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From the runways of Los Angeles and Moscow to department stores and online shopping, adaptive fashion is moving out of designers’ basements and into the spotlight. ELLEN STOHL surveys the current scene with an eye towards future trends. IAN RUDER checks in with the Open Style Lab at Parsons School of Design to see how the next generation of designers is learning to make next level garments.

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Our health care insurance infrastructure is being dismantled, and it comes at a critical time. Spinal cord injury and traumatic brain injury rehab centers have been under attack for years, with less and less rehab time covered by Medicare and private insurance companies. Now the new administration seems likely to make the problem worse by cutting funding. Having adequate rehab time is critical to regaining independence, but being outright denied rehab can be catastrophic.

My nephew Nick, father of four, sustained a severe TBI in April of 2014. He regained consciousness in a Santa Maria, California, hospital four weeks later. I advocated for him to be transferred to Santa Clara Valley Medical Center in San Jose, California, a TBI and SCI rehabilitation center, part of our nation’s Model Systems network supported by the National Institute of Disability Research and Rehabilitation. Our best rehab centers are part of this national network. His HMO denied the request and sent him instead to a long-term care hospital in Los Angeles — a remodeled nursing home. At 46, he was the youngest person there, the only one with a TBI.

Over the next 18 months he was transferred 12 times to various facilities in the state. He never received the full-time specialty care that a severe TBI demands if the person is to have a chance of regaining full speech and movement. He showed signs of improvement, including intermittent talking and moving of limbs, but never enough to avoid the next transfer to a different facility, dictated not by his doctors, but by his HMO’s need to cut costs. Each time he was moved, his new facility gave him less, not more of what he needed.

One of the last places he was in — another nursing home — was shut down due to health care violations literally moments after he was transferred from there. He died in a hospital in late 2015, never making it to a TBI rehab center.

His HMO network had refused to work with the family to transfer him to one of a handful of specialized TBI rehab centers in the state. Nick was a surveyor. His HMO was provided by his employer, the state of California. If this is not proof of failure of our health care system, I don’t know what is.

Our health care system is failing many who deserve a chance to recover from severe injuries — SCI as well as TBI — by allowing insurance companies to call the shots when expert, specialized health care is needed. Insurance companies are not qualified to make these decisions. Their primary concern, profit, works in direct opposition to providing the expert medical care that severely injured people need in order to survive and prosper.

Sadly, neglect of severe TBI and SCI survivors is just the tip of the iceberg. We now have a president who seems bent upon decreasing the availability of affordable health care insurance while simultaneously cutting funding for rehab and research. This is a tragically flawed approach to health care that must be reversed.

— Tim Gilmer
Since Ellen Stohl crushed her spinal cord in an automobile accident and was diagnosed with incomplete quadriplegia in 1982, she has had to actively question social constructs to rediscover and recapture her strong sense of self and purpose. Today she is a mom, wife, college instructor, writer and so much more. Her goal is to help others realize who they really are and, more importantly, who they could be, beyond preconceived, stereotypical expectations.

A routine dive into a friend’s pool left Maureen Gazda with a C5 incomplete spinal cord injury at the age of 12. Now, almost two decades later, she is still diving, only this time it’s into her career as a writer. The Massachusetts native has been a freelance writer for the past six years, writing for local papers and health related magazines. She has spent the past year as a news and feature writer for NEW MOBILITY and United Spinal. She is a dedicated volunteer and supporter of the Travis Roy Foundation. In her spare time she likes to read, hit the gym and travel.

Deanna Fike is the production manager for NEW MOBILITY magazine and the graphic designer for United Spinal Association. A graduate of Mansfield University of Pennsylvania, she holds degrees in both graphic design and art history. She lives in the Philadelphia area with her husband, Erik, and their two Boston terrier mixes. They spend their free time hiking, traveling, working on their 1925 bungalow and running a small wedding photo booth business on the weekends. They are expecting their first child in the spring of 2017.

Mike Ervin is a playwright, an author, an activist and the one and only Smart Ass Cripple. In addition to writing for NEW MOBILITY, he has been published in everything from the New York Times to The Progressive to Jobber and Warehouse Executive magazine. Mike has also been active in ADAPT for decades and boasts of being arrested about 20 times. He blogs regularly at smartassripple.blogspot.com. Smart Ass Cripple’s Little Red Book, which has a blue cover, and Smart Ass Cripple’s Little Yellow Book, which has a red cover, are available at lulu.com.
The Better to Die Message
I was extremely moved by this article I read and reread [“People of the Year: “The Resisters,” January 2017]. When I was in a wheelchair and in an iron lung after a car accident, and my whole physiology was falling apart and I was struggling to recover, I had a respiratory supply company that worked with my home care. On her last day I asked the chief respiratory therapist how I seemed to her. She said I looked like a chronic patient and she didn’t expect me to recover. She suggested that I should let myself die rather than cost society so much money.

That’s exactly the message that people with disabilities get, and it’s the same message Hitler taught to anyone with a difference. I salute your resisters and try to do the same on a lower key. I did recover and continue to survive now without a wheelchair and only on respiratory assist most of the time. I have myelopathy and balance issues and many restrictions. I continue to be mistreated at my residence and cannot get adequate entitlements and services despite my restrictions. So I salute your resisters.

Tzippy Israel
Via newmobility.com

What About the Other Side?
In the interests of journalistic balance, NM needs to publish an opposing article to “The Resisters,” here in Maine there is a long tradition of libertarian self-determination and rugged independence, especially when it comes to the decision of when, where, and how we die. This means no interference by government, courts, lawyers or anyone. We respect the right of people who disagree with us to accept such intrusions in their own lives. We equally expect those same folks not to impose their own choices on us when we are making our own final decision that can only come from each individual person’s conscience. Maine has always been a “live and let live” state. We are now blessedly becoming a “die and let die” people whenever the inevitable approaches.

Nick Fowler
Cape Elizabeth, Maine

Who Better Than Us?
I applaud the efforts of these advocates (“The Resisters”), even those I may not always agree with, because they continue to raise their voices when others try to silence them. Who can tell our stories better than we can? We are not all going to agree on every issue, but I am grateful for my peers who are willing to bring light to these matters.

Denise DiNoto
via newmobility.com

Resisters Force Choices on Others
All these people did was harass two families while they were going through the most difficult time of their life. They demonstrated a complete lack of compassion by forcing their choices on others. They claim society wants to see people with disabilities dead as they are too much of a burden. I have never been offered assisted suicide by a medical professional. Protesting a piece of fiction is absolutely ridiculous. I highly doubt that Me Before You led to an increase of suicide attempts by people with disabilities. If it started a dialogue about suicide, great. I don’t know how these people live with themselves after the pain they caused the Bolen family and the Snow family.

LaLa Slipchuk Young
via newmobility.com

Films Promote Assisted Suicide
I have been offered assisted suicide. See link to my essay: http://onlinelibrary.wiley.com/doi/10.1002/hast.38/abstract. More generally, films that kill disabled characters have a long history in Hollywood. They are wildly popular because others do indeed think death is preferable to disability. And yes, strangers have said this to me.

Bill Peace
via newmobility.com

We Are Seen as a Burden
The world needs to hear more about the resistance to the “better dead than disabled” message that is pounded into the collective [un]conscious. As someone with multiple disabilities, including two degenerative ones, I know that the struggle is real — that society will always see us and our lives as burdens. Thank goodness for the resisters, who are putting it on the line to say no to this horrible, insidious narrative.

Anita Cameron
via newmobility.com

Working as a Team
I just finished reading your article [“Partners in Healing: Using Teamwork to Get Through a Medical Crisis,” January 2017]. It is informative and encouraging. I am thinking about ways I can apply some of your techniques to my husband’s and my situation, which could benefit from some changes in our approach. I especially think he should be keeping a log, and he agreed. Hope you’ll share more of your insights with us in the near future.

Marina Shultz
via newmobility.com

To the Editor ...
That was an eloquent and impressive editorial you wrote about President Obama. Sadly, we won’t hear the likes of him again in our lifetime [Bully Pulpit, January 2017].

Name Withheld

You Idiot! What a bunch of crap! Everything has gone up since this Ass President was given office. I still think Obama is non-American! [Bully Pulpit, January 2017].

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United Spinal to Trump: Consider People with Disabilities When Repealing Affordable Care Act

James Weisman, president and CEO of United Spinal Association, sent a letter to President Trump on Jan. 23 asking him to ensure that a replacement plan is in place before Congress repeals the Affordable Care Act. The ACA, and in particular, the provision that prohibits insurance companies from denying coverage or charging higher rates to those with pre-existing conditions, has been transformative in helping people with a variety of disabilities to afford private health insurance.

In the letter, Weisman argues that access to the private health insurance marketplace has far-ranging implications for those with spinal cord injuries:

[The ACA] is the gateway to employment for paralyzed people. For generations, people with disabilities could not risk losing the support of government programs for their health care, like Medicaid and Medicare, to go back to work, or even seek employment for the first time, because their employers’ insurance policy would impose waiting periods before covering disabling conditions or not cover them at all. This kept people at home who were educated, trained and employable, and dependent on taxpayers for their health care.

In his campaign and in recent statements, Trump vowed that there would be a replacement ready for the ACA as soon as it is repealed. The Republican majority in Congress, however, has made moves toward repealing the ACA, while offering few details as to what a replacement plan may look like. Weisman wants to make sure that Trump’s pledge of “insurance for everyone” includes people with disabilities.

In an interview with NEW MOBILITY, which is owned by United Spinal, Weisman emphasized: “This is a civil rights issue and an access to health care issue. People with disabilities shouldn’t be sicker than everybody else just because they don’t have access to health care. Market forces will make people with disabilities the victims unless government steps in.”

For more information about what the potential repeal of the ACA means for people with disabilities, please follow NEW MOBILITY’s five-part series on the subject.

Part I can be found at newmobility.com/2017/01/what-repealing-the-affordable-care-act-means-for-you/

Mobile Fitness App Available for Wheelchair Users

One of the nation’s leading rehabilitation hospitals for spinal cord injury, Shepherd Center, launched a pilot for a mobile fitness app on Feb. 8 aimed specifically at wheelchair users and those with spinal cord injuries. The app, dubbed SCI-Ex, features exercise recommendations and video demonstrations, videos of how to transfer onto machines and how to use gripping aids, all broken down based on level of injury.

Anyone who has tried to search for adaptive fitness information online knows how difficult it can be to find specific, coherent information to help develop a fitness routine. “We heard from patients, Shepherd staff and YMCA staff that there are little to no useful videos/information about how to help someone with mobility impairments (specifically SCI) in a gym. There were no resources out there,” says Shari McDowell, program director for Shepherd Center’s SCI Program.

So they decided to do something about it. The SCI-Ex pilot is the first step in creating a centralized, informative resource to help wheelchair users, training professionals, and caregivers learn adaptive fitness techniques.

“The app includes exercises for the entire body, but can also be broken down based on specific muscle groups, types of exercises, and based on a user’s functional ability and level of assistance required to perform the movements,” says Brandon Clift, a lead exercise specialist at Shepherd Center.

At first look, SCI-Ex is easy to navigate and use. Training recommendations for frequency, intensity, and duration are included alongside individual exercise demonstrations, and users can save specific exercises to create a personalized routine.

While the number of exercises currently available on the app is fairly limited, Shepherd Center is soliciting user feedback, and says that they plan to expand the app’s content in future versions once they secure funding. McDowell stresses that they want to obtain as much feedback as possible so they can make modifications to future content if necessary.

Even with limited initial content, SCI-Ex already seems far ahead of most online fitness resources for people with spinal cord injuries. If you’re looking for help on how to workout from a wheelchair, SCI-Ex is a good place to start.

The app is available for free on both the Apple iTunes and Google Play stores, and can be accessed by searching “Shepherd Center.” For a sample video, go to www.newmobility.com/2017/02/fitness-app/
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“If I could drive, I could work; and, if I could work, I could probably support a family. It was just enough to give me a vision for change.”

The Art of Self-Reinvention

If you are the type of person who is very physical, getting back on track after a spinal cord injury can be complicated. This was certainly the case for Joseph Barrett. Injured in high school in 1992, he was a big fan of being active. But now he was faced with a C5-6 injury.

“I’m always amazed by the way that others respond to their disability. Some people seem to hit the ground wheeling, where others need a good bit of time to adjust. I would say that it took me a good five years to come to terms with my disability,” says Barrett, from Hartford County, Maryland. “Initially, I couldn’t move my arms. Fortunately, I regained the use of them, although I used 10 to 20-pound dumbbells as opposed to 125-pound weights pre-injury.”

He admits it’s easy to get trapped into comparing one’s old abilities to one’s new abilities, but his perspective changed when he witnessed someone his level do something he wanted to do — drive. “That really hit me hard, because I knew that if he could drive, so could I. If I could drive, I could work; and, if I could work, I could probably support a family. It was just enough to give me a vision for change.”

With that fire, Barrett returned to school and graduated with a master’s degree in vocational rehabilitation counseling. Then he landed a job as a Voc Rehab counselor in Pennsylvania. Now married with a son, and with a job he loves, Barrett is in a great place. “I think everyone with a disability can be a mentor, even if you don’t realize it. People are watching how you carry yourself. I really feel obligated to help families out by using my experience.” [For more stories on the benefits of driving, see this month’s Motorvation on page 44].

Universally Cool Shoes

“Universal design with fashion in mind” — this is the mission behind Billy Footwear, the world’s first shoe company to make shoes that work for everyone, including those with limited dexterity. “I didn’t want to wear shoes that screamed ‘adaptive,’” says Billy Price, a C6 quad from Seattle, Washington. This is what led him to co-found Billy Footwear, a company that is all about fashionable shoes and promoting universal design.

So far his company has designed seven stunningly cool shoes with a drop-jaw universal element that works great for quads — a zipper that wraps around the base of the shoe, allowing the wearer to place their foot in unobstructed, and then close the shoe with the pull of a zipper-pull. And Billy Footwear sells shoes for everyone — men, women and children — as well as in various styles, like high-tops, loafers and oxfords. The average price for a pair of Billy shoes is $100.

Visit billyfootwear.com

Summer Camp Dreaming?

Every year a group of women with paralysis of all ages and from all around the country attend the annual Camp Discovery, held in Colorado for women with SCI. Part peer-mentoring and part adapted sport discovery-zone, this camp has changed many lives. To register for Camp Discovery 2017, visit its site: campdiscoveryco.com
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When one of Angel Gonzalez’s oldest friends approached him about possibly investing in a new fitness trend back in 2011, Gonzalez didn’t hesitate to sign on. “I’m always down for an investment. If there is some money to be made, let’s give it a shot.” The only catch was Gonzalez had never heard of the new trend, a blend of personal training and competitive fitness called CrossFit.

Since its inception in 2000, CrossFit has become one of the fastest growing fitness sensations on the planet. If you’ve never seen a CrossFit competition, or tried a WOD (“workout of the day”), imagine your basic day at the gym. Throw in dashes of weightlifting, gymnastics, running and rowing, hone the resulting mix with a focus on functionality and short, intense workouts, and then add a borderline-fanatic social community. Voila! That’s CrossFit. Thanks to the appeal of this unique blend, today there are more than 13,000 registered CrossFit gyms (or “boxes,” as they call them), and over 100,000 people have been certified to coach with countless more “athletes” (the CrossFit term for anyone partaking) all around the world.

Gonzalez, a T10 para and wheelchair athlete, only needed to attend one competition to understand the appeal. It was easy to envision all of his wheelchair-using friends getting into CrossFit alongside the obviously growing number of non-disabled athletes. The business prospects and the personal prospects — a new, fun way to work out — were both alluring, but again there was a catch. “There was no such thing as adaptive CrossFit back then. I was trying to find people to connect with to bounce ideas off and there was nobody. Like, no one.”

Gonzalez did not let that deter him. Over the last six years, he and a small
The principles to CrossFit instructors, therapists, adaptive athletes and anyone who is interested. “Now, if you look at Instagram or go online, there are adaptive athletes doing CrossFit all over,” he says. “It has exploded.”

STARTING FROM SCRATCH

When Gonzalez first started searching for details on adaptive CrossFit, the only wheelchair specific content he could find came by way of a Canadian wheelchair user named Chris Stoutenburg. An acclaimed wheelchair basketball player with two Paralympic medals — gold and silver — Stoutenburg had recently turned to CrossFit after burning out on wheelchair basketball and deciding regular gym work “just wasn’t cutting it.” The variation in CrossFit WODs and the emphasis on functional movements appealed to him. “You’re never doing the same thing day after day,” he explains. “Every day is a big challenge to do all sorts of different movements, rep schemes, ways to approach fitness through endurance, and weight lifting. And all of that is a much better way to train than just doing a bit of weight training, a bit of cardio. This is never dull. Every day you’re taking on a new challenge.”

Along with a friend who had just opened his own box, Stoutenburg started adapting workouts and movements for a pair of local amputees. “We just kind of started from scratch,” he says. “We figured we’ll try a bunch of stuff, stay true to what we want to accomplish and make it up as we go.” That meant focusing on mimicking the functional impact of exercises, not the way the movements looked. “We tried to make sure the work related to being able to do things better in your everyday activities.” As an example, Stoutenburg substituted an adapted floor-to-chair transfer for a burpee — an exercise that is sort-of a jump from a push-up to a standing position — pointing out it developed the same strengths through the process of getting up when

Kevin Ogar lifts weights as part of his WOD.

group of other committed athletes have worked to develop adaptive CrossFit into a vibrant, growing community. Today, Gonzalez owns his own box in Houston, Texas, helps organize national and regional adaptive CrossFit competitions and travels the country teaching

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Stoutenburg posted videos of his adaptations on YouTube. When Gonzalez found them he saw a kindred soul and the two began a friendship. They began sharing and critiquing each other’s video workouts, laying a foundation for other wheelchair athletes. “It was always a work in progress,” says Gonzalez, “trying to figure out how we can make it efficient for us, how we can make it more challenging, how can we show the next adaptive athletes what we’re doing and how to do it right without getting hurt?”

As athletes themselves, Stoutenburg and Gonzalez are all too aware of the extra wear and tear wheelchair users are exposed to. They emphasize stability work and building core strength, and each has his own rules on what they will or won’t teach. Stoutenburg shies away from muscle-ups, a CrossFit mainstay that blends a pullup and dip, because he believes it adds stress to wheelchair users’ already taxed shoulders. For wheelchair users, Stoutenburg has set up protocols to ensure athletes don’t break their chairs by exceeding the weight limit, or their bones when they attempt to lift more than they can handle.

With more and more adaptations to share, and a growing community of people with all types of disabilities, Stoutenburg launched WheeWOD.com in 2014. The site offers free daily programming, including how-to videos for both seated and standing athletes, listings of upcoming events and more — effectively serving as a hub for wheelchair users interested in CrossFit. “We’re working on a full video description of standards and progressions to get to those standards,” he says. “We’ve got a whole library and films that are just being put into production.”

SPREADING THE WORD

While Stoutenburg and Gonzalez were ramping up their efforts, others were also pushing to expand CrossFit’s audience to people with disabilities. David “Chef” Wallach, a CrossFit owner and coach in Virginia, started the first CrossFit competition for adaptive athletes, the Working Wounded Games. The success of the Games inspired him to start Crossroads Adaptive Athletic Alliance, a nonprofit aimed at educating instructors about adaptive CrossFit, connecting the adaptive community and spreading the word about the sport’s benefits. In addition to the Working Wounded Games, Crossroads organizes instructional seminars about adaptive CrossFit all over the globe. Stoutenburg and Gonzalez are among the many coaches who travel to lead the seminars.

Sara Olsen, a board member of Crossroads and a coach herself, says the need for the seminars became evident as the adaptive athletes connected. “You had these pockets of people figuring things out either by themselves or with their coaches, and a lot of people coming up with similar ideas but nobody to share them with,” she says. “We can only do so much as a single nonprofit, but the more people we teach, the more likely that these pockets of places where there are adaptive athletes are going to grow to whole towns and states where accessibility is the norm. That’s really kind of our goal.”

Since Crossroads became a certified 501(c)(3) in 2014, Olsen guesses they have conducted around 20 seminars, drawing...
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a mix of trainers, adaptive athletes, therapists, and box owners. Each seminar has at least two teachers for anywhere from 18 to 40 students. The seminars are free for adaptive athletes, and trainers receive certification and continuing education credits towards their CrossFit trainer status.

“The more people we educate and expose to all of the types of athletes that are out there, the more common it becomes and the less intimidated coaches are when somebody wheels into the gym,” says Olsen. “The more we get out on social media and through word of mouth or other specific networks, the less intimidating it becomes to athletes, too.”

While athletes today come from all disabilities, from SCI to amputee to ALS and CP, in the early days wheelchair users competing from a seated position were scant. Olsen estimates that the percentage of wheelchair-using athletes has grown to almost 15-20 percent since Crossroads started teaching seminars.

Gonzalez has led many of Crossroads’ seminars, including the first one ever (he insisted it be held at his box) and loves being involved. “Who better to get your info from than adaptive athletes themselves? This way it’s not somebody doing all the seminars who’s done a bunch of research and just repeats what they read — it’s actually hands-on coaches who work with adaptive athletes or are adaptive athletes themselves.”

In addition to seminars, the number of competitive adaptive competitions has grown, expanding the sport’s visibility each time. Stoutenburg has helped organize an adaptive division at Wodapalooza, one of the sports bigger annual events, and has also run an online adaptive version of the CrossFit Open — CrossFit’s equivalent of the Olympics — for the last three years.

“How to get your CrossFit on

With CrossFit boxes popping up everywhere and the growth of adaptive sites online like WheelWOD, it’s easier than ever to get your adaptive WODs on. Vanessa Cantu advises, “Don’t be afraid to just take the first step in finding a CrossFit box near you and talk to the owner or the coach. More than likely they’re willing and wanting to help, they’ve just never been approached about adaptive CrossFit. And if they’re hesitant and don’t want to help, go to the next box. There’s going to be somebody who wants to take advantage of that situation and learn from it.”

“The first rule of CrossFit

Social media is one of the factors helping propel the growth of adaptive CrossFit. Online commenters have often twisted the famous quote from the movie Fight Club to poke fun at the exuberance of CrossFit athletes, saying, “The first rule of CrossFit is that you always talk about CrossFit.” That rule has held true for adaptive CrossFit. “If you look at Instagram now or you go to WheelWOD, there are adaptive athletes all over, sharing photos and stories about how it has transformed their lives,” says Gonzalez.

Stoutenburg says it’s easy to identify the newcomers by their social media feeds. “Every social media post will be about something they’ve done in CrossFit. The rest of the stuff in their life seems to fade out of the picture for a little bit. It doesn’t matter if its adaptive or nondisabled, that’s just what it is.”

Why the overwhelming appeal? “You start to do things that you’ve never been able to do, and I think that’s why it’s so popular,” he says. “It’s just mind blowing that they are doing things that they never thought they would do or ever try to do. You get your ass handed to you on a daily basis and you come back for more.”

That’s almost exactly how it worked..."
for Vanessa Cantu. Cantu was paralyzed at 15 in a 1998 car accident. An active high school athlete before, the paralysis and additional injuries led her down a rough road where she struggled with drugs and abusive relationships for the next 15 years. Three years ago, at the age of 30, Cantu sobered up around the birth of her child and started CrossFit at a local Texas box owned by her sister’s boyfriend, Angel Gonzalez.

Cantu hadn’t used a wheelchair for years, having progressed to walking with crutches after years using KFOs and AFOs, but borrowed one upon realizing that was the only way she could compete. After some training she entered her first competition with high hopes. “I got my ass whooped,” she says. “I realized how tough everything was, but I was also quickly hooked, to the community, to the people that were there, and I realized that I could do everything they did, I just needed to work at it.”

Seeing and interacting with other people with disabilities and working with coaches that believed in her helped Cantu change her life. “It started with someone else putting that effort and time into me for me to even start believing in myself,” she says. “CrossFit exposed me to something different, something that I could relate to and that I just didn’t see on a day-to-day basis.”

Gonzalez and others say their ultimate dream is an adaptive division at the CrossFit games and true integration into the CrossFit world. Having helped with the logistics behind the Working Wounded Games and the day-to-day of Crossroads, Olsen knows the complexities involved in attaining that goal. “Do I think there’s potential for it? Sure. Do I think it’s in the near term? Probably not without hiring somebody with that expertise on their staff to help with the programming.”

Stoutenburg agrees. “Right now my focus is on just getting more people involved,” he says.

RESOURCES
- CrossFit (official site), CrossFit.com
- Crossroads Adaptive Athletic Alliance, crossroadsalliance.org
- Redefined Fitness, redefined.fit
- WheeWOD, WheeWOD.com

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WHEEL THE BURN: MAKING THE MOST OF YOUR LOCAL GYM

BY MAUREEN GAZDA

Whether it’s a hard cardio session in a spin class or a rigorous muscle building session with weights, gyms and fitness centers are dedicated to helping people feel the burn, but what do they offer to those of us active, fitness-loving chair users who want to “wheel the burn?” From beginners to full-blown bodybuilders, fellow wheelchair users weigh in on their experiences at the gym and provide helpful advice to those looking to get “wheelie” buff.

THE BODYBUILDER: REGGIE BENNETT

As a wheelchair-using bodybuilder for the past 23 years with numerous titles to his name, Reggie Bennett is no stranger to the gym, calling it his “second home.” A lifelong athlete, Bennett acquired a T12-L1 spinal cord injury 33 years ago at the age of 13, but found solace and comfort shortly after that through working out.

As a lifetime gym member with a strenuous workout regime, Bennett acknowledges the lack of accessibility at gyms but says with a little trial and error anything can be adapted.

“There is very little access for a person with disabilities in a standard gym as the equipment is not set for us, nor are there programs in gyms today that offer much assistance,” he says. “All of my workouts had to be modified to fit me. It took years for me to find what worked and what didn’t. There were times I fell while attempting to use some of the equipment, but I was determined to win that battle of being able to work out on my own.”

Reggie’s advice: “There are no tricks — I would say just get in there and do it for you. Learn to be healthy and physically active to reduce your risk of dependence.”

As a C5-6 quad, Rachelle Friedman Chapman needs some assistance getting set up to work out, but she doesn’t need any help finding motivation.

THE REGULAR: RACHELLE FRIEDMAN CHAPMAN

As the mother of an energetic toddler, devoted wife, full time blogger, motivational speaker and author, Rachelle Friedman Chapman has a busy schedule, but the C5-6 quadriplegic always dedicates time to stay active and hit the gym. A member of Planet Fitness for two years, Chapman spends a few days a week in the gym strengthening her arms and core.

With no finger function and weak triceps but strong wrists, biceps and shoulders, Chapman says she concentrates on using equipment that will continually strengthen her upper body. Her number one piece of advice to quadriplegics who want to use the gym is to have a companion to help with access to less accessible equipment.

“At my injury level I need my husband to help me strap my hands to the equipment with Active Hands gloves because I have no grip,” she says. “There’s a bunch of options for me where I can roll up and not even have to get out of my chair. The standard arm equipment with built-in seats are still useful, but my husband helps me with the transfer.”

Rachelle’s advice: “If you don’t have hand function, then you definitely need the Active Hands gloves. If you can transfer and have hand function, then you could easily get a full independent workout.”

Rick Hayden has been a leader in the disability community for years, but just started going to the gym regularly in the last year.

THE NOOB: RICK HAYDEN

Although he’s been rolling through life on wheels since a motorcycle accident left him a T8 paraplegic in 1976, Rick Hayden’s fitness journey as a frequent gym member only began less than a year ago.

“I turned 61 last April and realized I was in the worse shape I’ve ever been in,” Hayden says. “So I made the decision to go try the new gym in town that promised to be different. It was, and it was a great decision.”

Hayden goes to his local gym three to four times a week and says the experience has only been a positive one. “Access to the gym is excellent, including parking and restrooms. I can use approximately 80 percent of the equipment. They offer two multipurpose machines where I don’t have to transfer on and off, “ he says. “I have access to experienced and knowledgeable trainers willing to experiment to find what would work best for me.”

Rick’s Advice: “Meet with the decision makers prior to joining, and see what reasonable accommodations they are willing to make.”

Maintaining an upper body that even the Rock would envy, Reggie Bennett has learned that there are no substitutes for hard work.

As a C5-6 quad, Rachelle Friedman Chapman needs some assistance getting set up to work out, but she doesn’t need any help finding motivation.

Rick Hayden has been a leader in the disability community for years, but just started going to the gym regularly in the last year.
Mendocino sits on a bluff high above the Pacific Ocean, so unchanged since the 1800s that the entire place is a National Historic District. Green and lush as the Shire in J.R.R. Tolkien’s Hobbit, this town practically invented farm-to-table cuisine. The same families have been fishing, crabbing, growing grapes and foraging for mushrooms in Mendocino’s fertile soil for over 150 years. It was once a booming center of the logging industry — its redwoods rebuilt San Francisco after the 1906 earthquake — but the area quickly became sleepy after logging ended. As a result, it is largely untouched by the modern world.

Northern California offers many other tourist destinations, from the nearby Napa and Sonoma wine countries to Big Sur and Carmel south of San Francisco. But those places are crowded, expensive, and frankly, done-to-death. Mendocino is off the beaten path — a rare combination of rural and urbane. My husband Christopher and I, recently married, drove there last December for our “mini-moon.” Since Christopher has cerebral palsy, uses a forearm crutch to walk and is no longer able to climb stairs, we were more than a little curious about how accessible Mendocino would be.

On the winding drive from the Bay Area to Mendocino, we snaked along the Pacific Coast, waves crashing against pristine beaches far below. My favorite parts of the drive were the long quiet miles through ancient redwood forests. State Route 128 takes you from highway 101 to the coast through Anderson Valley, a landscape dotted with wineries. Mendocino’s improving wines are drawing more tourism to the area. Many of the wineries are accessible and incidentally, dog-friendly, but currently there is no comprehensive list.

Along the way we stopped at the rustic chic Mosswood Market, a café and bakery. The tangy homemade chicken soup was the Mendocino cuisine I had been craving, as were the crispy grilled sandwiches on locally baked bread. With soups from $4 and sandwiches from $9, the prices were low key and unpretentious. Cups of artisanal Flying Goat coffee are $1.75, and it’s some of the best coffee I have ever tasted. The hours are 7 to 4 Monday through Thursday with some slight variation on the weekend, but they start serving coffee and pastries at 5 a.m. for the workers at nearby Anderson Valley Brewing Company. The Victorian glass front doors are opened to allow wheelchair-using patrons to enter, and bathrooms are accessible through the shop next door.

Even though wine was not our focus on this trip, we
popped in at accessible Lula Cellars winery, the last winery on Route 128 before the junction with Highway 1 to the coast. Wide wheelchair-friendly doors admitted us to an unassuming and homey tasting room. We tasted a couple of wines, including an amazing rosé, and then chatted with the winemaker, Jeff Hansen. As down-to-earth as his tasting room, Hansen decided to craft his premium wines and sell them directly to the public after a long career in Napa; his prices range from $20 for whites to $45 for pinots. While we didn’t splurge much on wine, we appreciated that Lula’s accessible bathroom was large enough to turn a power chair around in.

**The Historic Town of Mendocino**

For a quick history of the town, we visited the Kelley House, the home of one of the town’s founding families and now a museum and archive for the area. We weren’t there at the right time for one of the $10 per person, two-hour docent-led tours of downtown, but curator Anne Cooper put in a moveable threshold ramp and showed us around the house. The rooms were furnished much as they would have been when the Kelleys lived there. The doorways narrowly cleared 30 inches and some of the turns were tight, but the memorabilia from Mendocino’s history was fascinating. My favorite origin story of the town is about the treasure ship Frolic that wrecked on this part of the coast and led to the discovery of the redwood forests — the source of Mendocino’s wealth. The house has a second story that can’t be accessed but the exhibits are all downstairs. In order to use the bathroom, it was necessary to go around the block.

The Historic Town of Mendocino

We then browsed around the compact downtown. Because Mendocino was an artists’ colony in the 1960s, founded by disciples of Diego Rivera, among others, the small shops sell art, pottery, and handicrafts over the key chains and T-shirts you usually find in tourist towns. Main Street has numerous interesting shops, many with either ramps or direct street access. Even in winter, wildflowers sprout along the roads, which are mostly more than smooth enough for wheels with the rough patches avoidable by crossing the street. Christopher couldn’t get over the awe-inspiring views of the ocean, visible from almost any place you stood.

One local wheelchair user reported that Mendocino was truly a small town in the best sense. Merchants and restaurant owners go out of their way to accommodate you — several have installed ramps in spite of the age of their buildings. A ramp has recently been built at the commercially important intersection of Kasten and Main Street. For a place that depends on looking as antique as possible to keep tourist dollars flowing, the village has a good attitude toward becoming more accessible.

**Accommodations**

It was December and brisk, so we took refuge in the centrally located Mendocino Hotel, entering through ramped accessible doors. The hotel lobby and lounge are richly paneled in dark wood and filled with period-appropriate furniture. We warmed ourselves in front of the pewter fireplace in a cozy corner. The restaurant here isn’t known for the local, inventive cuisine you can find elsewhere in town, but my French onion soup, which cost $9.95, tasted good on a chilly afternoon. The bistro menu in the bar offers entrées from $13-$17; its restaurant entrées run $28-$37. There is one accessible room in its gardens that starts at $139/night, midweek in the off-season, although management assured me that price would be lower with AAA or AARP membership. The entire ground floor of the hotel is accessible, including the bathroom adjacent to the bar.

That night we slept at the Little River Inn, about five minutes south of the village. This magnificent white Gothic Victorian has been run as an inn and restaurant by five generations of the same family. Our deluxe ocean view fireplace room was big enough to be a suite. We were so excited about the room that Christopher was afraid to look in the bathroom, since accessible hotel bathrooms remind him of hospitals. Instead, this bathroom was large and light, with a built-in gray and white tiled bench that stretched from the roll-in shower to a Jacuzzi tub. Using the bench and two of the tub’s grab bars, Christopher was able to lower himself in. He observed that people with limited upper body strength could also use the tub with some assistance.

Little River Inn’s restaurant is justly famous for its thin but...
tery Swedish pancakes from an old family recipe. We’re still dreaming about Grandpa Ole’s hotcakes and the thick bacon they served, produced by the local Roundman’s Smokehouse. My breakfast cost around $20 because I had Eggs Benedict and hotcakes, but it was worth it. Entrées in the restaurant are around $20-$32, but seasonal seafood may vary, and it couldn’t be fresher, caught just miles from the inn. A burger in the Whale Watch Bar is spendy — $14.50.

**Highlights**

The highlight of our trip came the next day. We visited the Mendocino Coast Botanical Gardens, 47 acres filled with native plants and rambling paths. We followed the accessible south trail, which was wide enough for two wheelchairs and had very few rocky patches. The path took us past a heather garden, a fairy circle of eucalyptus trees, and through a bent-branch gate. The accessible bathroom along the way was hidden in a charming simulated rustic cabin. At the end, we reached a coastal prairie with panoramic views of the open sea. We could see why the lady in the gift shop had told us it was an ideal spot for watching whales.

Our final evening was spent at the Brewery Gulch Inn, named the best hotel in Northern California by Condé Nast Traveler. This boutique luxury lodge built from reclaimed redwood from the nearby Big River is one of the few modern properties in the area. The pebbly parking lot didn’t prepare us for the graciousness inside. The ground floor of the hotel is dominated by the Great Room, anchored by a four-sided glass and steel fireplace and filled with arts and crafts furniture. At the far end of the room there are floor-to-ceiling glass doors that open onto a wide accessible deck overlooking the ocean.

The staff was eager to cater to our every need. That, combined with the freshly baked pastries and spa water by the front desk, enhanced the feeling of staying at a good friend’s country house. While more expensive than many of the hotels in the area, the price of the room includes a dinner prepared by their Wolfgang Puck-trained executive chef, who cooks exclusively for the hotel’s guests, and an enormous gourmet breakfast.

We stayed in the Redwood Room, home of a 5-star accessible bathroom, with a private deck overlooking the white caps of Smuggler’s Cove. The room was snug and meticulously appointed. We lolled in front of our own fireplace and wrapped ourselves in the soft throws provided. The doors to our smooth-surfaced deck opened wide. We mentioned to them that there was a stair preventing us from getting from the deck to the lawn below and they said they are building a ramp to correct this oversight.

After the sumptuous breakfast the next day, we grabbed some of the inn’s homemade muffins for the road. On the way home we stopped in Navarro River Redwoods State Park so I could take a picture of my new husband surrounded by moss, mist and 1,000-year-old trees.

**Resources**

- Mosswood Market, 707/895-3635. *The bathrooms are only accessible through the back of the kitchen before 10 a.m.*
- Lula Cellars, 707/895-3737; www.lulacellars.com
- Anderson Valley Winegrower’s Association, 707/895-9463; www.avwines.com

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• Kelley House Museum, 707/937-5791; www.kelleyhousemuseum.org
  They use a threshold ramp to allow access up the few steps but
  museum rooms are somewhat crowded with tight turns on
  fragile wooden floors. The second story is not accessible. Access-
  sible restrooms across the street on the headland can be reached
  by going around the block. Audio tours are available, including
  self-guided multimedia tours on a rented tablet.
• The Mendocino Hotel & Garden Suites, 707/937-0511; www.mendocinohotel.com
  The main floor is accessible and includes an accessible
  bathroom in the restaurant.
  Price for the accessible room:
  Low season: $139/night midweek, $229/night weekend
  High season: $179/night midweek, $269/night weekend
  Discounts available with AAA or AARP membership.
• Little River Inn, 707/937-5942; www.littleriverinn.com
  The restaurant is accessible but the bathroom, located in the bar,
  is not. The bathroom in our accessible room was phenomenal.
  Price for an accessible room:
  Low season: $165/night for a Traditional Ocean View room
  High season: $295/night for a Garden Retreat room
• Mendocino Coast Botanical Gardens, 707/964-4352; www.gardenbythesea.org
  Paths are clearly marked for accessibility and electric carts are
  available to borrow on a first-come-first-served basis.
  $14 general admission, $10 for seniors 65 or older
• Brewery Gulch Inn, 707/937-4752; www.brewerygulchinn.com
  Price for the accessible Redwood Room:
  Low season: $360/night midweek, $400/night weekend
  High season: $445/night

Also Recommended By Locals
• MacKerricher State Park, 707/964-9112; access.parks.ca.gov/parkinfo.asp?park=42&type=0
  Once part of an Indian reservation, this park, which encompass-
  es beaches, dunes, forest and bluffs, has a remarkable number of
  accessible areas, including a 300-foot boardwalk, campgrounds,
  picnic areas, and trails with sweeping vistas.
  Free.
• Mendocino Film Festival, 707/937-0171; mendocinofilmfestival.org
  Founded by Sydney Pollack, the 2017 festival will be held June
  1-4. Many genres of film are represented, with special emphasis
  on stories of triumph over adversity and social justice. All of the
  venues are accessible, including the 400-seat tent.
  Most tickets are $11 in advance or $12 at the door, $20 for special
  events such as screenings followed by live music.
• Point Cabrillo Light Station Museum, 707/937-6123; pointcabrillo.org/visit/museums
  Located on a point, like any good lighthouse, the grounds are a
  great place to watch migrating whales, harbor seals, sea lions
  and birds. Disabled parking is located next to the 1st Assistant
  Lightkeeper’s House (which has been restored to its original
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  Admission is free but donations are appreciated.

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MARCH 2017 23
Cue the lights, hit the music, and get ready to strut your stuff. It is one of the last shows of LA Fashion Week and the models are lined up ready to do their little turn on the catwalk. The entourage is not your typical set of super models. These models all have disabilities, and they are wearing the latest styles from Bezgraniz Couture, a Russian company whose new collections of functional modern clothes and accessories include more elbow room, extra zippers and alternative tailoring to address the needs of people with disabilities.

Fashion is a $1.2 trillion global industry, with more than $250 billion spent annually on fashion in the United States, but to date very little of that money has focused on the needs of people with disabilities. While several small companies have attempted to address those needs, few have been successful, and mainstream designs aimed at consumers with disabilities are few and far between.

But if the scene on the Los Angeles runway, along with some other positive developments are any sign, the major players in the fashion industry may finally be stepping up to give the world’s most underserved populations some new and exciting fashion options.

**ADAPTIVE FASHION TO THE FOREFRONT**

Fashion-leader Tommy Hilfiger took a step toward giving people those choices last year when it launched a new adaptive children’s collection in collaboration with the adaptive fashion-focused nonprofit organization, Runway of Dreams. In doing so, Hilfiger became the first American designer fashion brand to launch an adaptive children’s line, but the founder of Runway of Dreams, Mindy Scheier, does not want to stop there. The Runway of Dreams collection has the same designs as its traditional pieces but includes modified closures, adjustability, and alternate options to get in and out of the garments.

Those are the three major requirements that Scheier fights for in adaptive fashion. She founded Runway when she was unable to find a fashionable pair of jeans for her son, who uses leg braces as a result of muscular dystrophy. A former fashion designer, she spent the night switching out a button and zipper fly for magnets and
adding wide openings on the bottom of pant legs, then sealed them with magnetic closures. This not only made the jeans easy to pull on and fit over her son’s leg braces, it also caused Scheier to question why modifications like this weren’t readily available for consumers with disabilities.

Armed with a new mission, Scheier set out to bring adaptive fashion into the big leagues. When she pitched her idea and presented her off-the-rack adaptations to Tommy Hilfiger, the fashion giant was almost immediately onboard. Hilfiger’s enthusiasm was more than a token gesture and has proven to be profitable. “The impact has been fantastic,” says Gary Sheinbaum, CEO of Tommy Hilfiger Americas. “We’ve had customers purchase from almost all 50 states and in the first quarter two of our top six selling styles on tommy.com were from this collection. In fact, 20 percent of our kids’ business was driven by this special capsule.”

Tommy Hilfiger’s collaboration with Runway of Dreams may have brought adaptive fashion into the forefront, but their design relied heavily on an already established successful adaptive line of dress shirts for adults, called MagnaReady. Maura Horton, of Raleigh, North Carolina, designed what would become the MagnaReady shirt as a response to her husband’s battle with Parkinson’s. “In my husband’s case, he was always taken aback by the amount of energy and time it took him to get ready because the Parkinson’s disease had affected his dexterity and range of motion. I remember vividly when he said to me that he had to start off each day with an obstacle and that can set the tone for the whole day.”

Horton’s solution incorporates custom-designed, machine-washable magnets behind the non-functional button flap of traditional button-up shirts. The adaptations made the shirt easy to put on and take off inde-
pendently, but the style was indiscernible from other traditional designs. “The system not only helped him feel independent and accomplished, but it also helped him save time and energy for other battles he might fight in the day,” says Horton.

Horton sold about 20,000 shirts through her online store from 2013-2015. Last year she partnered with PVH, a global apparel company that owns Tommy Hilfiger, IZOD and Calvin Klein. Together they developed a collection of Van Heusen men’s dress shirts using the MagnaClick adaptive technology. Last fall the shirts were rolled out to select retailers, including Belk, JCPenney and Kohl’s, both in stores and online, as well as on Amazon.com.

Although this is not the first time major retailers have carried adaptive clothing, it is certainly the biggest collaboration to date. And, if the current trend takes hold, it won’t be the last. Movements to create accessible, inclusive designs are happening worldwide.

FROM RUSSIA, WITH VISION

Tobias Reisner and Janina Urussova, the founders of Bezgraniz, believe the fashion market for people with disabilities is just beginning to emerge. They know that niche markets can be profitable, but argue the key to making them profitable is changing the perception of them.

“Society creates disability via inaccessibility and stereotypical attitudes,” says Urussova. “Fashion and clothes are one of the most effective solutions to change the mind, and how they are presented is the key to create that change.”

Since 2008, Bezgraniz — the name means “without borders” in Russian — has used art,
innovative workshops, educational forums and fashion shows to broaden societies’ perception of beauty and break through the barriers that negatively impact people with disabilities. Bezgraniz started by holding contests to get designers designing clothes for people with disabilities, and to figure out how such clothing could be scaled on an industrial level.

In March 2014, on the heels of the Paralympics in Sochi, Bezgraniz developed the first fashion collection dedicated to adaptive clothing ever to show at Mercedes-Benz Fashion Week Russia. They have continued to develop and show fashion for people with disabilities since, most recently in Los Angeles.

Nonetheless, Reisner and Urussova believe that unless the current ideations of disability and beauty evolve, the clothing market will continue to ignore the needs of people with disabilities. With that in mind, they have also embraced out of the box approaches to get people thinking, like their 2014 project Acropolis, where they restaged classic Greek sculpture using models with disabilities. “It allows society to engage in open intellectual conversation about the body and disability in the modern world and challenge its own views and how we define the ‘norm,’” says Urussova.

She stresses the importance of individual differences. “We need to learn to accept other bodies as art pieces for their unique structure and personal beauty. Lack of communication creates a roadblock to an effective marketing campaign. We need to open the market and create a viable business model.

*And how the clothes are presented is the key to creating that change.*

Bezgraniz - LA Fashion Week
Photos: Manny Llanura. Stylists: Anna Chemykh and Vladimir Tilinin
by measuring bodies and creating designs that meet the needs of both fashion and individual physique.”

To move in that direction, Bezgraniz is working with design schools in London, Russia and the United States to make adaptive design part of the core curriculum. Elsewhere, Massachusetts Institute of Technology launched Open Style Lab in 2014 to teach adaptive fashion [see page 31], and Lucy Jones, a 24-year-old fashion designer from Cardiff, United Kingdom, made Forbes’ list of 30 Under 30 for 2016 for her innovative “seated designs” for people in wheelchairs. And Christiano Krosh, a designer in Brazil, has a new line that caters to the needs of disabled consumers. Krosh uses Velcro, zippers, hidden openings and even Braille labels to create designs that are fashionable and functional.

New fabrics, innovative technology and increased global awareness have created an opportunity to move adaptive fashion onto the runways and into established retail stores. All it takes is education, awareness, and someone to lead the charge. Urussova believes working together will make the difference. “There are wonderful pockets of practices worldwide, but no one is connecting them and bringing them together to create one movement. When that happens, there will truly be an inclusive new ‘norm’ in fashion.”

“Fashion helps you feel good, which helps you project a positive attitude in the world. Dogs have clothes, but I can’t find a decent pair of pants in a store that fit my body and needs.” — LoLo V, 30-year-old wheelchair user due to ALS and star of “Sitting Pretty” on YouTube.

THE SLOW ROAD TO INCLUSION

There have been several small companies that have attempted to address the fashion needs of people with disabilities, but their success has been sporadic at best. In a sign of the difficulties facing adaptive designers, designer Izzy Camilleri decided to shutter her pioneering adaptive line IZ Collection last fall. Camilleri, who gained fame dressing celebrities like Angelina Jolie and David Bowie, launched IZ seven years ago after a local TV personality who used a wheelchair requested a custom garment.

She grew the line to feature a wide range of functional, fashionable options for men and women. She regretted having to close but said the sales weren’t high enough. “It’s not a decision that came quickly or overnight,” Camilleri told the Toronto Star. “The growth has been quite slow, and it’s difficult to sustain a slow growth. We produce locally and ethically, and it’s hard for us to juggle pricing.”

Designer Stephanie Alves started crafting adaptive fashion solutions in 2011 and went all in with the 2013 launch of ABL Denim, a line of adaptive jeans. Alves and ABL Denim took a huge step forward for the industry when she partnered with Walmart to sell her adaptive jeans on the web. The jeans are still available on the ABL Denim website but most sizes on the Walmart site are out of stock, suggesting that the jump to the mainstream may need more heavy hitters to pick up the cause.

Wendy Crawford, a C5-6 quad, founder of mobile WOMEN.org and co-founder of The Raw Beauty Project, thinks getting designers to consider people with disabilities as a viable market is difficult for a few reasons. “There is a lack of education regarding the clothing needs of people with disabilities. How is a designer to know if they haven’t encountered a disabled person in their own personal lives?” That’s probably why so many adaptive fashion solutions start in the minds of people with disabilities.
raz Cue, a 52-year-old writer from Las Vegas and a C5-6 incomplete quadriplegic, generally settles for off-the-rack clothing but finds the selection rarely meets his specific needs. “Some designs work better than others, but I wish I could find pants with higher backs, longer legs and no back pockets, so I could sit comfortably and look stylish.”

Like many people with disabilities, Cue finds the process of shopping a bit annoying. He buys a bunch of different items, tries them on at home, and returns the ones that fit funky. If he does find something that fits well and looks good, he buys several copies in various colors. “Finding something that really works isn’t easy, so when I do, the goal is to get many years’ worth,” he says.

Ronnie Raymond, 63, a United Spinal Association board member and wheelchair user due to multiple sclerosis, has found clothes specifically made for people with disabilities are often not very fashionable. “Most designs are so utilitarian that they are boring,” she says. Like most people, Raymond wants fashion that fits her style and her body and makes her stand out in a positive way. She is frustrated that in the past there has hardly been anything available for someone like her. “If I wanted to look good, I simply had to have my clothes made, or have clothes that were made for a nondisabled person altered to fit me.”

Tamara Mena has experienced similar issues. Mena is a bilingual motivational speaker, host, and model. She has always enjoyed dressing up, and that didn’t change when she found herself paralyzed from the chest down after an auto accident. “I have always loved fashion. Ever since I was young, I loved putting outfits together. Just because I am now in a wheelchair, it does not mean I don’t like looking good, put together and fashionable.”

As a bride to be, Mena was especially disheartened when it came to finding a wedding dress. “It was not fun going to look at wedding dresses. I had to worry about so many other things that other able-bodied brides don’t have to. Sure, I had to think about the look I wanted and my body type, but more importantly, I had to think, ‘will it work with my wheelchair?’” Mena found it very frustrating because often the dress that works with the wheelchair was not always the one she liked the most.

Like so many others, Mena wishes she wasn’t stuck with that conundrum. “Wouldn’t it be awesome to have more designers consider the wheelchair or atypical body configurations and do something about it?”

Heidi McKenzie got her start designing adaptive fashion after a 2007 car accident left her a T4 paraplegic. Instead of settling for clothes that didn’t fit the bill, McKenzie designed her own line of jeans, Alter Ur Ego, that is both functional and fashionable. “Finding the right pants is so hard for someone in a wheelchair,” she says. “Bending over and sharing your bum with the world is just one issue. There’s length, if it cuts into your hips, risk of pressure sores if pants have back pockets with rivets, and on top of all that, finding the right fit.”

LOOK GOOD, FEEL GOOD
The right fit is not only important when it comes to looking good; it also helps people feel good. Studies show that feeling comfortable in certain clothing or fashion pieces can significantly boost confidence and self-esteem. McKenzie believes wearing clothes that are both functional and fashionable can break down social barriers. “If you come into a room well-dressed, people will react to you differently. You are more approachable,” says McKenzie. “Something as simple as someone complimenting an article of clothing you are wearing can spark a conversation, and it didn’t start with ‘Why are you in a wheelchair?’ Being asked that question over and over gets to be aggravating.”

Like McKenzie, Dr. Sheri Prentis, founder of Be Sassy
& LIVE, also found her way into fashion through disability. She knows that what works for the disability market can, at times, diminish an individual’s sense of style. Prentis has clinically disabling lymphedema (persistent swelling) of her right arm, hand and fingers due to her rigorous treatment for breast cancer. She has to wear a compression glove and sleeve daily in order to control the swelling.

Faced with a selection of unattractive and uncomfortable gloves, Prentis designed her own line of compression garments that are stylish, comfortable and more affordable. “Fashion is an integral part of everyday life and a form of expression of our personalities, our ideals and our attitudes,” she says. “Fashion has the ability to transform an individual, to lift one’s spirits, and to open opportunities.”

Stephanie Thomas was born with congenital disabilities on her right hand and feet. She designed Cur8able, a fashion and lifestyle website, to empower people with disabilities by helping them create styles that allow them to dress independently in a stylish and dignified manner while also bringing adaptive fashion into the public’s view. A fashionista herself, Thomas has seen various trends come and go, but only a few that address the needs of people with disabilities. She has often experienced the frustration of shopping for accessible shoes and clothing. “Having the ability to make choices about how you want to present yourself to the world is powerful, but something most people take for granted,” she says.

But if Mindy Scheier has her way, the fashion world may be perched on the brink of truly inclusive designs. “Why has no one done this before?” she asks in a Runway of Dreams video. “We have never been more ready. Adaptive clothing will be in the mainstream. I won’t stop until it happens.”
The concept behind Open Style Lab sounds like a spinoff of the hit fashion reality show, Project Runway: a designer, an engineer and an occupational or physical therapist are paired with a client and tasked with designing a garment that improves their quality of life. The teams have 10 weeks to get to know and work with their client before a winner is selected at a final showcase.

But there’s one big difference that separates Open Style Lab from Project Runway and elevates it from a fun way to pass a weekday night to one of the more exciting developments in the fashion world. That difference? All the clients are people with disabilities, and all the work and research taking place in Open Style Lab is aimed at educating the design industry and moving it toward a more inclusive understanding of disability.

“What we’re trying to do is get the next generation of design students to open up and start talking in a new vocabulary as well as get to work with the people that they fantasize about in design imagination — like the elderly or people in a wheelchair,” says Grace Jun, executive director of Open Style Lab. “Our big goal is to get the next researchers and people with disabilities to come together in one space and provide them with that experience.”

Open Style Lab started in 2014 as a 10-week interdisciplinary public service program held in the summer at MIT in Massachusetts. That summer program is now run out of Parsons School of Design in New York City, and Open Style Lab has added a biannual class for Parsons students that uses the same team-based structure.

Both programs seek out clients with all types of disabilities and have produced a stunning array of unique garments that speaks to the potential of inclusive design. For instance, a heated bomber jacket that could be adjusted via Bluetooth by its paraplegic user while he rides his motorcycle in Slovenia; or a stylish blazer made of a high-tech breathable fabric with quad-friendly pull-down flaps designed for a man with a high-level SCI who struggles with temperature control. These kinds of results are often on the cutting edge of fashion, design and technology.

By working across disability, Jun says she hopes to instill new perspectives and a deeper understanding of how future products can be designed in a more inclusive way into her students and the fellows who take the summer program. She has seen how the personal interactions with clients can transform even the most seasoned fellows in the summer program.

“Though they are professionals or researchers or have graduated from college, most of them come to me and say, ‘I don’t know how to ask [the client] about this or that,’” she says. “I tell them, ‘Look, he’s got to go to the bathroom and he can only use one hand, just figure it out and just ask him. Don’t worry about it, just do it.’”

Jun’s passion for Open Style Lab and its mission is obvious, and based on the enthusiasm of her students at a recent showcase, its infectious. That’s a good thing for the future of inclusive design.

“This field is starting to gain popularity,” she says. “It’s definitely changing and there is a big change in the way we think about social responsibility.”

While the spring and fall classes are restricted to Parsons students, the 10-week summer program is open to any professionals in the fields of design, engineering or therapy. Both program options need interested members of the disability community to serve as clients. If you are interested in either option, or simply want to find out more, visit www.openstylelab.com or email hello@openstylelab.org.

“We’re mostly looking at purposeful or considerate uses of technology. As a society we have so much, but does it really help do what you need to do?” asks Jun.
Serving scenic San Diego, Imperial, Riverside and San Bernardino counties, the Southern California Chapter of United Spinal Association is there to help anyone with a spinal cord injury or disease find the resources and services they need. Like many chapters, members fly to Washington, D.C., to advocate for SCI at United Spinal’s Roll on Capitol Hill [below].

In addition to offering multiple peer support options and regular events, the Greater Kansas City Spinal Cord Injury Association co-hosts one of the nation’s largest disability expos, the Midwest Ability Expo [below]. Last year’s event drew almost 200 exhibitors and thousands of attendees and this year’s figures to be bigger and better.

GET CONNECTED!

United Spinal has more than 50 local chapters nationwide, connecting people with SCI/D to their peers and fostering an expansive grassroots network that enriches lives.

To find a chapter near you, or to find out how you can start one where you live, go to www.unitedspinal.org or call 718/803-3782 ext. 7410
The hottest ticket in Connecticut last year was the Spinal Cord Injury Association of Connecticut’s Twilight Gala [right]. With dancing, food, guest speakers and an auction, the event raised over $30,000 to support the chapter’s mission of supporting people with spinal cord injuries and diseases.

United Spinal Association of Virginia is one of the many chapters to offer a certified peer mentoring program [above]. Trained chapter members reach out to people with new SCIs to provide the support and resources needed to ease the transition back into the community.

United Spinal Association of Houston connects individuals living with disability, caregivers, hospitals and healthcare professionals, DME manufacturers and suppliers, and others. The chapter has a huge peer network, knowledge of all the latest resources and fun events (like “Let Your Super Hero Out” day [left]).

*Not Pictured: Our Hawaii and Puerto Rico Chapters*
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THE PAIN THAT NEVER STOPS

BY TIM GILMER

For as long as I can remember, more than 40 years, I’ve had a stabbing electrical pain that attacks my left groin when I least expect it. If it weren’t so bothersome, it would be funny. I’ll be cruising through the day, happy as a lark, and ZAP! — I nearly jump out of my wheelchair. If I were a cartoon character, my hair would stand straight up and my eyes would bug out.

Such is the nature of neuropathic pain. It is not like any other. It doesn’t ache or throb or hurt like a bruise or a sore tendon; it acts like an electrical signal gone haywire. Most people who have it describe it as a burning, tingling kind of sensation that is always there. My neuropathic pain is different in that it is mostly quiet, but when it strikes, it can feel like a single jolting electric shock or a series of sharp, stabbing jabs with a sharp-pointed knife. Sometimes it seems to have no explainable cause, but when it becomes strong and repetitive, it is a warning signal telling me I have a UTI, a rash, hemorrhoid irritation, a pressure sore or some other problem.

Not a day goes by that I don’t feel it at some time or other.

People with SCI tend to experience neuropathic pain at or below the dam-
aging areas of their spinal cords. Diabetics with severe neuropathy mostly feel it in their lower extremities. The pain is always related to damaged nerves and is a symptom of electrochemical nerve impulses being misdirected, amplified, or electrified. No single painkiller seems to erase it entirely, but there are ways to dampen or dull it — to quiet the constant white noise of pain.

Valerie Bohrman, 28, of Hood River, Oregon, knows about pain, both professionally and personally. She was three months from completing her residency as a nurse anesthetist in 2013 when she sustained a C5 incomplete spinal cord injury in a rollover car accident. Her mother, also a nurse anesthetist, made certain that Valerie was well-medicated for pain during her first two weeks in ICU. But when she emerged into the “real world,” she experienced the full effect of neuropathic pain for the first time.

“The pain is absolutely maddening,” she says. “I can understand how people can go crazy with it. From my shoulders down it felt like thousands of bugs with hot pokers on their legs, marching under my skin. For the most part, my whole body felt this, but different in each area. But it’s worse in my hands, feet, calves, and abdomen.” Since her SCI is incomplete, her neuropathic pain attacks a number of areas below her injury level.

Bohrman routinely takes a very high dose — 4,500 mg/day, three doses of 1,500 mg — of Neurontin (generic name: gabapentin), an antiepileptic medication that is often prescribed for neuropathic pain. She also takes Cymbalta (generic name: duloxetine), an antidepressant, and marijuana. According to a June 2015 study in *Pain and Therapy,* “Management of Neuropathic Pain Associated with Spinal Cord Injury,” no single drug can eliminate neuropathic pain, but antiepileptic meds, antidepressants, opioids and marijuana are effective in dampening the pain.

Each drug she takes for overall pain relief is important, and for different reasons. Neurontin reduces excitability in her CNS, which lowers her pain intensity to a tolerable level. Cymbalta, an SSRI med, increases norepinephrine, a form of adrenaline that helps overcome pain, and high-CBD cannabis (little or no psychotropic effect), works like a relaxant, which reduces the perception of pain.

“For cannabis, I use a CO2-extracted oil concentrate in a vaporizer for instantaneous relief. It’s a strain called ‘Herbie,’ which is 50 percent CBD and 19 percent THC. It’s my ‘rescue drug.’ If pain ramps up during the day, I take a few puffs and feel it within 30 seconds or a minute. I also use it every night. There’s no cognitive effect, just relaxing, and it helps me sleep better.”

**WHAT TRIGGERS PAIN, AND WHAT DAMPENS IT**

While Bohrman’s pain is constant, the severity fluctuates depending on what’s going on in her life. “At certain times, like when I’m stressed, I feel the pain heightened,” she says, “like with a bladder infection. My menstrual cycle and constipation also aggravate it.”

Some people feel different levels of neuropathic pain relative to body positioning or time of day. “The time I feel it the most is at night when I’m sitting still and no other stimulation is going on,” says Bohrman. “On the other hand, it is lessened when I’m using my standing frame and doing stretching exercises.”

Neuropathic pain tends to affect different people in different ways. Arwen Bird, 42, of Portland, Oregon, was injured in 1993 from a burst fracture at T8. She feels her pain ramp up when she exercises. “Especially with swimming,” she says. “It increases the burning sensation, but the endorphins I get from swimming help me manage it.”

Unlike Bohrman, when Bird uses a standing frame, her pain level increases. But the pain that comes from exercise seems less bothersome to her because activity keeps her mind focused on something other than pain. “I especially love paddleboarding,” she says. “I’ve found my sport. Being on the water is where I want to be.”

Bird says her pain wasted no time in making itself felt. “I’ve had pain since the moment I was injured. When I woke up, I had this burning sensation in my legs. Like frostbite, when your toes get so cold they feel like they start to burn. It is constant.”

There is no consensus about the incidence of neuropathic pain, but a recent study estimates as many as 40 percent of people with SCI experience it. In the beginning, Bird says she thought the pain was something that came with SCI and she would just have to bear it. But in 2012, she experienced a level of pain from a simple cut that overwhelmed her, so she started taking Neurontin, like Bohrman. Up until that time she would treat non-neuropathic pain (musculoskeletal pain) with opioids like Vicodin or OxyContin. “That gave me a little relief from the neuropathic pain as well, but now that I take Neurontin, I can feel that it does a better job.” She takes a lighter dose than Bohrman, 900 mg three times/day, for a total of no more than 2,700 mg/day.

As for using high-CBD cannabis for pain relief, she doesn’t like the effect of feeling groggy. “I feel like I can’t connect with the people around me. I tried some and it does help. But it’s not social and functional for me.”

Bird sees a pain specialist regularly, an anesthesiologist. “I also see his physician’s assistant. It helps to have a relationship with someone who knows me and knows what kind of pain I have. Most people don’t understand neuropathic pain, and sometimes they don’t believe you when you try to explain it.”
Does Your Bladder Bug You?

MedStar National Rehabilitation Hospital and the United Spinal Association are working together to understand more about people with bladder dysfunction (neurogenic bladder). We are developing a questionnaire to better understand your urinary symptoms and are conducting telephone focus groups to learn about your experiences.

You are eligible to participate in this series of focus groups if:

• You have a neurogenic/neuropathic bladder; and,
• You are able to void normally (you don’t use any type of catheter to empty your bladder).

If you meet the above criteria and are interested in joining one of our one-hour telephone focus groups, please contact:

Inger Ljungberg, MPH
inger.h.ljungberg@medstar.net EMAIL
202-877-1694 PHONE

This research is being conducted in association with United Spinal Association.
Tracking the cause of a spike in neuropathic pain can be like detective work. Often there is no clear specific location to pinpoint, but when the pain ramps up, there is usually a reason. “Definitely UTIs will aggravate it,” says Bird. “And when the weather gets really dry, I find my pain increases. Humidity feels better. It’s like my body ‘reads’ the larger environment.”

Bird is learning that one of the most important things you can do to dampen pain is to concentrate on what brings you joy. “I’ve started to learn how to play the piano. There is a meditative quality to it. Just following the notes and moving my fingers, it’s like I can almost feel the neurons firing in my brain, and I just keep moving through it, whether I understand it or not. I try to employ that a lot in my life. I’ve started hanging out with friends who are involved with climate science, and the challenge for me to keep up with these smartypants people is enjoyable.”

So are simple pleasures, like gardening in raised beds, tending her plants, and watching and listening to all the different types of birds who come to her back yard, which is adjacent to a green space. “If I had one piece of advice to give someone who is navigating through pain,” she says, “I would say go outside and observe nature and all the living things and reflect on it, breathe in some fresh air. And go hug a tree! It really does make a difference.”

**HAVING AN ACTION PLAN**

Matt Patterson, Sr., 64, of Astoria, Oregon, experiences neuropathic pain due to stenosis of his spinal cord that began unnoticed after an undiagnosed traumatic injury. Technically speaking, he is not paralyzed, but damage to his spinal cord has occurred at the C5-6 level. “There...
was no obvious injury, but any number of incidents could have caused it over a period of time. Then came calcification of the spine, which restricted the spinal column and made the cord get smaller and smaller."

He wears a knee-ankle foot orthotic on his right leg and has no feeling in his hands due to the stenosis, and not much feeling in his legs. He also has clonus all over his body — a big muscle group fights against a small muscle group, causing a kind of shivering. “That’s what it looks like to an onlooker,” he says, “but I don’t feel it. It’s a fast shiver, happens four to eight times per second, more on my right side than my left.”

Patterson describes his pain as pins-and-needles from his wrists to his fingers. Sometimes it shoots all the way up to his elbows and shoulders. “It’s a burning, tingling pain,” he says, “kind of like when your hand falls asleep and you start to regain feeling, but it is a burning sensation.”

Like Bohrman and Bird, Patterson’s pain never goes away, and he also takes Neurontin to keep it at a manageable level. “On a pain scale of 10, it goes down to a three if I stay busy and active, and when it stays at that level, you can forget it for a while,” he says. But it can shoot up to a seven.

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“Today I went outside to get in my van and go pick up my daughter, and I forgot to put my gloves on. My hands get cold and the pain goes up. Or just resting my arm on the armrest can trigger it. Pressure at a joint can do it. For me, infection is not a problem (he does not have a neurogenic bladder), but I have a hypersensitivity to touch and cold.”

He credits his ability to manage his pain to having a four-step action plan. "Number one is to be sure and take my meds. I take Neurontin at a dose of 1,200 mg three times/day. If I am only two hours late in taking it, I will know it immediately. I need them, and I’ll pay for it if I don’t take them.”

Number two on his action plan is to focus on staying active mentally and physically. “I play chess and read, and listening to music helps. It’s easier to dwell on the pain than to think of something else. It takes effort to stay focused on something else, because the pain never goes away.”

Number three is to know what causes a pain spike, then fix it. “You’ve got to search out the cause,” he says. “I’ve got to stay away from cold, stay warm, stay active. And I take classes — Living Well with Chronic Pain — that kind of thing.”

Number four? Have a sense of humor. “I have to, with six kids,” he says. I was married and had three kids, my wife died, I remarried and now I have six. Just one living at home now.”

**GOING WITHOUT MEDS**

Tom Wolford, 60, from Roseburg, Oregon, says he had neuropathic pain from the beginning after his C6-7 injury, but when he was offered a pain med, he refused. “I didn’t want to get addicted to it,” he says. He also describes his pain as a burning, tingling sensation that fluctuates in intensity. “Sometimes it’s bad. It goes from a three to a seven and then I have a hard time sleeping. I feel the pain from my nipples on down.”

Sometimes one or two aspirin and a shot of alcohol will help calm the pain. “Usually I’ll have whiskey with coffee, or...”
I’ll take a shot or two and chase it with Pepsi or 7-Up. I do that whenever I need it. Not every single night, just when I need it. If I get stressed out, like getting in an argument, it gets worse.”

Wolford takes 1,200 mg/day of gabapentin, but unlike the others in this story who take it for pain, he says his doctor prescribed it for spasms. I mentioned to him that others take two or three times that dose for pain and asked if he thought that might help his pain. “I would rather get the dose down,” he said. “I’d like to take less if possible.”

Like others I interviewed for this story, Wolford stresses the importance of staying busy to distract from the pain. “I like to do research on the Internet,” he says. “I’m kind of a tinkerer-inventor. And I love driving out in the woods and making the rounds. I really like in the summertime to go into the high lakes and streams. I used to work on a survey crew, so I’ve always liked being in the woods.”

What about cannabis? “I tried it a lot when I was younger, and I don’t want to do that now,” he says. “I know about high-CBD marijuana but I don’t trust it. If I smoke that stuff, you might as well put a dust pad on me and set me in a corner,” he says.

I have learned while researching this story that while neuropathic pain is manageable, each person has to find their personal way of dealing with it.

When I woke in ICU following my plane crash, I could not sleep at night due to the burning, tingling sensation, and I thought I was losing my mind. Morphine took my mind off it in the hospital, and I self-medicated with alcohol and marijuana for 20 years after that. In 1986 I stopped using marijuana and only drank at night, but not every night. Like Tom Wolford, I got used to the pain, but lately the severity of the stabbing knife in my groin, when it attacks, makes me turn to opioids (hydrocodone with acetaminophen) for relief.

Hydrocodone helps, but the delayed side effect of constipation also triggers the stabbing knife, so it cuts both ways. Just in the last month I have tried a cannabis edible, dark chocolate, with high-CBD content. It also helps, but at the modest dose I have tried, it is mainly a relaxant that only slightly dampens the pain.

I am not through searching and experimenting. I plan on taking Bohrman’s advice: “Patience and persistence is essential. It takes time to find the right combo/cocktail. If it isn’t working right, be persistent with doctors about trying something else.”

And there is always Plan B: More music.

**MY TAKEAWAYS**

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**WHAT IS NEUROPATHIC PAIN?**

The following was paraphrased from WebMD’s article, “Pain Management: Central Pain Syndrome”

Central pain syndrome, sometimes called neuropathic pain, is caused by dysfunction of the central nervous system, which includes the brain, brainstem, and spinal cord. The disorder is most often caused by strokes, multiple sclerosis, Parkinson’s disease, brain injuries and brain tumors, and spinal cord injuries. It may occur soon after damage to the CNS or months or years later.

This type of pain is characterized by a number of different painful sensations but most often is felt as a constant burning sensation that can be amplified by light touch. It can also increase with temperature changes, most commonly brought on by cold temperatures. The pain can be mixed with a loss of sensation, such as numbness or tingling, and is most prominently felt in the hands and feet, especially the lower extremities. Occasionally, it can be experienced as brief, repetitive, intolerable bursts of sharp, “electrical” pain.

Pain medications provide at best partial relief. However, those medications that have been found to be most effective are anticonvulsants (antiepileptics), and antidepressants, or combinations of different medications.

**RESOURCES**

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Cindy, your story underlines the importance of doing daily mirror-skincHECKS. Even with a perfect cushion, a pressure sore can crop up from a variety of skin insults — a bruise, weight gain or loss, or changes in weight shift frequency. Being evaluated at a wheelchair-seating clinic is vital for anybody with frail or aging skin. Although the clinician should be well versed on the latest and best cushion options for your needs, here are a couple cushion options you might want to ask the clinician about:

Aquila SofTech is an alternating pressure air cushion that automatically does weight shifts for you, as often as every 30 seconds. The key to the SofTech — and all Aquila cushions — is two groups of air bladders that alternate pressure from side-to-side via a battery-operated pump, which provides a gentle weight shift. The SofTech cushion is self-contained. It is a water-proof-coated foam cushion with air bladders, air pump and battery integrated into the cushion, which has a total weight of five pounds. All Aquila cushions are designed to prevent bottoming out.

The Aquila cushion pump is surprisingly quiet, similar in volume to the internal cooling fan in a laptop computer. The battery can pump up to 40 hours on a charge. A remote control enables five firmness (air pressure) settings, controls the length of time between air pressure shifts — ranging from 30 seconds to five minutes — and includes a battery status light.

Each Aquila cushion is custom built to address a client’s unique seating needs — from width and depth, number of air bladders, to off-loading areas where there is currently an ulcer, according to Steven Kohlman, Aquila’s president.

A 2014 study published in the Veterans Affairs’ Journal of Rehabilitation Research and Development used high tech instrumentation to look at ischial tissue health of 13 wheelchair users with SCI after using an Aquila alternating pressure air cushion for two weeks, in three-week intervals, for 18 months. The study concluded that the alternating pressure air cushion dynamically and continuously alters [reduces] ischial pressure distribution with sustained and positive tissue health effects compared with performing diligent weight shifts on the subject’s personal cushions.

Eric Schroeder, 42, of La Crosse, Wisconsin, who has spina bifida, spinal stenosis and chiari malformation, fought an ischial pressure sore for three years before it progressed to stage IV and he became bedridden for a year. “I heard about the Aquila SofTech from a surgeon,” says Schroeder. “My wound care clinic sent me to a surgeon because they felt it was time for a skin flap. My surgeon said he had success with several people who had pressure sores that healed while using the Aquila. He said he would rather have me try that route first.”

When Schroeder got his Aquila cushion, he was sitting in his wheelchair for only an hour at a time. His wound healed in three months. “It’s been three years since I got the Aquila and I haven’t had another pressure sore, and I’m up in my chair for 12 hours a day.”

Larry Yenter, 50, of Rochester, Minnesota, 26 years as a C5-6 quad, has been using an Aquila cushion for four years. “Before the Aquila, I kept getting pressure ulcers and tried lots of different cushions to stop them.” Over the years he had three skin flap surgeries with both ischial tuberosities shaved down. “When I heard about the Aquila, I was so excited I paid cash for it. I haven’t had any skin issues since I’ve been on it. Between my job as an accountant and an active life, I’m up in my chair at least 12 hours a day.”

MSRP for Aquila SofTech: $4,300; Medicare approved.

Ride Custom Designs (Aspen Seating) does custom-molded cushions and backs for people with severe skin integrity and/or orthopedic issues who have tried all other options. Aspen Seating requires traveling to their Denver clinic for a complete fit and molded cushion (takes about one week).

Ride cushions are an extension of Aspen seating. The Ride Custom cushion is custom molded to address similar challenges to those addressed by the Aspen Seating cushions, but it is less expensive and can be fitted close to home by working with a certified Ride provider (usually through a DME supplier).

Ride Designs and Aspen cushions protect tissue by transferring weight from high-risk ischial and coccyx areas to low risk areas. They are made of a patented, lightweight, composite material that allows air and moisture to pass through.

“I’ve been using an Aspen Seating system since 2006,” says Paul Callahan,
57, of Newport, Rhode Island, 35 years as a C3-4 quad. Callahan, a two-time Paralympic sailor and CEO of Sail to Prevail, developed pressure ulcers on both trochanters (hip bones) and his left ischium when his previous cushion failed during a race in the 2004 Paralympic sailing trials. “I had skin flap surgery to repair the trochanter ulcers and was told that the only way the ischial wound would heal is to stay off of it, so that’s what I did — stayed in bed for the better part of two years, but the ischium wouldn’t heal.”

Callahan found out about Aspen Seating from a friend. “I checked out the website, called them up and did my research,” he says. Around the same time a wound care nurse had told his wife that she should be prepared for her husband to deal with this the rest of his life.

Callahan flew to Denver and got fitted with an Aspen seating system. “When I got home with the cushion, the most amazing thing happened. My pressure sore started to heal faster when I was up in my chair, on the cushion, than when I was lying in bed. So I said forget being in bed and returned to staying up in my chair 15 hours a day, and the sore ended up fully healing within a couple of weeks! I won’t sit on any surface without an Aspen seat under my butt — and I’ve remained pressure sore free to this day.”

MSRP for Ride Custom Cushion: $1,590. Medicare approved. Aspen seating system price varies depending on individual seating requirements. Covered by Medicaid and many private insurers, but not Medicare. As always, check with your provider.

Resources
- Aquila Cushion, www.aquilacorp.com
- Sail to Prevail, www.sailtoprevail.org/about-us

ROHO cellular-designed dry flotation cushions have a reputation for providing outstanding skin and soft tissue protection, but adjusting and checking proper air pressure is vital to get the most protection from the design. This used to be a challenge for people with higher-level injuries, especially when relying on caregivers. The addition of the Smart Check inflation sensor makes proper pressure checking easier. The sensor, a small electronic device with a short tube and a quick-connect clip, fits onto a valve located on the corner of ROHO Sensor Ready cushions. While sitting on the cushion, you push a button and the monitor shows whether the cushion pressure is too firm, just right, or too soft — making it easy to dial in ideal pressure. The monitor can be tucked into a cushion pouch when connected so you can periodically check cushion pressure.

Presently the Smart Check is compatible with Sensor Ready cushions; ROHO plans on expanding the technology to more products.

MSRP: High and Mid Profile Sensor Ready cushions: $618; Hybrid Elite SR Cushion: $473.25; Medicare covered. MSRP for the Smart Check sensor is $160 and is not Medicare coded.

www.roho.com/?s=Smart+Check
In the minds of many drivers who are disabled, driving is considered to be a gift. In reality, it can often be an expensive undertaking that requires a modified vehicle of some type with a price tag that might exceed $50,000. While it is true that some people requiring such accommodations may be able to drive with a fairly minimum investment of a few hundred dollars for a set of hand controls, the joy of being able to travel freely in one’s own vehicle — even if only as a passenger — can make that investment worthwhile, no matter what the cost. In order to find out why, we conducted an informal survey of a few individuals who shared what they considered to be their best day of driving, even if that drive extended beyond a day. Their responses varied, but a few common themes emerged.

Many people who become paralyzed as adults have previous driving experience and long to get back behind the wheel. Perhaps that is why NM columnist Allen Rucker, a para due to transverse myelitis from Southern California, feels that his first day of driving solo with hand controls — which was also the day that he passed his driving test — produced the best drive of his life.

Rucker’s preparation allowed him to pass his driving test on the first try; according to the driving examiner, that was unusual. “She told me most people just show up with their hand controls installed but have never used them,” according to Rucker, “and she showed me a huge hole in a nearby hedge that someone had driven through because he hit the accelerator instead of the brake. He failed the test.”

That initial reintroduction to driving with hand controls was a great experience for Rory Calhoun as well, an outdoor recreation specialist who works in Olympia, Washington. “I really enjoyed the occasion, my first time after becoming paraplegic, when I got to drive the rehab department’s car and realized I had a level of independence coming soon, so I wasn’t going to need to rely on someone to help me out,” he says. “After getting my 4x4 Blazer fitted with hand controls and leaving the rehab center, I was free and never looked back.”

As someone who loves and works in the outdoors, Calhoun, unsurprisingly, puts off-road driving at the top of his list of favorite types of drives. Something as simple as being able to pull off at a viewpoint and control his view from the driver’s seat is a liberating feeling.

When Jesse Case, a T7 para from Western Washington, thinks of best drives, it usually includes having something hooked to the back of his Dodge pickup truck. He and his family enjoy camping, and he hauls an accessible camping trailer to interesting destinations throughout the summer. Surprisingly,
what he considers to be one of his best drives was a multi-day trip to 29 Palms, California, to deliver his daughter’s car that was towed behind the pickup.

Riding in the back of a van is a common occurrence for many people who use wheelchairs. That is required when using public transportation options like paratransit, airport shuttles, taxis and ride-share services. The drawbacks are many, as restricted vision out the side windows and the inability to see traffic lights and road signs detract from the joy of travel. For Sheri Denkensohn-Trott, a C4 quad from Arlington, Virginia, the design of her first van, a full-sized 1983 Ford Econoline, required her to ride in the back of it. Being lift-transferred in and out of the van without having to leave her wheelchair was nice, but the lack of vision and control was frustrating.

When she purchased her next van, six years later, it was a minivan that allowed her to roll into the front passenger position and simply lock into place with an EZ lock device. What did that change mean? As she puts it: “Liberation! I faced forward, was able to see out of the windows at the normal height and, most importantly, I had control. I was not the driver, but being co-pilot was fabulous, and it continues to be a source of joy and independence.”

**Remarkable People, Surprising Opportunities**
When Mary McKnew decided to travel from her home in Washington, D.C., to Miami, Florida, to attend an annual meeting of the National Spinal Cord Injury Association (now United Spinal Association), she decided on including some friends. McKnew is paraplegic, and the three friends that accompanied her included another high incomplete para and a quad. Since the four friends did not have much money at the time, it was decided that the best way to reach the annual meeting was to take a road trip. They managed to load the three wheelchairs into and onto her hand control-equipped Mercury Cougar sedan and set off on the drive, straight through to Miami.

“We took turns driving,” she said, “and I took the first shift. When it came time to spell me, I simply climbed over the seat so that I could sleep in back.” That method of changing drivers became the norm, as they would not need to transfer into wheelchairs to make the switch. It also provided some of the most amusing experiences on the trip, as the other drivers were not as flexible and strong as McKnew but managed to clamber over the seats in their own style. “That method of transferring between seats may be
ill-advised,” she admits, “but everyone was eventually successful in doing it. The entire trip turned out to be a lot of fun.”

The ability to drive can sometimes override the frustrations of breakdowns and similar events that can happen on a road trip. For JR Harding, a quad from Tallahassee, plans for a weeklong getaway at a resort about 120 miles away hit a snag part way to the destination. Harding was driving his full-sized Ford van, loaded with everything needed for the week, accompanied by his caregiver. “While refueling the vehicle, about 25 miles from my destination, the fuel pump on the van went out,” he said, “and I found myself stranded in Apalachicola, a historic fishing town located in the panhandle of Florida.”

Not to be deterred by the breakdown, Harding called the manager at the resort destination, who drove the 25 miles and loaded everything that had been in the van into the back of his pickup truck. That included the wheelchair. Harding got to ride in the cab of the truck. Other events that day included finding a local mechanic who did the repair at a reasonable cost and delivered the van to the resort a few days later, getting catheterized in the middle of a parking lot with passersby looking on, and actually arriving at the destination ahead of his wife and mother who had been traveling in a separate car due to the amount of supplies that were in the van.

Was the trip a success? “It was quite a day! Without the help of the park manager and the local mechanic, we would not have had a spectacular holiday without worries,” according to Harding, “but sometimes there are simply remarkable people in everyday life, and in everyday places.”

Astrid Gallagher says she has driven across the United States about 50 times in her 81 years, all while seated in her power wheelchair. Gallagher is non-ambulatory due to post-polio syndrome and, while she can use the foot controls in her Ford Econoline van, the vehicle is equipped with hand controls.

The 2010 trip from her home in Arroyo Grande, California, to Washington, D.C., has a special meaning to her, as a side trip provided her with a new experience that she hadn’t considered possible in the past. Approaching Utah, she noticed a sign for the Bonneville Salt Flats and decided to check it out. The salt flats seemed busy, with racers testing all types of vehicles. She asked someone who appeared to be in charge if she could give it a try, and they approved.

The 75-year-old Gallagher headed out on the track in her large van, with its comparatively puny 302 cubic inch engine, and accelerated as quickly as she could. “At 95 mph the van started shimmying,” she says, “so I turned around. I was very happy. The salt caked underneath my van lasted for several days, getting plenty of weird looks.”

The looks might have shown even more amazement if people had known how Gallagher managed to accumulate the salt in the first place. Best drives are like that. You never know when they’re coming or under what circumstances.
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There are many developmental phases cripples go through in our desperate attempt to survive crippledom. You can’t always tell that you’re in one of these phases when you’re actually in it. Sometimes it is only clear in retrospect. Some cripples find a comfortable niche in one of these phases and never come out of it. But I can see where I’ve been through a few of them myself, such as:

The Basketball Phase: This is where cripples immerse themselves in cripple basketball. I entered this phase as a kid but didn’t last very long in this phase because I sucked at playing basketball. It was crushing at the time, but I now consider that to be a blessing because if I had been even remotely good at playing basketball, I’m sure I would have dedicated myself to cripple basketball forever, dribbling my blues away. But instead I entered:

The Bootstraps Phase: I entered this phase as a kid but didn’t last very long in this phase because I sucked at playing basketball. It was crushing at the time, but I now consider that to be a blessing because if I had been even remotely good at playing basketball, I’m sure I would have dedicated myself to cripple basketball forever, dribbling my blues away. But instead I entered:

The Self-Advocate Phase: If I wasn’t going to pay for all the extracurricular stuff cripples need with my own money, then I’d have to convince agencies and charities to pay for it for me. So I had to get my hustle on. Here’s what that phase was like, metaphorically. Suppose being a cripple trying to make it on your own was like being on a sinking ship, and the agencies and charities were the lifeboats that could hold only about one tenth of the cripples on board. I had to dedicate myself to figuring out how to negotiate my own space on the lifeboat. Sorry, all you cripples left behind. I truly feel sorry for you, but a guy’s gotta do what a guy’s gotta do. But the self-advocate phase is a game of settling for what you’re given. Like for instance, all the public buses and train stations at the time were inaccessible. All the solitary hustling in the world couldn’t get my wheelchair up and down those steps. So after college, I found myself ready to enter:

The Activist Phase: I dedicated myself to joining up with the hell-raising cripples who blocked public buses in the street and disrupted meetings of the transit board until the transit board agreed to make stuff accessible. It’s big fun irritating smug people in power, especially when you beat them. But it’s stressful, too. The thrill of victory is short-lived because there are always a thousand more battles ahead and it’s time to move on to the next. So sometimes I’m tempted to say screw it and move on to the next phase. But I don’t know what that would be. It’s too late to go back to trying to make a boatload of money. So I’m afraid that all that’s left at this point is:

The Lottery Ticket Phase: I’ll dedicate myself to taking a nickel and scratching away, every day, every day.
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Of the estimated 3.6 million who participated in the historic women’s marches that took place across America and around the world, it’s estimated that 45,000 were people with disabilities. That is the largest gathering of people with disabilities ever, reported outlets such as Newsweek, Vox and Mic.

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