I got my Quantum iLevel. I found bright, interesting T-shirts and skirts to slip over the seat

back, used a lovely, soft lambskin fur for the seat and color coordinated the duct tape for the arms. I added a Harley “Lady Rider” patch for the back of the headrest and acquired a chrome “Limited Edition” for the front. Most of the comments and conversations I had were upbeat and complimentary in the mode of “you go, girl.” Now for the Quantum, a friend has offered to install neon ground effects

Lori Kowalski
Newmobility.com

Patient Advocacy

I have found that you need a patient advocate — whether a professional or family member who learns the job — when you are hospitalized, and then you have to become your own advocate afterwards [“Finding My Patient Advocate,” April 19 NM blog]. It is exhausting to fight for what you need. It takes being tenacious to the point of wanting to give up, but you just keep going.

Sheri Denkensohn
Newmobility.com

Wound Bed Advice

I am a T12 para, physical therapist, former clinical manager for Span-America (therapeutic bed manufacturer), and have a history of pressure ulcers and one small flap surgery on my right ischium. Clinitron beds are excellent pressure equalizers, so if you have to lie on the flap site, they’re the best option [“Finding My Patient Advocate”]. However, they are painful to lie in because you’re floating on liquid, sand and air. Many have experienced severe neck, back and shoulder pain. It’s difficult to move in it or for caregivers to take care of you. There are versions



now that have the sand just under the trunk and those are easier to stay on, but still expensive. If you can lie in a couple of positions, like on your left and right sides, and not put pressure on your flap area, and if you are diligent about turning regularly and eat lots of protein, you can probably do well on a good low-air-loss mattress.

Laurie Rappl
Newmobility.com

Portable Hand Controls

I have rented cars with hand controls in multiple states over the years, always at a major airport [“Problems with Rental Car Hand Controls,” Everyday Advocacy, April 2018]. I have had companies flat out botch the reservation and lose the fact that I needed to have hand controls on the car, and I’ve had to scramble and arrange alternate transportation on the spot. Because of this I have begun to carry my portable hand controls as a backup when I fly.

John Nicholas
Newmobility.com

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ADA LAWSUITS: SHOULD SOCIETY BE WORRIED ABOUT SERIAL LITIGANTS, OR SERIAL VIOLATORS OF THE ADA?

In March, the *Pittsburgh Post-Gazette* reported on a lawsuit filed against the University of Pittsburgh Medical Center, the largest nongovernmental employer in Pennsylvania, alleging violations of the Americans with Disabilities Act. The lawsuit was filed on behalf of Josie Badger, a wheelchair user with a doctorate in health-care ethics, who alleges that parking lot slopes, lack of appropriate signage and steep curb cuts, among other violations, have limited her ability to fully and equally access many of UPMC's locations.

The *Post-Gazette's* article shares a tone with many stories on ADA lawsuits from around the country, and is illustrative of the way that the mainstream press often portrays these lawsuits and those who file them. "UPMC has become the latest target of a disability-rights activist who has retained a Pittsburgh-based law firm to sue nearly two dozen corporations in federal court in recent years over alleged violations of the Americans with Disabilities Act," reads the lead sentence of the article.

The article immediately frames UPMC as the victim in this story with the use of the word "target." The yet unnamed disability-rights activist, with her dozens of similar lawsuits, is thus cast as a pesky interloper, clogging the legal system with the minutiae of parking lot angles and ramp measurements. It's as if, regardless of what the law — now nearly three decades old — actually requires, a minimal effort at access

is all businesses should reasonably be expected to provide.

From the *Lowell Sun* to *60 Minutes* on CBS, this same type of coverage surrounding ADA lawsuits is prevalent. There is often an attempt to show balanced reporting, but the overall tone tilts to the side of business. Take the case of the *Lowell Sun*, of Lowell, Massachusetts, which reported in April on Dino Theodore, a man who, like Badger, was suing his local hospital for ADA violations, and had already sued many of his region's businesses for similar violations. The *Sun* paints the sheer number of lawsuits as a problem with the individual and his attorney:

"The hospital is just one in a long list of companies in Massachusetts and New Hampshire — there have been more than 50 over the past decade — that Theodore and [lawyer Nicholas] Guerrero have sued in federal court over their compliance with the landmark disability rights law.

"The work has earned them a reputation as shysters among some of those on the other end of their lawsuits."

Usually when a news publication wants to make a point, it will use a quote to let a member of the public make it for them. But the *Lowell Sun* doesn't even bother with that. If whoever called Theodore such a loaded term as shyster didn't want to be quoted, why would a reporter feel it necessary to insert it into the article?

The article actually goes on to present a decent overview of the disability



"There's no mainstream media coverage of the systematic inaccessibility of our healthcare system. Instead we get articles about the local wheelchair user who's brought dozens of lawsuits on unsuspecting businesses."

rights movement, but language matters, and the language used from the beginning of the article makes a clear point: ADA lawsuits are a problem, one that isn't the fault of the business.

No effort is made to frame the sheer size of the access issue, or to ask a simple and valid question: What



percentage of businesses are still in violation of the ADA? As wheelchair users across the U.S. know, the numbers aren't good. Even looking just at doctor's offices, a 2013 study by Tara Lagu, Ph.D., a researcher at the University of Massachusetts who has written extensively on public health, found that nearly a quarter (22 percent) of subspecialists reported that they would be unable to accommodate a specific patient with a mobility impairment. That's a rather shocking number, one that deserves to be mentioned when framing the story of specific lawsuits, but rarely is. Given that they're in the same state, perhaps the *Lowell Sun* should have contacted Lagu to get some much-needed context for its story.

If it feels like we are picking on the *Lowell Sun* and the *Pittsburgh Post-Gazette*, we are. But unfortunately, this kind of myopic reporting is all too ordinary. There's no mainstream media coverage of the systematic inaccessibility of our healthcare system, and too few

articles about the cute local bistro or hair salon that has two steps to enter and whose owners offer casual indifference when asked if there's an access ramp.

Instead we get articles about the local wheelchair user who's brought dozens of lawsuits on unsuspecting businesses. If wheelchair users alone were to bring a lawsuit every time they encountered an ADA violation that substantially limited their access to a business or other public accommodation, our courts would be backlogged into the next decade.

The 800-pound Gorilla

The hulking backdrop to all of this is H.R. 620, a piece of legislation that Republicans in the U.S. Congress have been trying to pass for years, and finally jammed through the House of Representatives in February. The bill was sold by its backers as an attempt to stop so-called "drive-by lawsuits," in which an attorney and plaintiff sue large numbers of businesses for ADA violations. The law would allow businesses up to four months to start making "substantial progress" toward removing barriers before they could be sued.

H.R. 620 was no doubt helped along by Anderson Cooper's *60 Minutes* report on drive-by lawsuits, a veritable parable of the ignorance of nondisabled society to the needs of those with disabilities. It places the ADA — with its "275-page manual that details everything from the exact height of a mirror in a bathroom, to the maximum thickness of carpeting, to the angle at which water can come out of a drinking fountain" — squarely in the frame of bureaucracy and regulation gone amok.

Perhaps along with these examples, it would be relevant to share how carpet thickness may have a large effect on a wheelchair user's ability to get from point A to B or, when you think about it, what exactly is the point of a mirror if you can't see yourself in it?

In one segment of the *60 Minutes* piece, the audience is made to feel for a hotel owner who "says he didn't know he was required to install" a pool lift, and after being sued by a serial litigant, we are told that he ended up "paying \$3,000 to buy a lift, that so far, no one has ever

used. He also spent thousands of dollars in attorney's fees."

The report makes no mention of the size of the manuals for building code and worker safety regulations and what seemingly trivial things they might cover. Businesses accept these regulations because they know they have to comply. Multimillion dollar settlements could potentially await those who decide to flout worker safety rules or modify buildings so that they no longer meet code. But if a business restripes its parking lot to remove or lessen accessible spaces, or never bothers to install a pool lift, the only punishment it typically faces is having to provide the access the law already demands. At worst, it may have to pay opposing attorney's fees and nominal, state-restricted settlements, as in the case of the noncompliant hotel owner.

To cast that same owner, or any other business owner as the victim, is both reflective of, and helping to fuel, a larger attitude in which providing meaningful access for people with disabilities is seen as more trouble — and expense — than it's worth. H.R. 620 is that attitude codified at one of the highest levels of government. Regardless of whether a companion bill ever makes it past the Senate and into law, it represents a troubling window into how a powerful segment of our society views the framework that supports the civil rights of the disability community.

— SETH MCBRIDE

Resources

- "UPMC becomes latest target of disability-rights activist suing over alleged ADA lapses," www.post-gazette.com
- "From a wheelchair, Lowell man's a force for accessibility," www.lowellsun.com
- "What's a 'Drive-By Lawsuit?'" www.cbsnews.com/news/60-minutes-americans-with-disabilities-act-lawsuits-anderson-cooper
- "Access to subspecialty care for patients with mobility impairment: a survey," www.ncbi.nlm.nih.gov

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CHAPTER NEWS

TAKE A LOOK AT THIS FILM

"If I'm with the right person, I don't feel like I'm paralyzed."

So says *Push Girls* star Angela Rockwood, one of 17 people who share their most intimate and honest perspectives on love and disability in the new film, *Take a Look at This Heart*. The film, by director and producer Ben Duffy and executive producer Dan Garcia, is 98 percent done, according to Garcia, after over a year of relentless work. He and Duffy have been raising funds to secure the rights to music for the film, work on final edits, and get the word out across the country.

A crowdfunding campaign on Indiegogo earlier this year raised almost \$4,000, and United Spinal Association donated \$2,000. The duo is still looking for funding and working to set up screenings across the country. If you are interested in donating you can do so through the New York City Chapter of United Spinal Association at www.nycspinalcord.org/donate-2/take-a-look-at-this-heart-fundraiser. If you are interested in arranging a screening in your community, or simply want to watch the trailer or find out more about the movie, visit the official website at www.takealookatthisheart.com or email Garcia at dangarciapresents@gmail.com. "We're almost there," says Garcia. "We just need some help to make that final financial push."



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LIVE WELL

By Josie Byzek

DIANE KETELSEN LOVES A CHALLENGE

Aspiring sports photographer Diane Ketelsen, 31, was studying fashion design at University of Oregon when she took a photography class, and it changed her direction. "I fell in love with the photographic image and I knew it was something I wanted to get into," she says.

Although she wasn't sure right away what she wanted to photograph, she did know she didn't want it to be easy. "Being a person with a disability, I grew up in a family where I wasn't really encouraged very much, so I like the challenge of photographing sports



because it forces you to react fast," says Ketelsen, who has cerebral palsy. "When I'm photographing an event, I get lost in the moment of capturing that action, that emotion. There's a sense of freedom when I have a camera in my hand."

Ketelsen uses her Amysystems track hybrid when shooting events since it's faster and more functional over mixed surfaces than her manual. Also, she shows up an hour or two ahead of time. "That way I can get set up, decide what the lighting is going to be and what the shutter speed should be. That gives me more preparation to get consistency in my photographs," she says.

Also, even though Ketelsen wants to be challenged, she's realistic about what she can physically do. "With my disability, sometimes the camera gets heavy, I get tired. Sports is very intense, very fast, so I tell myself if I miss the shot, it's OK."

Ketelsen is the administrative assistant at Emerald Art Center in Springfield, Oregon, where she shows her work. "They are helping me grow in my communication and passion and I'm very grateful for them," she says. "I'm blessed to be able to work there and be part of that community." Follow her journey at dketelsen.wordpress.com.



The Versa system



HEALING THROUGH ACTIVISM, MEMOIR WRITING

Back in 1977, HolLynn D'Lil was one of hundreds who participated in the historic demonstrations to get Section 504, one of the earliest disability rights regulations, signed. "It changed my whole life when I became an activist, and that felt really good," she says.

Now D'Lil (center in photo above) has gathered up her memorabilia and self-published it in *Becoming Real in 24 Days: One Participant's Story of the 1977 Section 504 Demonstrations for U.S. Civil Rights*. The book contains first-hand documentary and oral history that will make disability studies students very happy.

"It was healing to write this book," says D'Lil, 72, a T5 para from Graton, California. "When I came into my disability, I lost my civil rights. I was 22, and I felt like I was thrown back to when I was younger than 18 again. I was dependent, treated differently — there is a lot of damage that occurs to our self-esteem. So much stigma was associated with disability." Writing the book, she realized much of that stigma has been turned around by the activism: "I'm very proud I did what I did and persevered, and so proud of everybody who got involved."

Does she think she is "real" now? "Yes, I am. And steadily becoming more so every day." Learn more at becomingrealin24days.com.

KAYAK PADDLE SOLUTION

Angle Oar offers two mounted paddle systems to make recreational, adaptive kayaking much easier for people with limited arm motion or stamina.

The first, Versa, features a paddle that can be kept straight or angled in a sort-of tee-pee shape, which allows for much less range of motion. The mount lifts upward to make getting into the kayak a bit easier, and the unit can be removed with a pin. The second, Gamut, uses YakAttack RotoGrips to hold the kayaker's own paddle between two soft rollers. It's positioned between the legs, so is not recommended for kayaks that have built-in cup holders or other such features in the center of the boat.

Sit-in kayaks use a hinged mount that attaches on the cockpit rim and sit-on-tops use a plate mount that is secured to the kayak's floor. For more info, including a list of most compatible kayaks, go to www.angleoar.com.

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EVERYDAY ADVOCACY

By Michael Collins

SMALL TOWN ADA VIOLATIONS: BUILDING A GROUP CASE

Q. *I am a wheelchair user in a town with fewer than 50,000 people. I have a lot of problems accessing local businesses and restaurants, with many acting as if access laws are not in existence, or do not apply to them. Barriers include step entries, door handles that I cannot grasp, doors that require too much pressure to open and, for those businesses that I can enter, restrictive seating and inaccessible restrooms.*

Unfortunately, I am not alone in my concerns, as many of my friends who use wheelchairs or other mobility devices, or even those who are blind, face similar problems when seeking accommodations or trying to frequent said businesses. I am not a shy person, so when I run across these problems I try to bring them to the attention of the business owner or manager. I try to demonstrate the problems I encounter and recommend solutions that will improve, or create, the access my friends and I need.

We have discussed filing complaints or taking an egregious violator to court, but are wary of what might happen to us in this smaller community. I have read about other people and their attorneys who file these types of complaints and how they are branded negatively in the local press and sometimes even prevented from bringing subsequent lawsuits in front of those same judges. My friends and I don't want to go through that, as it would seem to put us at risk of being branded

as "troublemakers." We only want to exercise our right to access and enjoy the society we live in.

Our latest concern is legislation being considered by Congress that would seem to take away our ability to sue or get access created in a timely manner when it comes to ADA violations [HR 620, which passed the U.S. House of Representatives]. Worse yet, I hear that similar legislation is being drafted to present to our state assembly that would cover our state's access laws as well as the ADA. While we hope these bills do not become laws, my friends and I are trying to decide how best to gain the access we need here at home. We're currently talking about taking this on as a group, so that several perspectives can be addressed. That might also make it a bit harder for the media to accuse any one of us of simply making trouble without having a valid complaint. Do you have any suggestions about the best way to go about this? Do you think this approach might work?

— Frustrated, and parked at the doorstep

Your concerns are definitely valid, and widespread throughout the disability community. The types of businesses that you have mentioned are classified as *public accommodations* since they sell or rent goods or services to the public. They are covered by Title III of the Americans with Disabilities

“It is not unusual to find property owners who change parking lot striping and, in the process, remove or diminish the number or size of the required accessible spaces.”

Act and in many state civil rights laws or building codes that are “substantially equivalent” to the ADA. Public facilities that are owned by the city, county or state should not be overlooked, either. Even though much of what these government entities do is covered by Title II of the ADA, they need to comply with the same architectural guidelines. That would include such features as transit stops, the city hall, recreation centers, parks, curb ramps, sidewalks and municipal parking garages.

I have not heard of anyone using the type of approach that you are considering, except in major class action lawsuits that include a large number, or class, of plaintiffs who are disabled. Your idea makes sense but would require some preparation on the part of you and your fellow

team members. Taking this on without being fully prepared will simply result in disappointment if someone accuses you of making recommendations that are not within the law or that would not hold up in front of a judge or jury.

If your goal is to correct the conditions, here are the steps that I consider important. Please remember that these are simply a layman's recommendations, and not derived from any other source:

- Assure that those who join you in this endeavor can provide multiple perspectives. As one example, it would not be helpful if you only considered access for people who use wheelchairs and ignored conditions at the same location that might impact people with vision loss.

- Learn the applicable laws and regulations, state and national, and how to determine if features are out of compliance with either. Find someone with real experience working with the architectural guidelines, and get them to train you about how to take measurements and record what you find. It is best if the person tutoring you has received some formal training about the requirements.

- Watch for features that might have been changed after they were approved by a building code inspector or public works department. This might include parking facilities that do not have enough overhead clearance to allow access with a raised roof vehicle. You will also find that once constructed, it is not unusual to find property owners who change parking lot striping and, in the process, remove or diminish the number or size of the required accessible spaces.

If the property was constructed after the effective dates of the ADA or state laws, include the city or county authorities in whatever complaint or lawsuit might occur. They have a responsibility to approve the

plans prior to construction and also to follow up to make sure that structures follow approved plans.

The ADA Architectural Guidelines, as well as many state building codes, are readily available online. Printing out a copy of the sections that cover what you find and providing them to the property owner or business that is out of compliance will not take that much time.

In those instances where there is an applicable state law, you may hire an attorney and sue in a state court. State civil rights laws may allow the payment of an award to the plaintiff, plus attorney's fees. You can check that out through the state's *National Disability Rights Network* office or a knowledgeable attorney.

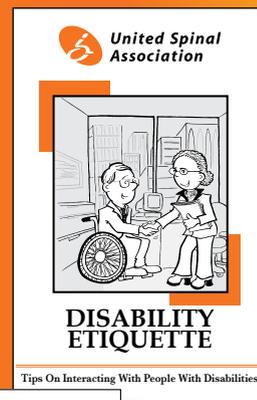
As I have explained in previous columns, the U.S. Department of Justice, as the top law enforcement agency in the country, can take action against entities that are the subjects of ADA violation complaints. The steps the DOJ takes may include civil action in a federal court, but its primary goal is to eliminate the recurrence of those violations through arbitration or mediation. Settlements have been reached in many DOJ cases, and these are available for reviewing on the DOJ's ADA website.

It is important that you file a DOJ complaint along with whatever other action is taken. Without a record of multiple complaints, the DOJ cannot assume that these violations are a pattern or practice within the industry. Good luck with your plan, and let us know how it works out.

Resources

- National Disability Rights Network: ndrn.org/index.php
- DOJ ADA resources: www.ada.gov
- Filing an ADA Complaint: www.ada.gov/filing_complaint.htm

Did You KNOW...



United Spinal Association produces more than 30 brochures and pamphlets on subjects like *Disability Etiquette, Fire Safety for Wheelchair Users at Work and Home* and *Understanding the ADA*. You can download them for FREE or order printed copies on our website at www.unitedspinal.org



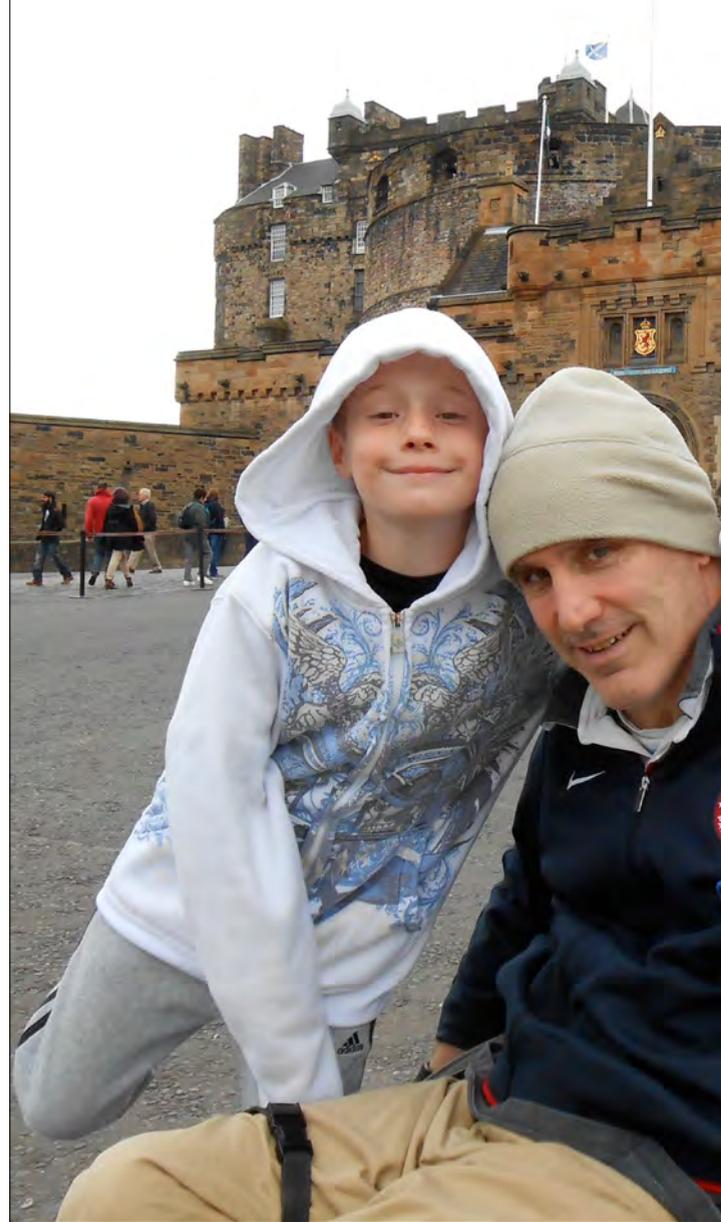
FATHER, COACH, TRAVELER **Ed Suhr**

Ed Suhr, 55, is originally from Brooklyn, New York, and now lives in Portland, Oregon, but his life has taken him all over the world from China to South America, Europe to New Zealand.

Travel Advice: Stay Flexible

The best advice for managing life and travel with a disability, Suhr says, is something he learned while he was a cadet at the United States Military Academy at West Point: “Stay flexible and keep a sense of humor.” It’s a motto that has served him well in the 30-plus years since he sustained a C5 SCI near Fort Benning, Georgia, a few months after he’d graduated from the academy. West Point is designed to push your mental and physical limits. “You need to be able to embrace the suck,” Suhr says with a laugh. The same applies to the years after his accident. “There are so many potential frustrations that we have, if we’re not ready to take those with a little bit of humor and some flexibility, we’re going to be screwed.”

Perhaps the most obvious times that abiding by this maxim comes in handy is when traveling, as Suhr has often used international wheelchair rugby tournaments as jumping-off points to see the wider world. Suhr relates the time when he traveled to Venice with a group of quads, members of U.S.



Wheelchair Rugby team, in 1995. “We ended up in a less than ideal hotel situation. We were dropped off at the wrong boat stop, and had to get carted over 10-12 flights of stairs just to get to it. The hotel was virtually inaccessible — some rooms were glorified closets. There was an elevator, but we had to take wheels off just to fit in. A lot of the guys packed their bags and left the next day, but a few of us stayed, along with one of the nondisabled team staff. It might not have been perfect, but we enjoyed the next few days and got to see Venice. If you’re not able to adjust and go with things, sometimes you’re going to miss out.”

That willingness to be flexible has stayed with Suhr as he’s become a father. Suhr met his wife, Trisha, a physical



CAN'T LIVE WITHOUT: Ergo seating [an alternative method of angling seat tubes, offered by many manual wheelchair manufacturers] makes a huge difference for me. I'm way more stable and it's much easier to push. I think my posture's better, which makes my breathing better.



ON LEADERSHIP: If our communities are going to thrive, everyone needs to contribute in their own way. Sometimes people need to be led along that path.



Suhr and his sons, Daniel and Conor, tour Stirling Castle, a short distance from Edinburgh, Scotland.

therapist, at a rugby tournament. Together they have twin boys, Daniel and Conor, now 13. "After the 2012 Paralympics, we all went to Edinburgh, Scotland, with Trisha's parents. One day Trisha and her parents went wandering in the city. I hung with the boys so they could get some school stuff done and asked them if we should go to a restaurant near the hotel, but they wanted to go to a pub we had been to a few days before. Conor liked the hamburgers, and Daniel wanted the haggis. Of course, the pub was a steep, hilly mile or so away, but I told them, 'If you can help me get there ...' We ended up having a lot of fun as all three of us pushed my chair up the hills and over the cobblestones."



FAST AS A SPEEDING GLACIER:

My rugby nickname is Glacier. Since it's self-inflicted, I have to be OK with it. Describe your speed as "glacial" one time and bam, instant nickname.

HOW DID I GET HERE?

Put Me in, Coach



Suhr has coached at all levels, from local teams happy to win a single game to national championship and Paralympic gold medal winning squads. These days, he coaches his son's youth basketball team.

Suhr didn't have much of a choice about becoming a coach. "I started coaching rugby in '91," he says. "The sports director of the EPVA at the time was coaching us and he needed to get back to doing more of his job, so he kind of dropped it into my lap without even consulting me. All the guys were comfortable with it, so in the long run it ended up working out better for everyone."

But the most valuable thing he sees in sports has nothing to do with the outcomes of games. "It's about giving people the opportunity to grow in different ways," he says. "They can come out and be active, and learn from their teammates. At a practice people aren't bitching about how bad life in a chair is, they're having fun and competing. People with new injuries, or even someone who doesn't start playing until many years after an injury, can really learn from that. They learn how to be more positive and proactive."



WHY I JOINED UNITED SPINAL: I've been a member since before there was a United Spinal! I first got involved with the EPVA because they had a big presence in the rehab hospital, and they got me motivated to go do stuff outside of the hospital. But I stayed involved because it was a good way to help people move forward after their injuries.

United Spinal Association's
7th Annual

Roll

On-Capitol Hill

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A special thanks to NRRTS for sponsoring this year's Roll on Capitol Hill Program Booklet.

BY BOB VOGEL

The 34th International Seating Symposium returned to Vancouver, British Columbia, March 6-9, offering a glimpse of the latest and greatest and what is to come in the seating and mobility field. With close to 100 educational sessions and workshops covering a wide spectrum of mobility-related disability subjects, ISS is a must-attend event for physical and occupational therapists as well as seating and mobility technology providers.

But the real draw for many is the exhibit hall — think the ultimate Abilities Expo — where manufacturers showcase their newest products and technology. This year, 75 exhibitors filled the hall, giving attendees a hands-on opportunity to evaluate the coolest adaptive equipment and new technology, from manual and power chairs, to cushions, accessories and more. Here is a look at some of the products that stood out this year.

Seating



iShear

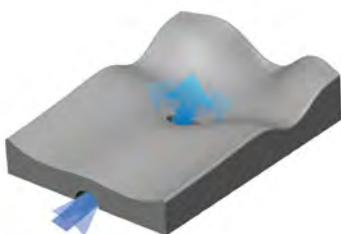
Introduced to the U.S. market in March 2017, iShear provides clinicians a way to identify, quantify and reduce shear with a system that looks similar to a pressure mapping device. An iShear mat is placed under the wheelchair cushion and it measures shear forces, which are shown in real time on a laptop or tablet.

Minimizing shear is vital for avoiding pressure sores because shear can cause tears in tiny blood vessels deep in the tissues. This can cause an injury that manifests as a major skin ulcer, which often erupts with no sign or visible warning.

The iShear system enables clinicians to adjust seating and positioning to minimize shear and lets wheelchair users and/or caregivers view shear forces on a screen, as they are happening. They can also see how changes in posture and movements can reduce shear, hopefully devising ways to keep it to a minimum.

At press time, iShear is in use at five rehab centers and by 10 seating professionals in the U.S. It is an item you may want to ask about prior to your next seating eval. MSRP of the system is \$2,365.

iShear, ishear.com



Ride Designs Java and Custom 2 Cushion

When it comes to enemies of skin integrity, add heat and moisture to pressure and shear. Ride Designs, known for outstanding skin protection, has taken the successful ventilation channel from its flagship cushion, the Java, and included it as an option to the Ride Custom Cushion 2. In both cushions, the ventilation channel provides even more airflow to Ride's breathable spacer fabric cover, and the combination helps keep skin dry and cool in any climate.

MSRP for Ride Custom Cushion 2 is \$1,590 and is covered under Medicare. The ventilation channel is a \$147 option that can be bundled in Medicare pricing.

Ride Designs, ridedesigns.com

CoolCore

Stealth Products is creating an environment for healthier skin by reducing heat and moisture using CoolCore, a unique, patented material, in the covers of its line of cushions, which range from contoured foam to gel. CoolCore's breathable fabric helps remove heat and moisture by wicking away moisture and hastening evaporation to help keep the skin cool and dry.

MSRP varies by cushion — from \$375 to \$500 — and they are covered under Medicare.

Stealth Products Cushions, stealthproducts.com/522/



Certain products, like ultralight-weight manual chairs [CMS K0005] require very specific letters of justification, and clients should discuss the amount Medicare allows vs. the actual price of the chair including desired options with their provider prior to ordering. Medicaid coverage is less certain, as coverage is up to each state, and they are often on extremely tight budgets.



AllRounder 02

Skin protection is vital, especially when we are out of our chairs. The AllRounder 02 cushion made by Vicair, a company in the Netherlands, is perfect for this because it acts like a protective shoe for your butt.

Like the original AllRounder, the 02 has five chambers filled with hundreds of “smart cells” — tiny air packages that distribute pressure. Improvements to the 02 include leg and waist straps made of tough, heavy-duty material with super strong buckles. The outer shell is also made from durable material, and it’s waterproof and washable.

Available in small, medium and large sizes, the AllRounder 02 is great for activities ranging from playing on the floor with your dog or kids, to camping, sailing, or any activity where you aren’t in your chair.

MSRP is \$268, plus shipping from the Netherlands.

Vicair AllRounder 02, vicair.com/product-detail/vicair-allrounder-02

Mobility



Matrix MX2 Back

Matrix MX2 backs, by Invacare subsidiary Motion Concepts, are made of carbon fiber and are ultra-light-weight. They provide the postural support of a rigid back and are engineered to employ carbon fiber’s ability to enable subtle flex and dampening, which translates to a smooth ride. In addition, the shell has cutouts for extra breathability. The backs match chair widths from 14 to 18 inches and are available in heights of 16, 12, 9 and 6 inches — likely the shortest commercially available carbon fiber back. Mounting options include fixed or quick-release, and mounting can be adjusted in terms of height, depth and angle.

MSRP is \$795-\$940 depending on hardware, and it’s covered by Medicare.

Motion Concepts, motionconcepts.com

NAVIONE Power Assist Wheels

Yamaha’s NAVIONE power assist wheels fit most manual wheelchairs and come as a package that consists of two quick-release wheels and a battery pack that is mounted under the chair. Control input comes from the push rims, and pushing on the rims engages power assist. NAVIONE’s unique features include “wheel-to-wheel communication,” meaning the wheels can be programmed to adapt for wheelers that have uneven arm strength. The system also features rollback prevention, downhill speed control, extra power on uphill sections and stability control to keep the wheelchair tracking straight on off-camber surfaces and side slopes. The total weight of the system is 34 pounds, and battery weight is approximately 6 pounds. Battery range is 12.5 miles for nickel batteries and 22 miles for lithium batteries, and speed is programmable up to 4 mph.

MSRP was unavailable at press time but should be on Yamaha’s website by June 1. Medicare coverage is pending; approval is expected by June 1.

Yamaha NAVIONE, yamahanavi.com

Catalyst 5Vx Folding Chair

Ki Mobility has redesigned its Catalyst 5Vx folding wheelchair. It features double cross braces for a rigid ride, an axle plate that gives 2 inches of center-of-gravity adjustment in half-inch increments, 5 inches of rear seat height (seat angle) adjustment, and 4 degrees of camber adjustment.

Made of 7000 series aluminum, the Catalyst 5Vx weighs 24 pounds and has a transport weight of 13.9 pounds with the rear wheels unattached. It comes in seat widths from 14 to 22 inches and depths of 14 to 20 inches.

Among its very cool options are a single anti-tip that easily swings out of the way, and side guards made from foam padded aluminum or carbon fiber. Another option are its “transit wheels” — roller blade wheels that extend below the rear frame, making the chair at least 7 inches narrower for navigating extreme tight spaces and doorways when the rear wheels are removed.

MSRP is \$1,895 and it’s covered by Medicare.

Ki Mobility, kimobility.com





Quickie 7 Series

Although they have been available for a few years, the Quickie 7 series rigid chairs by Sunrise Medical caught our eye. Each 7-series frame is custom designed and built for the end user from 7000 Series aerospace aluminum that is heat treated to increase strength and enable using thinner, lighter weight tubing. This makes it 18 percent stronger than previous designs and creates a chair that weighs a mere 18.89 pounds, with a transport weight of 11.1 pounds for the 7R. Experienced wheelers who know their exact dimensions can order the non-adjustable, fixed-back 7RS that drops the weight by 1.1 pounds. Available in widths from 12 to 20 inches.

Among the cool options is the Freestyle Backrest, a center mounted rigid backrest that enables a wider range of motion. The 7R MSRP is \$2,495, the 7RS MSRP is \$2,795, and both are covered by Medicare.

Sunrise Medical, sunrisemedical.com



TiLite Pilot

Instead of taking an adult-sized chair and making it smaller, TiLite by Permobil designed its newest chair for kids, the Pilot, from the ground up. Among cool features are front caster arms that enable the chair to grow in width and depth as its user grows, and also allow better centering over the rear wheels for pushing. The Pilot employs carbon fiber seating and frame components to keep it lightweight — its transport weight is 11 pounds. It comes in widths of 8 to 14 inches and depths of 9 to 15 inches. The official launch, including website info, will be in mid-2018.

MSRP is approximately \$2,800, and it's covered by Medicare.

TiLite, permobilus.com/products/manual-wheelchairs-by-tilite/



Veloce

The Veloce is a relatively new addition to Motion Composites' line of fully adjustable carbon fiber wheelchairs. The total weight of the Veloce is 17.6 pounds and transport weight, with the rear wheels removed, is 11.98 pounds, making it one of the lightest folding wheelchairs around.

The Veloce is a folding chair with a minimalist look, energy efficient ride and quick responsiveness of a rigid chair. That's in part possible thanks to the oval shaped cross tubes and oversized pivot axles. Made of T700 high-modulus carbon fiber, the Veloce is strong and nimble, yet dampens minor vibration in a way that is unique to carbon fiber, resulting in a smooth, quiet ride.

Additional standard features include single sided caster forks, rubberized hand grips for easier transfers, integrated impact guards in high wear areas, and a one-piece footrest that folds up as the frame is folded.

Available in widths from 14 to 20 inches and depths of 14 to 20 inches, the MSRP is \$4,795, and it's covered by Medicare.

Motion Composites, motioncomposites.com

Gadgets



Kinova Robotic Arm

Kinova offers a robotic arm with a three-fingered hand that greatly increases independence for people with limited or no hand or arm function. The device mounts to a power chair and is controlled by the wheelchair system — joystick, head control, sip-and-puff or any other type of controller.

The robotic arm provides greater daily independence and less dependence on caregivers by enabling a user to accomplish a wide array of daily living tasks. These range from scratching one's nose or adjusting glasses to eating and drinking, picking things up, pushing buttons for doors or elevators, to holding a phone or camera.

MSRP is \$82,300. Mark Clark, Kinova regional account manager, explained it could be covered under Medicare but nobody has tried it yet. Clark also said it has been covered under private insurances and by the VA.

Kinova, kinovarobotics.com

Editor: New Mobility's policy is to disclose author-product relationships when appropriate. Accordingly, Bob Vogel recently became an ambassador for Motion Composites. He received an Apex wheelchair in exchange for feedback and promotion of the chair on various social media platforms; he will also be a paid representative of Motion Composites at up to three disability expos. The Apex is not the wheelchair described in this article.



Eric Howk. The Man

By Ian Ruder

Eric Howk misses his dog and the Seattle home they share. As the guitarist for hit band Portugal. The Man, Howk has been on the go so much for the last 18 months, he has barely had time to see either. In fact, he has spent so much time on the road that the Uber app on his phone is convinced he lives in The LINE Hotel in Los Angeles.

Howk estimates that between concerts, media bookings and other gigs, he made more than 365 appearances, all over the world, in the last year alone. Among the highlights, the band brought the house down with a performance at last November's American Music Awards and then surprised even themselves when they won Best Pop/Duo Performance at the 60th Annual Grammy Awards in January.

Such is the life of a rock star. And after a whirlwind year that saw the band skyrocket from indie sensation to mainstream success, that is exactly what Howk, 36, has become. It's a life Howk has stubbornly pursued since he was a teenage guitar prodigy in Wasilla, Alaska — not so much the Grammy and the fame, but making great music and touring the world with friends.

"It's a damn good life. Even when it's terrible, it's all right," he says.

It would be easy to marvel at how Howk accomplished this despite sustaining a spinal cord injury in 2007, but after talking to him and the people who know him, the more interesting story may be that no one ever really doubted he would.



Live from the ICU

Unless you have been living under a rock, you've undoubtedly heard Howk's riffs on one of Portugal. The Man's two smash hits, "Feel It Still," and "Live in the Moment." With a throwback rock vibe and the catchiest chorus of the year, "Feel It Still" quickly became the earworm of 2017, finding its way into ads for everything from Apple to Vitamin Water en route to going double platinum and reaching number one on six of the major airplay charts. "Live in the Moment" followed that success by hitting number one on the Billboard Alternative chart and breaking the record for most plays in a week.

This level of success was new for Portugal. The Man, and for Howk, who joined the band in 2015. With a rotating cast of musicians, led by singer John Gourley and bassist Zach Carothers, Portugal. The Man had built a loyal following over seven albums and 11 years but had never really reached the mainstream.

Howk grew up with Gourley and Carothers in Wasilla, Alaska, and was talking with them about joining in 2007, when everything changed. "We had just got pretty close again, and he was about to join our band, and then suddenly the accident happened," says Carothers. Howk was sitting against a wall in a friend's yard when the wall collapsed. He fell 12 feet and ended up with a T4 spinal

cord injury. While the injury unofficially tabled the discussions about joining Portugal. The Man, there were signs all around that it did little to slow his musical momentum.

Before Howk even started rehab at Harborview Medical Center in Seattle, an impromptu visit from some of his friends led to what was perhaps the first recording session conducted in a major trauma center. "I knew they were coming by to visit. I did not know they were gonna bring a small recording studio into my room," he says. But they did. "At this point I haven't even sat up yet for longer than 10 or 15 seconds without getting all light headed and passing out. I've still got a neck collar and I'm fully hooked up, I think I had a nurse take out a couple of IVs because they were making noise on the mics. ... I had strummed around and messed around on some guitars before that point, but that was definitely a trial by fire."

Other than a brief moment when he woke up in the middle of his spinal surgery, Howk was always confident that playing guitar would remain a central part of his life, and this just confirmed it. "After my injury, I knew

I had my hands," he says. "And if I didn't have my hands, I'd work my way up to being a world premiere slide guitarist or something. I'd figure something out."

Howk learned to sit slightly off-kilter to maintain his "floppy" balance while playing, and often rolls without his chair's right armrest to accommodate the body of his guitar. "It's like so many things, there's a period of adapting and a good measure of stubbornness that comes along with that. But you set out in your life to do something, and when something happens it's up to you to make that sort of a nonissue and find a

Four months after his injury, Howk played on stage for the first time. "Well, no one ever asked me if we wanted to cancel."



Photo by Maclay Heriot





Photo by MacLay Heriot

way around it.”

His next trial by fire came four months later when he played on stage for the first time. His band, The Lashes, had a long-booked gig at Bumbershoot, Seattle’s premier music festival. In typical fashion, Howk plays down the fact that he got back in the swing of things so quickly.

“Well, no one ever asked me if we wanted to cancel,” he says.

Despite the success, The Lashes were coming to an end. “Everyone looked around and took inventory and said, ‘Nah, I don’t think we wanna do another 60-day tour in a van that’s not running great with no prospects of climbing our way out of it,’” he recalls. “But, I wanted that.”

The Budding Businessman

With a huge network of friends and connections in the music industry, Howk had no trouble finding bands to tour with after rehabbing. Taking advantage of his self-described “truck driver’s soul,” he drove himself all over between gigs to feed his musical compulsion. At the same time, back in Seattle he got involved behind the scenes, joining an ownership group that bought and refreshed the Crocodile, a famed Seattle music venue.

The Crocodile had won over Seattle music fans thanks to shows by Nirvana, Pearl Jam, R.E.M. and many more, but it held even more significance for Howk. “All of my firsts were there,” he says. “I played all of my first big shows at the Crocodile. My early bands opened for The Strokes and The Libertines back in the day ... it’s really the first place I learned how to manipulate my ID so it looked like I was 21.”

When Howk saw a sign in the window announcing the 2007 closure, he started asking around to see if anything

was stirring. Marcus Charles was part of a group looking for investors with local connections. When he met Howk, he knew he’d found his man.

“Eric has always had credibility in the music scene, before and after he got hurt,” he says. “I was really impressed by him and wanted him to be involved.” The fact that Howk was only months removed from his injury didn’t faze Charles at all. “He’s the ultimate explorer, trying to figure out what he wants to do with his life and where he wants to go. He’s always up for an adventure and trying new things,” he says. “I think that’s rare to find in human beings.”

Howk’s exploration didn’t stop there. In 2011, Howk partnered up with another group to start The Forge, a bar on Seattle’s up-and-coming waterfront. Like Charles, investor Mike Ager instantly hit it off with Howk, knowing he had found an ideal partner. Howk’s connections were appealing, but it was his personality that sealed the deal.

“He’s infectiously positive about everything. You don’t see him ever get down or bummed out,” says Ager.

Photo by Noah Witt

“Whatever crisis there is, or hassle, he has this very sort of calming presence. He can be the mediator and take in everyone’s ideas and positions and then articulate them and come up with solutions that everybody can get along with.”

Longtime friend Nathaniel Bradford was the one who introduced Howk to Ager. He seconded all of Ager’s comments, highlighting Howk’s intelligence and selflessness. “He just makes everything make sense,” says Bradford. “I think we are all so close to the business that we exist with our heads up our own asses a lot of the time. And what Eric brings into it is just being like, ‘Hey, I know that you guys are doing this and you guys are doing that, but here’s a little bit of how the actual world works.’ He brings a new perspective without any ego, working toward the better good for everyone. ... He’s just so fucking capable in every way, shape and form.”

Buoyed by their success, five years later the group opened The Sovereign, another bar, less than a mile away. Howk describes The Forge as “somewhere between Cheers and the bar from *It’s Always Sunny in Philadelphia*,” while The Sovereign has a slightly more refined feel.

For Howk, owning a part of the bars fulfilled another childhood dream. “It’s the clubhouse! Who doesn’t want to own a bar? If I go back in time and tell 12-year-old me that this is what you’re gonna be doing, he’d be like, ‘yeah!’”

Making the Band

That same enthusiasm was on display when Howk rekindled talks about joining Portugal. The Man with Carothers and Gourley in 2015. “He had jammed with us whenever we were in the same place, whenever we’d play Seattle or we were at the same festival,” recalls Carothers. “And we always wanted him in the band, but he was always in so many other bands.”

All that experience had given Howk the confidence that he needed to persuade Carothers and Gourley. On paper, being a part of a major touring band seemed really hard, says Carothers. “I would talk to Eric, and he would say, ‘Every day is different, some days are really easy, some days are really hard. There are a lot of things that don’t look like you can do them, but you just figure it out.’ With that, we just decided to go for it.”

“I snuck in there,” Howk says with a smile. “I peeked in under the radar.”

Once officially in the band, all the theoretical discussions about access obstacles became real. At the top of the list are inaccessible venues and transportation.

“It’s impossible to find an ADA accessible tour bus,” says Carothers. “Like, they don’t exist.”

That makes for some interesting nights on the road when the band is between gigs.

“I’ve got to *Cliffhanger* my way around,” says Howk,

citing the movie where Sylvester Stallone plays a mountain climber tasked with taking down the bad guys. “Because scooting my way on over ... let’s just say it’s a dirty place to be. There’s a lot of peeing in bottles and stuff. It is not glamorous.”

Howk relies on Carothers to get in and out of a myriad of inaccessible vehicles. “He literally carries me around the country,” says Howk, “throwing me into Sprinters and 15-passenger vans and catching me as I fall out of them.”

After nursing a set of constantly sprained ankles thanks to rough transfers, Howk has learned to be careful and to try and grab a second person to help. It’s one of the many ways the band’s demanding schedule has pushed him out of his comfort zone and helped him grow. As an example, he mentioned how he has streamlined the equipment he needs to travel. “There used to be things that I would absolutely not travel with-

out, like I would not go anywhere without a commode. That’s what I learned on and I’m used to.” He has also weaned himself off baclofen, tizanidine and lorazepam, learning that some simple stretches and coffee are way better for his body and his busy life.

Still, some realities can’t be escaped, and when it comes to inaccessible venues, Howk has learned to grin and bear it. “We’ve had to get me onstage some crazy ways, but we always get me onstage,” he says. From being carried through the crowd and lifted onto the stage, to navigating narrow ramps too steep to even walk up, Howk has seen it all. He documents each venue using his own rating system and a color-coded collection of notes.

Carothers has developed a routine to assess what lies ahead. “I get up every morning, grab us coffees and I go in and scope out the venue. I’ll send him a text like, ‘Everything is fine,’ or ‘Today’s gonna kind of suck, man.’ Every day is different, but what are you gonna do? We haven’t found a stage that we haven’t got him up on yet, so it works.”

Howk laughs when retelling the all-too-common conversation the band’s stage manager has with local staff when the rare venue does have a wheelchair lift onto the stage.

“He will oftentimes go up to a guy at a venue and be like, ‘I noticed you’ve got a lift. Does that thing work?’ And nine times out of 10, the answer is no. But on the occasion that it does work, the guy’s usually like, ‘Oh, yeah. It works just fine. What’d you have in mind? A bass cab or a couple of PA speakers or a drum set?’ And he just shakes his head.”

Grammy Fame

Howk’s best accessibility story revolves around the band’s unexpected win at this January’s Grammys. After Lady Gaga nearly tripped over his chair on the red carpet, Howk and the band were eagerly awaiting the announcement of their category when one of the handlers approached them.

“We’re gonna need you guys to take your seats at the event, and then when the category before your category comes up, we’re gonna sneak you up side stage so that you can go up there and do your speech,” he told them.

Howk remembers mentally process-



“Someone hands me a wireless microphone. ‘Hey, just in case, if you can’t reach the podium mic and you wanna say some words.’ I’m like, if? If?! If this Grammy goes to anyone else right now, I’m gonna burn this building down!”

is coming up and I’m looking at Paul Shaffer and the CBS Orchestra, freaking out a little bit, and someone hands me a wireless microphone. ‘Hey, just in case, if you can’t reach the podium mic and you wanna say some words.’ I’m like, *if? If?! If this goes to anyone else right now, I’m gonna burn this building down!*”

Howk didn’t need to break out the matches.

He rolled on stage with the band and became the second person with a spinal cord injury to receive a Grammy, according to the awards department. The first? None other than Christopher

Reeve. He won a Grammy for Best Spoken Word Album in 1998 for his memoir, *Still Me*.

If it wasn’t already crazy enough hearing the band’s music played on pop radio alongside stars like Chance the Rapper and Demi Lovato, the Grammy win catapulted the band into even more fame.

“My family’s a lot bigger now,” jokes Howk. “I have cousins that I hadn’t heard from in years and years and years. I’m like, ‘Oh yeah, I remember you. I haven’t talked to you since I was 6, but yeah, we’re cool.’ It’s pretty crazy. The super popular kid from high school that was never friends with me and never reached out or anything, just friend requested me on Facebook. I’m letting that hang for a bit.”

Still, Howk hasn’t reached the level of



Band members (clockwise from upper left) Zach Carothers, Zoe Manville, Jason Sechrist, Kyle O’Quin, Eric Howk and John Gourley at the Grammys.

ing what the handler’s words meant. “Are you telling us ... wait ... what are you telling us right now?”

“Oh, yeah, no, uh, good luck,” the handler slyly replied.

“Then we get up there, our category

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recognition where he gets mobbed when he goes out in public, and that is fine with him. “One out of every 200 dudes in an airport will be wearing a Coachella T-shirt and a tie-dyed headband, and he’s gonna know who I am and yell ‘Eric Howk!’ and come running over, but by and large, none of us are really media darlings or personalities.”

Howk jokingly describes Portugal. The Man as “36-year-old fat Alaskan pop stars,” but it is clear he is happy with the level of stardom they’ve attained. Instead of Mick Jagger, Howk says he wanted to be Ron Wood, “the guitar player with mystique.” Borrowing a quote from *Almost Famous*, he added, “like one of the out-of-focus guys.”

“That’s exactly where I want to be,” he says. “I’ve tried fronting my own bands. I hate it. I hate the ‘all eyes on me’ kind of thing. I love sneaking in there, having my moment and taking it for a second, and handing it right back. I’ve always just kind of wanted to be on a team.”

Even now, when he is on one of the most visible and successful teams in the industry, Howk hasn’t let it change him. “That’s what’s hilarious and that’s why he’s the perfect guy to have something like this happen, because it doesn’t change him at all,” says Ager. “He’s the exact same guy he’s always been. It doesn’t matter if he’s in a situation that’s tough or easy, he’s the same, consistent, good guy all the time.”

“He cut his hair, and he wears a jacket that I’ve never really seen him wear before,” adds Bradford. “But other than



Photo by Macley Herriot

that, he’s the exact same person. You send him a text, you get a response. He never talks down to you. He never pretends like anything is more important than the friendships he had going into it.”

Untrodden Territory

While Howk hasn’t let success go to his head, it has opened new doors and brought new responsibilities, which he admits he is still trying to figure out. A tweet from one of his followers after the band’s performance on national TV in last year’s American Music Awards drove the matter home. @MusicQueen87 wrote, “I cried when I saw you on the AMAs because I’d never seen a mainstream musician in a wheelchair on TV before. It was a magical feeling.”

Howk choked up on hearing the

tweet. He remembers what it was like adjusting after his injury and has said he cropped his wheelchair out of his photos for the first few years. Now, in a matter of a few months, Howk had become one of the world’s most visible musicians in a wheelchair.

“I mean, all this stuff is untrodden and new territory to me,” he says. “The easiest and most obvious thing I think I can do is not miss shows and have a public and a visible job. I think the second that you start really trying to sell yourself as a motivating or inspiring figure, it loses some of its earnestness and genuine intent. I’m still trying to figure that out. I’m still trying to draw that line all the time.”

Howk has embraced early opportunities to use his visibility for good — stopping in to visit newly injured people at Craig Hospital, helping with a fundraiser for March of Dimes and recording a series of PSAs for National Telecommuting Institute, a nonprofit that helps people with disabilities find jobs.

NTI has been around for 26 years, but director of marketing Mike Sanders says the ads Howk recorded have helped the organization connect on a larger scale than normal. “We’re on over 400 radio stations right now and people have been calling us up, saying if it wasn’t for Eric Howk, if it wasn’t for Portugal. The Man, I would never have heard of NTI.”

Howk was one of the people who had never heard of NTI before connecting with Sanders, but the organization’s goals especially resonated with him. “A lot of their messages are things that I personally hadn’t really thought of myself, and



Photo by Macley Herriot

“I cropped my wheelchair out of pictures for the first few years. Visibility helps all of us grow as a society, and we all shine on.”

— @EricHowk on Twitter

they hit home,” says Howk. “If you want to work, there’s a way. I was doing construction, and I pretty much, like, threw that away the second I realized that I was gonna be a paraplegic. Now I realize that’s ridiculous and I’m sure I would be totally valued and useful on a work team.

“NTI’s whole message is what would you like to do? And here are some of the things that you could jump into right now. I think that’s killer.”

Carothers is proud of the way his friend and bandmate has embraced the spotlight. “I don’t think he realized that he could do as much, or have the platform to help as many people,” he says. “I think he’s super excited about it. When you do have a voice, you should use it.

And he’s used it for very good things.”

How Howk decides to use that voice going forward remains to be seen, but there’s no question his eyes are open and he’s an articulate spokesperson for many of the issues affecting wheelchair users. “If there was ever a time to get riled up and to point out some hypocrisies and not just let things take their course without shining a light on them, I think it’s now,” he says. “Look at the number of things this administration has deemed disposable, the number of social programs that are on the chopping block, and the number of things that are going away. I think that’s the biggest problem with what’s happening, things sort of gently going by the wayside. And suddenly we look around and there are no safety nets left for anyone or anything. It’s terrifying.”

For right now though, Howk’s eyes are focused squarely on the music, and the continued success of Portugal. The Man. The band is wrapping up some U.S. dates this month before heading to Europe for a month of shows.



“Reunited.” — eric_howk on Instagram

“I love my job,” he says. “It is never really hard for me to get out of bed and do this thing. Even if the music ended and touring was over, getting back into Portugal and into touring and all that was vindicating. It scratched an itch that I was always gonna have and I proved something to myself.

“I would be heartbroken if it all ended and it all went away, but I would be proud of what I was able to accomplish and I’d be all right.”



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Rolling with Dad

BY TEAL SHERER

When my dad called to tell me he'd fallen off a ladder putting up the outdoor television and had broken his leg and needed surgery, I cried my eyes out. Probably an overly dramatic reaction, but ever since my mom died four years ago, I've been holding onto him more tightly. It has been one thing after another, with my dad having bladder cancer, then prostate cancer, my stepmom's heart surgeries and my stepfather's liver cancer, not to mention my in-laws' health scares. It was too much. I knew I needed to be with my dad, and my husband supportively agreed to hold down our fort.

I flew diagonally across the country from my home in Seattle to Osprey Cove, a retirement community in St. Mary's, Georgia. My dad and stepmom kept me in mind when building their custom one-story home, so it was perfect for my dad, who was now also on wheels. When I arrived, my dad was two weeks post-op and maneuvering his \$115/month rental wheelchair pretty well. He had just opened a bottle of pi-

My dad was very familiar with the whole 'not being able to walk' thing. He helped me position my sliding board while I learned to transfer, and he installed my shower bench. Now it was his turn to use a sliding board and shower bench.

not noir. I watched him angle and re-angle his wheelchair and then Go Go Gadget his arm to successfully grab wine glasses off the hanging rack. Wheelchair to wheelchair, eyes to eyes, we clinked our glasses.

Considering my dad couldn't put weight on his leg for another four weeks and was missing the best time of year in St. Mary's to play golf, he had a positive outlook. But I guess that didn't surprise me. My dad was very familiar

with the whole "not being able to walk" thing. When I was 14, I was in a car accident and crushed my L2 vertebra and have been paralyzed from the hips down since. My dad helped me position my sliding board while I learned to transfer, and he installed my shower bench. He also helped me put my jeans on before school. I'd lie in bed while he'd hold my legs high and I'd shimmy them up over my hips. Now it was my dad's turn to use a sliding board and shower bench. And it was his turn to transfer onto the La-Z-Boy couch, aka his "perch," and recline to more easily get his shorts up.

After I became paralyzed, my neurosurgeon told me to stay in the best shape possible. He said there would be a cure for spinal cord injuries in the next 10 years and I needed to be ready. So I worked out my upper body with an arm bike and weights. I had leg braces made so I could stand, and my parents rented a motorized bike called a Quadriciser to move my legs. I swam, I stretched and I ate a healthy diet. It's been 23 years, and even though I'm not "cured," I continue to take care of myself. I even got certified as a health coach. When my dad mentioned he'd like me to help

him stay in shape during his recovery, it filled me with joy. I had the opportunity to apply all I had learned over the years to help him.

Working Out and Kicking Back

Since my dad's first physical therapy appointment wasn't for another week, we decided to focus on strengthening his upper body to make transfers easier, as well as work on his upcoming transition to a walker. Maybe it would even improve his golf swing! With the Bee Gees' "How Deep is Your Love" playing in the background, we got to work. As I guided my dad through some resistance band exercises, I instructed him to engage his core and keep his shoulders down and back. To keep him motivated, I played a video of Aaron Fotheringham doing a back flip in his wheelchair, and said, "If you work hard enough, Dad, this could be you."

After our workout, we'd reward ourselves by transferring onto the perch. Buttons pushed, we'd recline back, while our legs were raised. We'd read, watch movies like *Hidden Figures* or *The Intern*, and inevitably, we'd fall asleep. The La-Z-Boy is dangerously comfortable and should come with a warning sign, "IF YOU ENTER YOU WILL MOST DEFINITELY NOT STAY AWAKE." As a mom of a 2-year old, I was settling into this routine nicely.

Well rested, we were more than ready for happy hour and gin rummy. My dad is a very competitive card player. When he is at his other home in Knoxville, he plays every day with a group of guys at a place they call "The Treehouse." It's a windowless room in a strip mall, full of couches, a big screen TV, a bar, poker table and cigar smoke. (My husband once gained entry, which is how I know these specifics.) I hadn't played gin in forever, so I encouraged my dad and stepmom to go first in order to observe and plan my attack. My dad's strategy is to figure out what his opponent has, so he doesn't give them a card they need. Anytime you pick up a card, he obnoxiously repeats it over and over to lock it into his brain, "Eight of hearts, eight of hearts, eight of





hearts.” Thankfully I was able to tune him out, and after a couple days I was beating him at least half of the time. Though frustrated, deep down I knew my dad was proud of me.

A highlight of our day was when my dad and stepmom’s friends would drive over in their golf carts — my favorite was a neon green-and-white striped one named “Margarita.” They’d stop by for a chit chat, to drop off a good book they’d just finished reading, or to share a yummy home-cooked dinner. One of the couples was prepping for their annual 50-person shrimp boil and recounted their drama-filled day trying to find enough shrimp. Even though my dad and stepmom had only lived there a few years, it was like they had known these friends forever. They’d hilariously tell stories, crack jokes and give each other a hard time. It was pure entertainment, like a trashy reality show: *The Real Retirees of Osprey Cove*.

Dad Turns 70

After seven days, we had settled into a nice routine, and it was hard to say goodbye. Being injured forces you to slow down, to just be. And it felt good to just be with my dad. To sit with him, keep him company and bring him handfuls of mixed nuts to snack on, as he refused to keep the huge

Costco container by him in fear of eating too many and jeopardizing his waist line. I was going to miss my dad, our workouts and our nightly viewings of *Family Feud*.

Three months later, my sister and I waited curbside at the airport. It was our dad’s 70th birthday, and we’d flown in to celebrate. He pulled up in his Buick Enclave and walked over, with just a slight limp, to hug us. He looked well. We threw him a party with his closest friends, and my sister and I gave him a framed collage of photos from when we were young. Back then, 70 seemed so old.

The next day was beautiful, 68 degrees and sunny. As my dad and I headed through the garage to go on a walk, he stopped in front of his wheelchair, which was parked against the wall next to his golf clubs. He sat in it, bent over to grab his tennis shoes, and put them on. I laughed. His wheelchair had a new purpose.

My dad walked, and I rolled, through the neighborhood. We’d stop to chat with neighbors and to check out the new houses being built. When we finished the mile-long loop, my dad sat back down in his wheelchair and rolled into the driveway. He stopped, looked up at the sky and closed his eyes.

As I watched him sunbathe, I thought about how lucky I was to be his daughter. I pulled my chair up beside his, grabbed his hand, and held it tight.

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A Tribe of UNRULY WOMEN

BY ELLEN STOHL

comply. My friends help me transfer to a seat and park my wheelchair in the empty spot next to me. The first scene opens and out come the candy and the flasks, discreetly smuggled in under my chair. We pass them along throughout the film while we laugh ourselves silly.

It's just a typical night out for the Clitorati.

"DISCOVERING A GROUP OF LADIES WHO UNDERSTOOD THE TRIALS AND TRIBULATIONS OF BEING A MOM, WIFE AND A WOMAN MEANT I WASN'T ALONE."

"We were like celebrities, dressed to the nines and a little bit full of ourselves," recalls my friend Erin. "We strode along like we owned the place ... smoking where we weren't supposed to, taking photos where we weren't supposed to, and, finally, you riding the escalator in a wheelchair like you're not supposed to! —'What am I going to do? Break my neck? Oops, I already did.'"

Erin is our queen. She created the group and gave it its name, a play on the infamous Illuminati, a secret society whose aim was to create "a state of liberty and moral equality." Erin says the women of the Clitorati have a similar goal. "A state of temporary liberty to go a little wild and enjoy unconditional support to be seen as equals in all aspects of our lives." For me, discovering a group of ladies who understood the trials and tribulations of being a mom, wife, and a woman meant I wasn't alone. It was liberating finding my people. And the ladies of the Clitorati are definitely my crowd.

MEETING THE TRIBE

I have my daughter, Zoe, to thank for my membership. As a new mom, I was completely overwhelmed with trying to do everything right, and had little time or energy to meet people. So when my then-3-year-old wanted a playdate with another kid who attended her preschool, I popped a wheelie at the chance. My life had evolved from jet-set pseudo-celeb to teacher, wife and mom. It felt like every-

It's dark except for the previews on the movie screen and we are all dressed up like bridesmaids, with oversized, light-up engagement rings that blink on each faux bridesmaid's finger. We hustle to get situated before the movie, *Bridesmaids*, starts. Security has already asked us to lower our voices, and they approach us again to turn off the rings. We giggle loudly and pose for a quick picture before we dim the rings and take our seats. Just as the shutter clicks, the usher confiscates the camera stating, "No pictures or video allowed." We all protest: "The camera was pointed at us, not the screen!" The usher gives it back with a strict warning, and we

thing revolved around the kid, and I was losing sight of myself. I couldn't even get a shower alone without her fussing at the door. I desperately needed to find someone who understood the transformation I was experiencing and could help me strike a balance. Accessibility was always my concern, but I did not want to address it before I got to know someone. It was a given that I would host the playdate.

That is how I met Kristen, my first "mom" friend and the one who would introduce me to this tribe of unruly women. Comfortable in my own skin, I still found myself worried. Would I be cool enough, have the right snacks, be able to relate? During the mom part of our preschool's "Mommy and Me" period, Kristen always talked about organic foods, the problems with plastic, and alternative discipline. She was over a decade my junior, a vegetarian, and her husband had dreadlocks. They were both young, hip, and the epitome of cool.

Kristen sensed my apprehension. I kept a tub of Red Vines candy on the kitchen counter, and silly as it was, I somehow thought she might object to it. I couldn't have been more wrong.

"I love Red Vines," said Kristen. "Once I ate a few," she confided later, "I think we both realized we are not that different."

During that first encounter, Kristen and I talked about our birth and breastfeeding experiences, raising kids, and how it sometimes felt like we were single parents even though we had husbands. It was standard "mom" stuff, but the conversations were honest and vulnerable, and the laughter was real.

"I remember feeling so relieved to meet a mom like you," says Kristen. "A mom I felt like I didn't have to pretend around." And I felt exactly the same way.

Kristen was sure I'd fit in with a larger group of moms she hung out with and invited me to tag along to what they called Mom's Night Out. That's when I first met Erin, the organizer of the dinner.

"I don't remember hearing too much about you," says Erin. I really don't even remember knowing you used a wheelchair. Mostly, the vibe was like, don't mess with Ellen. You sat across the table

from me, and I still didn't notice the wheelchair. What I did notice was that you were outspoken, brash and loud. But you also smiled — or should I say grinned — and your eyes sparkled when you threw a martini-soaked napkin in my face to make a point. I knew I had met my match."

Erin knows that women desire to be accepted for who we are, to share an intimate connection and quiet conversa-

"THESE ARE THE FRIENDS I CRY WITH. THE ONES MORE ACUTELY AWARE OF WHAT I EXPERIENCE AS A WOMAN WITH A SPINAL CORD INJURY."

tions. To fulfill those needs, she coordinates our monthly outings for moms that include delicious dinners, fabulous game nights, and themed movie adventures. The large events are a wonderful place to celebrate and blow off steam, but we needed a more intimate meet-up to deal with the realities of life that plagued us all. That led to Wine & Whine, a small offshoot of the Clitorati.

The core faction of W&W includes Kristen, Erin, Nel, Grace, Martina, Molly, Andrea, and myself. We have met almost weekly for over 10 years to share our joys, sorrows, dreams, and desires. We are all married, or have been. We are all moms, and our ages span three decades. We are friends because we can say to the other, "What, you, too?" We find comfort and support knowing we

are not alone in our journey.

Andrea, my hero and mentor, has inspired me with all she has done. She is a freelance writer, a speaker, and a mom extraordinaire. She started and completed her book on raising a child with a disability, *Happily Ticked Off*, while I still write mine in my head. Funny thing, though, like all the ladies in our clutch, I'll say Andrea is my champion, but Andrea will swear I am hers.

"Ten years ago," she tells me, "my son had just been diagnosed with a disorder I was terrified of. What would happen to him socially, academically and physically? What would happen to me? Your transparency on what it's like to live with the unexpected gave me the shot of encouragement and hope



I needed to survive a terrifying time for me. You surrounded me with friendship and took me on adventures with four other women who changed the trajectory of my life in more ways than I can count!”

The support all of us have received from one another has helped each of us not only survive, but thrive. We constantly deal with the issues that arise with marriage, divorce, dating, raising kids, dealing with teachers, illness and life in general. Someone once wrote, “You can laugh like a fool in front of good friends, but you can only cry like a baby in front of your best friends.” These are the ladies I cry with, the ones more acutely aware of what I experience as a woman with a spinal cord injury. My friendships with these women are not about my wheelchair, but my wheelchair is a part of them.

WHEELCHAIR EDUCATION

I was the first woman in a wheelchair most of my now-friends had ever truly gotten to know, and looking back, almost all admitted to some degree of apprehension about how to address the chair. Molly remembers coming over for a Halloween party with her daughter. “You were in a wheelchair and I’d never hung out with anyone ‘like that’ before,” she says. “When we got to the house, there was a ramp next to the front door, and I wondered about so many things. I was most concerned about how much I should I help you.”

When Grace first came to my house, she arrived armed with a bottle of wine, a bag full of goodies in one hand, and a cute kindergartener in the other.

“I remember wondering,” says Grace, “do I acknowledge the chair? Look at it? Pretend it’s not there? As if the chair were a lazy eye. I wanted to do the ‘right’ thing, but what exactly was that?”

In both cases, we quickly found mutual understanding. “As soon as I met you, none of that mattered,” says Grace. “Your presence was huge — bigger than your disability — and, of course, we hit it off immediately.” Adds Molly, “Of course, there was no need to be scared. You greeted us the way you’ve been greeting us ever since ... with a big hug, a ‘Hello, doll,’ and warmth enough to melt all my worries away.”

Many people quit seeing the chair once they get to know me, but my closest friends never forget I need the wheelchair for mobility. Their understanding of my accessibility needs make them more amenable to hold our sessions at my house. They have learned how much easier it is for me in an accessible environment, and they are keenly aware when others are not as thoughtful.

“People can forget to be considerate,” Grace acknowledged to all of us in one of our sessions, “and I find myself getting defensive about the venues we meet at. Friends who plan birthday parties at bars where there aren’t tables for Ellen to sit with us at, or choosing seats at a comedy venue where Ellen has to make an incredibly long trek to the front of the theater just to get to the back of the theater where everyone is sitting... five feet from the stairs they were able to climb.”

But knowing my needs and the ob-

“KNOWING MY NEEDS AND THE OBSTACLES THAT I HAVE TO FACE REGULARLY HAS A DEEPER IMPACT ON OUR FRIENDSHIPS THAN SIMPLE ACCOMMODATIONS.”

stacles that I have to regularly face has a deeper impact on our friendships than simple accommodations. They accept the fact we must argue for the appropriate accommodations, or double-check if something is really accessible. They even accept the decision to leave if environmental factors wreak havoc with my ability to function. They accept me, warts and all.

Martina, our longtime comrade but latest travel companion, became acutely aware of some of the physical challenges of life in a chair when she broke her ankle and had to rent a chair with wheels. “It was not even a standard wheelchair, but I scratched nearly every doorway and trim just trying to enter and exit,” she says. “Forget about being able to rotate it in the bathroom! I don’t know how anyone in a wheelchair manages when so many places lack appropriate accommodations.”

On our last cruise, Martina was really miffed when a lack of access made things awkward. “We were on a Carni-

val cruise and dressed to the nines as Mrs. Claus and her Naughty Reindeer for the Halloween costume contest. We got tagged as finalists, but we weren’t even given opportunity to display our amazing costumes with all the other contestants who were being showcased on the ballroom stairs!”

Traveling together also brings a whole new level of intimacy to friendship — especially when one’s body has a mind of its own. On our first cruise together, my friends went to extreme measures to keep me warm. “Four of us huddled together in an interior room. It was like a high school sleepover,” says Grace. “The room was chilly, and you had trouble warming up. I remember you were cuddling with a hairdryer because it was cold, and me, falling asleep wondering if I would die that night by fire or electrocution. It’d be worth it either way.”

On the flip side, Kristen got a firsthand introduction into the realities of dysreflexia when the two of us vacationed together. I had never left Zoe before, but the opportunity to scuba dive in Cozumel presented itself, and I was beginning to realize how important it was to have friendship activities that did not revolve around being a mom. So, we packed our bags and didn’t look back. Along with scuba diving, there were drinks on the plane, shots by the pool,



shopping, shows, and a horseback ride through the jungle that nearly killed me.

“The tour guides were truly ignorant of the fact that we needed the ride to be short and sweet,” remembers Kristen. We only paid for the shorter version, but they insisted on giving us the extended one instead. I learned a lot about spinal cord injury on that trip, and how quickly you could overheat and stroke out. I knew it in theory, but that was the only time it got real.”

Speaking of getting real, my friends have shown a willingness to help with almost anything — however personal it may be. A bathroom stall at a bar in Ensenada we visited on our annual cruise provided a perfect example. “You could get next to the toilet but couldn’t shut the door,” recalls Nel. “It was too dark to see, so I was either holding the flashlight so you could cath or helping you cath.”

For some types of friends, cathing might be too much to ask, but not for my girls. “It’s crazy, but I don’t mind, I love just being able to travel together,” says Nel. And having a friend willing to

help you transfer on and off toilets and find your urethra in the dark certainly makes it easier to venture out of my comfort zone.

‘RIGHT AS RAIN’

Every one of my friends has been privy to the ignorance and lack of access someone with a mobility impairment experiences. Whether they wanted to or not, they have all become experts in ADA accommodations and issues like bed height and roll-in showers. They’ve all shared in the frustrations of accessible parking and social ignorance, and they’ve also reaped some of the benefits: early entrance to events, better seats at a lower price because the cheap seats aren’t accessible, and people just giving us stuff because I’m in a chair. Together, we laugh it off as payment for the crap we put up with.

My friends have been with me through staph infections, a broken leg, keeping me cool on hot days at the Renaissance Faire by dousing me with water, and picking me up from restroom floors.

And true friendships are a two-way street. Just as my friends have always been ready to help me, I have sat with them through cancer, hysterectomies, an autoimmune diagnosis, and divorce. We have held hands and hearts, sharing the sorrows and joys that come from living. We have picked each other up emotionally, mentally, and, quite often, physically.

As the years go by, our lives change. Kids grow and priorities shift, but our friendship remains, and we grow and mature together. Our last wine-tasting adventure provides a perfect example.

“We found ourselves back in our hotel room at 6 p.m., each of us elbow deep in a can of Pringles, watching some mind-numbing TV show,” says Grace. “We were more the *Golden Girls*, and less *Sex and the City*, but we were together.”

Looking back on the first dance party that I attended, it’s hard not to escape the feeling that our group was meant to be.

Reminiscing, Erin told me not long ago, “As you danced with us in your wheelchair, leaving it all on the dance floor as we all do, it felt right as rain.” **MI**

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PARA/MEDIC

By Bob Vogel

HETEROTOPIC OSSIFICATION

Q *I'm 34 and in my 10th year as a T6 complete paraplegic. About a year ago, I developed a pressure sore on my sacrum, and a couple months into the healing process I noticed my right hip was red and swollen. My doc put me through a bunch of tests, including a bone scan that confirmed I had heterotopic ossification – bone growth in the tissues around my hip. It has grown so much that it is affecting the range of motion in my hip. I was prescribed a medication called Didronel to stop the growth. My physician said we can discuss surgery to remove the bone growth to try and regain some range of motion, but not until another bone scan shows it has stopped growing. He also said it is a messy surgery.*

What causes heterotopic ossification? What are the signs and symptoms? In addition to medication for stopping growth, is there any way to shrink it? How hard is it to remove?

– Scott

Heterotopic ossification is a condition where bone grows in muscle, tendons or other soft tissues around joints in the body. The new bone grows three times faster than normal and can cause jagged, painful joints. In some cases, there is so much growth that it restricts joint movement. HO can also develop into areas that protrude and are prone to cause skin breakdown. In non-disabled people HO is caused by some type of trauma, such as dislocation of the hip or tears in a joint – the body “thinks” the trauma is a fracture and tries to heal it by making bone.

HO in people with spinal cord injury is called neurogenic HO, and the cause in acute SCI is not known. There is no

way of predicting who will develop it, says Dr. Douglas Garland, a retired orthopedic surgeon and former director of neurotrauma at Rancho Los Amigos Rehab Center, who has written peer-reviewed papers on the subject. When HO occurs in the acute stage of SCI, it most frequently happens within two months of injury. It can also occur years or decades later and manifests in 10 to 20 percent of people with SCI. It occurs below the level of injury, most frequently in the hip (70 percent) and at the knee (20 percent), but also can occur in the elbow or shoulder. Those with complete injuries are more likely to develop HO than those with incomplete injuries, and HO almost never occurs in people who do not have spasticity.

When HO develops in chronic rather than acute SCI, there is an underlying cause such as a fracture, a bad pressure ulcer or surgery for a pressure ulcer, says Kathleen Dunn, a recently retired clinical nurse specialist and rehab case manager. “Those who had it in the past may find it reactivated by such events years later.” Garland adds that even repeated urinary tract infections can cause HO because UTIs send bacteria throughout the body and can seed the hip with bacteria, causing an infection and HO. “The first thing I think about with new onset HO in chronic SCI is some type of infection,” he says.

The most common symptom for HO is loss of range of motion, explains Dunn. Other signs include one or more of the following: swelling, redness, skin that is warm to the touch around the affected joint, a fever that may increase at night, increased spasticity, pain – if you have sensation in the affected area

“When heterotopic ossification occurs in the acute stage of SCI, it most frequently happens within two months of injury. It can also occur years or decades later.”

– and autonomic dysreflexia. “If you are years out from your SCI and suddenly your hip or knee seems warm or swollen, or stiff, or you have other symptoms, you need to address it with your physician right away,” says Garland.

Diagnosis of HO starts with ruling out blood clots, a septic joint or osteomyelitis, as well as cellulitis and other forms of infection, says Garland. At the hip, the most common cause of HO is an infection. At the knee, it is usually caused by fracture – often micro-fracture – that went undiagnosed because lower leg bones become so thin from osteoporosis, it can be difficult to see on an X-ray. When everything is ruled out, diagnosing HO is done with a bone scan – a specialized type of X-ray that involves injecting a radioactive tracer into your body that will “light up” any HO, micro-fracture, or osteomyelitis. HO doesn’t show up on an X-ray until it has progressed.

If HO is diagnosed, the progression can be slowed or stopped by taking non-steroidal anti-inflammatory drugs like Motrin or Celebrex, or a class of bisphosphonates – etidronate disodium, or Didronel – all options to discuss with your doctor. “If you are prescribed these medications, it is important to keep taking them until your physician

says it is OK to stop, or HO can return with a vengeance,” says Dunn.

Both Garland and Dunn say that moving the joint can help preserve range of motion. Many information sites on HO list radiation treatment as a way to stop HO from growing, something Garland cautions against. “I don’t think it is a good idea to be irradiating your average person with SCI in their 20s or 30s because it affects the cells decades down the road and can cause cancer. As soon as agents like Didronel came along, I stopped doing radiation treatments on HO.”

The typical case of HO in a person with SCI runs its course in six months, says Garland. Ask for a follow-up bone scan to check that the area of HO no longer lights up.

Unfortunately, although medications can slow or stop the progression of HO, nothing can be done to shrink or reduce it except to surgically remove the HO, usually only if it is seriously interfering with range of motion, which is not to be taken lightly. It is important to find a surgeon with lots of experience with HO.

“Even with a skilled surgeon, it can cause lots of blood loss and has the potential for lots of complications, like infection afterward, so it really should be a last resort,” says Dunn. Garland emphasizes the importance of discussing with your doctor the expected surgical outcome and potential complications, and whether the surgery is worth it.

Prior to surgery, it’s important to have a bone scan to check that HO has completely run its course and isn’t growing anymore. If a surgeon cuts out HO before it stops growing, it will grow right back. In order to remove HO, the surgeon does a wedge resection to cut it out. The surgery is followed up with an appropriate NSAID or Didronel to stop the HO from returning following the trauma of surgery.

A caveat about surgery in acute SCI: a small percentage of HO cases — around 10 percent — fall under a different variant, known as Type II. Such cases are so rare that most physicians outside of major rehab centers are not aware Type II exists, according to Garland. The pri-

mary way to identify Type II HO is lack of response to treatment. Repeat bone scans will show the HO as “hot” well after six months — because Type II HO is very aggressive and continues to grow for quite some time. Identifying Type II is important because of its tendency to grow back following surgery. Once again, check to make certain a bone scan shows the HO has stopped growing.

For more information on HO, check out the resources below. The Craig module on HO provides a good primer, and SCIRE is an extensive peer reviewed examination of the level of evidence for various treatment options for HO in SCI.

Resources

- Craig hospital education module on heterotopic ossification, craighospital.org/resources/heterotopic-ossification
- SCIRE Heterotopic Ossification Following Spinal Cord Injury, scireproject.com/wp-content/uploads/heterotopic_ossification-version-6.0.pdf



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OUTDOOR TRACKS

By Kary Wright

BUGGY FUN

"OK, Joe, are you ready?" I say.

"I'm ready to roll!" My brother, Joe, is always game.

"I might need you to help steer or hit the brakes," I say — sarcasm intended.

"Just tell me what to do," laughs Joe.

I pull my left arm down on the hand control, the engine revs and off we go across the lawn. I move the wheel left and right to test the steering. The buggy zigzags, and we head toward the open gate that leads to the field. I hear the roar of the engine, feel the breeze in my hair, smell the familiar smells of spring — what a blast! We slow down going through the gate, dodge a fence post and steer to the right, accelerating as we head out across the open field. Joe holds on tight as I head for the whoop-de-doo! Our stomachs rise up to our throats as we go down over the hill, then at the bottom the extra G-force sucks us down into the seat. What an incredible feeling!



Kary took his brother, Joe, for a spin.

It all started a couple of months ago. While cruising through spinal cord injury websites, my wife, Terry, noticed an ad for an adapted dune buggy for sale. Knowing I'd be interested, she immediately sent it to my computer. I looked it up, not taking it too seriously. Usually anything that is already adapted is way out of my price range and is not designed for my specific injury. I'm a

C5-6 quad with no hand function and very weak arms, and it takes a lot of MacGyvering to make anything drivable for me. I took note of the phone number and decided to give it a try anyhow.

About 25 years ago, the thought of adapting a Honda Odyssey was floating around in my coconut, but I never got it done. Now here was a similar unit that is a two-seater and already adapted. Dirt-biking with friends was so much fun, but was it possible again?

Some days later, I made the call. As it turns out, the buggy was adapted by and for a quadriplegic. In further coincidence, he happens to live 30 miles away. It actually hadn't been for sale for a couple of years, but the website was never updated. After chatting, Landon and I discovered that we have pretty much the identical injury, with very similar hobbies and attitude on life. Then I recalled an email from a news team that had interviewed him, and by coincidence, me, in the past. They were letting me know that I should look him up because we are so similar. I remember not being able to find him at the time. I then got sidetracked and forgot about it.

The more we chatted, the more we

Frequently Asked Questions

What kind of engine is in it?

The engine is 250 cubic centimeters, liquid-cooled. It has high and low range and reverse. There is no shifting to do while driving.

How fast will it go?

In low range, it will do about 25 mph, but has lots of power for hills. Landon told me that it would do over 50 mph in high range.

Do you need much strength to drive it?

I'm quite weak and so far, tight turns are a bit hard. Like anything new, it will get better with time.

Is it street legal?

It does have all of the signal lights and brake lights, etc. I believe in some states it is legal to drive it on the road, but living on acreage, I have plenty of room to roam. It's always best to check with your state's motor vehicle division on what modifications are necessary to make an off-road vehicle street legal.

found we had in common. As it turns out, Landon and his friends were building another all-terrain vehicle for him that is much more powerful and expensive, and he did not have room for both of them in his garage. He received lots of offers from nondisabled people to buy the buggy, but with all the work he put into tweaking it to make it drivable by a quadriplegic, he did not want it to go to somebody who was going to just take all those adaptations off. He offered it at a bargain price that I couldn't refuse.

Landon informed me that the steering was low effort, taken out of a Saturn car. The hand controls were custom-made to fit the buggy, and the driver's seat can slide forward and back, and recline. He and his friends even made a second control, sort of an "oh-crap-handle" that allows the passenger to hit the brakes or the throttle in an emergency, and they can easily reach the steering wheel from the right side. I think this is an important safety feature, especially for the first few rides.

A couple of weeks later, my brother and I borrowed a utility trailer and headed over to Landon's house. The buggy was in great shape, almost new. He was a little sad to let it go, but was very happy their creation was going to somebody who could use it. I am so grateful he let it go!

So here we are, Joe and I, tearing around a plowed field on the maiden voyage. I steer to the right and we zip around the corner of a slough that is in the field, then back to the left and speed up for the long run toward the steep hill. I cannot believe the freedom of zooming around the field in an all-terrain vehicle. We race up the hill, and it climbs well for two-wheel-drive! After a quick turn-around, we fly through the field back to home. Joe jumps out and leaves the engine running.

"Any other volunteers to go for a ride with him?" Joe asks.

"I'll try it!" says our friend, Sheila.

She straps into the passenger seat, and the crew pushes us back down the driveway. I pull the throttle down, the engine roars once again and off we go, flying out into the field!

Driving an off-road vehicle is as fun as it gets!



"The previous owner received lots of offers from nondisabled people to buy the buggy, but with all the work he put into tweaking it to make it drivable by a quadriplegic, he did not want it to go to somebody who was going to just take all those adaptations off. He offered it at a bargain price that I couldn't refuse."

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ERVIN

By Mike Ervin

BROKE ASS CRIPPLES

If you're trying to bring together a large group of cripples, like to organize a protest or something, you can attract a good number of them the same way you attract alley cats. You put out free food. And just like alley cats, they'll keep coming back.

I know a whole lot of cripples that will be there right on time, every time there's free food to be had. Exhibit A is a married couple whose names I will change so that I can deny it's them if they ever read this and have a problem with it. I'll call them Lucy and Ricky. Whenever there's an event with free food, you can count on them to show up. They pile their plates high and often bring along a cloth shopping bag that they stuff full of leftovers until somebody tells them to stop. And I bet if somebody frisked Lucy and Ricky on their way out the door, they'd find they have more food stashed away in other creative places. Lucy and Ricky would make excellent smugglers.

I notice that people who live in nursing homes also tend to come running when the free dinner bell rings. I used to think that some cripple elder ought to take these people aside and talk to them about politeness and decorum. Teach them some manners. Impress upon them the importance of not developing a reputation as a freeloader.

But now the way I look at it is sometimes a cripple's gotta do what a cripple's gotta do, especially when those cripples are broke ass. For instance, the Technical Assistance Collaborative and the Consortium

for Citizens with Disabilities Housing Task Force periodically puts out a hair-raising report titled "Priced Out: The Housing Crisis for People with Disabilities." Last year's version found that the 2016 average monthly Social Security payment for the nearly 4.8 million adult cripples receiving Supplemental Security Income was \$763. But the report also says the average rent for a "modest one-bedroom rental unit" was \$861.

I believe Lucy and Ricky both receive SSI, which means their maximum monthly payment is \$1,125. If they were friends not living together, their SSI maximum would be \$750 each. But when two cripples on SSI get married, Social Security punishes them by reducing their income. So I imagine when balancing their monthly budget, Lucy and Ricky factor in a lot of free lunches.

Because rents are so high and SSI checks are so low, "Priced Out" says that, in 2016, about 87,000 cripples were homeless, and between 200,000 to 300,000 more lived in institutions, nursing facilities and other segregated environments. And the cripples residing in nursing homes are the most broke ass cripples of all. Every month the nursing homes confiscate their Social Security checks and give them back an insulting allowance of \$30 for the month. And nursing home food tastes like lukewarm sludge. So hell yeah, free food is alluring, especially when it's not powdered eggs and Kool-Aid. If I lived in a nursing home,

"I believe it was Jesus who said, 'There will always be broke ass cripples among ye.'"

I'd probably go to a hanging provided they served free popcorn.

Broke ass cripples have to hustle hard. I knew a cripple whose freezer was packed with plastic storage bags full of helpings of her leftover Meals on Wheels. And that was the barter currency she attempted to use to get people to do stuff for her. Like for instance, in exchange for doing her laundry or taking out her trash or whatever, she'd offer a friend or neighbor a bag of frozen chicken à la king. I suppose that's a crime, like maybe Meals on Wheels fraud. But at least she wasn't selling drugs or her body or Amway products.

Even if Lucy and Ricky weren't broke ass, I think they would still take home a lot of leftovers from cripple gatherings, just like I always do. They seem to enjoy the thrill of the hunt, so they would probably still engage in this type of urban foraging as a hobby. But I believe it was Jesus who said, "There will always be broke ass cripples among ye." How true. And if we, their brethren, don't supply them with the essential doggie bags that get them through the month, then who will?



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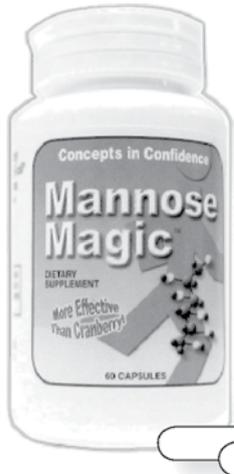


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Ken Jennings and that #HotPersonInAWheelchair

That 2014 Tweet by Jeopardy's biggest winner Ken Jennings saying "Nothing sadder than a hot person in a wheelchair" still burns Annie Segarra. So she Tweeted, "Cry about it, babe," and created #HotPersonInAWheelchair, which you can join on Twitter, Facebook and Instagram.



HE SAID WHAT?

What do Ken Jennings, Donald Trump and a more obvious troll named Daniel Lawson have in common? All three slammed disabled people on the internet, and got slammed back in return.

Definitely not Werewolves

A Twitter troll drew the fire he relishes by exclaiming real disabled people have no business being out after 5 p.m. Jennifer Lee Rossman's perfect response:



Paralympics are 'Tough to Watch,' says Donald Trump

Immediately after calling them "inspiring," Donald Trump said Paralympians are "tough to watch," which drew a collective gasp across the world and this response from the Paralympics.

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