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iLEVEL EMPOWERS
What if your wheelchair could tell you when it was going to need maintenance or when you needed a pressure release? Or what if it could drive you from point to point without you having to steer? BOB VOGEL says the time is now. Also, ELIZABETH JAMESON and CATHERINE MONAHON ask, why can’t we have wheelchairs that are both functional and beautiful?

**FEATURES**

16 **MAXIMIZING METABOLISM**
Paralympian SETH MCBRIDE shares how and why wheelchair users should keep tabs on their metabolism.

20 **CREATING A SAFE SPACE**
KATE MATELAN reports on how Van Brooks’ nonprofit, SAFE Alternative Foundation for Education, is transforming his Baltimore community.

35 **TECH TAKEOVER**
Technology is transforming work, and for wheelchair users willing to take advantage, REVECA TORRES finds there are more opportunities available than ever.
The rule of law is under attack, especially the civil rights of minorities, immigrants and people with disabilities. In an August 10, 2017, online essay posted on Rewire, Lisa Needham characterized it this way: “The [Department of Justice] is telling people with disabilities that it doesn’t care if their needs are met and it doesn’t care if they’re able to fully participate in society. This is troubling and lamentable.”

It is far, far worse than troubling and lamentable. The Trump administration’s policies, especially those of the DOJ’s Civil Rights Division, are proof of bias and discrimination toward people with disabilities. Think about that. The arm of the government that is responsible for protecting our civil rights is itself in violation of the Americans with Disabilities Act. The rule of law has been hijacked and replaced by the rule of prejudice.

Prejudice is defined as: 1. Preconceived opinion that is not based on reason or actual experience [it is based on ignorance]; and 2. Judgment or action that results in harm or injury in disregard of one’s rights. In our current political atmosphere, not only has the Republican-dominated House of Representatives voted to substantially weaken the ADA, the Trump administration has taken additional actions that strip us of our rights.

To put this in perspective, in 1990, Congress was overwhelmingly supportive of our need for civil rights protection and enforcement, with 93 percent of legislators voting in favor of the ADA. But those days are long gone.

Here is what we now have: A president who publically mocked and humiliated a respected disabled reporter; a secretary of education who at the time of her confirmation was ignorant of the Individuals with Disabilities Education Act; an attorney general who, as a senator, blamed IDEA for the “decline in civility and discipline in classrooms all over America” and, later, as AG, opposed his own Department of Justice’s previous stance on a civil rights discrimination case, resulting in a damaging limitation of the ADA’s “reasonable accommodation” clause. As if that was not enough, Attorney General Jeff Sessions also rescinded 25 guidelines, 10 of which were specific to the ADA. And remember Trump’s very first “success?” He appointed a new Supreme Court justice who, as a lower court judge, had issued a ruling against a student with autism so offensive that it was unanimously rejected by the Supreme Court.

Then in mid-February of this year came HR 620, a bill that was opposed by every national disability rights organization. Sen. Tammy Duckworth (D-Ill.) called it “a disgraceful message to Americans with disabilities that their civil rights are not worthy of strong enforcement.” The Alliance for Justice called the bill an “inexcusable affront to Americans with Disabilities.” And the Consortium of Citizens with Disabilities issued this statement: “We know of no other law that outlaws discrimination but permits entities to discriminate with impunity until victims experience that discrimination and [then the victims must] educate the entities perpetrating it about their obligations not to discriminate. Such a regime is absurd, and would make people with disabilities second-class citizens.”

Indeed, we are already there, not only in the thoughts of those in power, but in their actions.
ELIZABETH JAMESON

An artist specializing in the intersection of art and science, Elizabeth Jameson is inspired by the power artwork has to inform the narrative around chronic illness. Jameson, who has multiple sclerosis, transforms her brain scans into provocative images that challenge how society views disability and illness, and invites people to stare directly at the complexity of the imperfect brain. Her work is in permanent collections at major science centers, such as National Institutes of Health, The Center of Brain Science at Harvard University, and the Basque Neuroscience Institute in San Sebastian, Spain.

KATE MATELAN

By day, Kate Matelan is a senior digital copywriter and editor for QVC, but by night, she's a freelance journalist who covers more than retail. Matelan is known for her smarts, style and candid SCI musings. When she's not writing, you'll find her whipping up a new creation in the kitchen, being a full-time aunt, or wheeling along local trails — and slowing her roll when spotting a cute dog or two! As a 2010 Bucknell University grad, Matelan will always be proud of her orange and blue.

SETH MCBRIDE

When not writing and editing for New Mobility, Seth McBride likes to spend his time wrangling his 1-year-old son, Ewan, going for bikes rides, and wandering around outside with the fam as much as possible. McBride and his wife, Kelly, also love taking on large projects they have little time for — like recently buying a 1916 duplex that was in no way accessible. His writing interests typically include anything related to fitness, physiology, sports and adventure, but he appreciates a good story on just about any subject.

Want to contribute to New Mobility? Please send queries and manuscripts to Ian Ruder: iruder@unitedspinal.org
Another Couple We Love
All these couples have an inspiring story to tell and were well said ["Couples We Love," February 2018]. I could relate to their lives since I've been a C4-5 quad for 61 years, happily married for 41 years with four kids and nine grandchildren. I drove my van and worked for 40 years supporting my family and yes, love can flourish on wheels with the right loving wife, like I have.

Gale Williams
NewMobility.com

Seeing Beyond the Bag
[Re: "Relationship Baggage: Dating With a Colostomy," February 2018:] This is something that I don't have to deal with, and I am truly grateful for that. But I do relate to your fear of "telling all" regarding a private matter. I am now looking at my own imperfections in a new light as your gutsy attitude is really something to be proud of and to be learned from. Well done, and watch out new suitors for this liberated and brave woman.

Morag Wade Mackay
NewMobility.com

Struggling with Shame
Thanks for your candidness ["Relationship Baggage," February 2018]. I can relate because I deal with incontinence due to spina bifida. The shame I feel about it has really prevented me from even getting into relationships.

Lauren Bendik
NewMobility.com

ADA Can Be a Remedy
["Extended Elevator Breakdowns," February 2018] neglected to mention that prolonged and/or frequent breakdowns can be remedied via an ADA complaint — ADAAG 407.1. Although 407.1 is an advisory note, as an attorney, I successfully used it against a defendant in a lawsuit under pre-2010 ADA standards.

Edward Kopelson
Montclair, New Jersey

Ultralight, Ultra-longevity
I have an 18-year-old original TiSport from back in the day when insurance covered access and the word "Sport" didn't automatically eliminate access ["Making Ultralights Even Lighter," February 2018]. Now it’s TiLite. With the original FrogLegs (new caster wheels of course), this rigid framed chair still fits my body and is in great shape.

Molly Sacco Hale
NewMobility.com

Perfectly Said
"It’s time for me to clear away old resentments. I have to make room for the new ones." ["One Step at a Time," Ervin, February 2018.] I couldn’t have put the process of maturing into words any better.

Tish Aguilar
NewMobility.com

#DriedPlumsForever
It’s about time you joined the prune movement [Ervin, February 2018]! Now you can have another kind of movement.

Thomas Hack
NewMobility.com

Un-flap-able
I’m a C6-7 and I had flap surgery when I was 45. I also had a bone infection ["Journey to the Far Side of Tomorrow," NewMobility.com, February 15]. They shaved the bone to get rid of some of the infection and also smooth it out a bit to decrease any future pressure issues. Make damn sure they put you on a Clinitrion sand bed ... it is THE MOST IMPORTANT thing for your initial recovery in the hospital. They’re so good that you can totally heal without even having to turn! It's amazing actually. Best of luck.

Ken Todd
NewMobility.com

Tricky Casting
As both a filmmaker and father of a daughter with a T4-11 injury who does theater, I can see both sides of this argument ["Don’t Worry He Won’t Get Far On Foot," February 9]. If the script was written with the accident as the incidental event, then it does become an issue of how to cast for a story like this. However, Hollywood often ignores actors with disabilities and casts abled-bodied actors instead, as in the most recent series Superstore and Mom.

Sean Bode
NewMobility.com
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PASSAGE OF HR 620 SPARKS OUTRAGE IN DISABILITY COMMUNITY

The House of Representatives passed HR 620, the misleadingly-named ADA Education and Reform Act, which disability and civil rights groups say guts the Americans with Disabilities Act, with a 225-192 vote. The move sparked swift outrage from members of the disability community, who say the bill effectively makes them "second-class citizens." All but 19 Republicans voted for HR 620, while all but a dozen Democrats voted against its passage.

The final version of HR 620 would give businesses up to four months to respond to an ADA violation complaint and start making "substantial progress" toward removing barriers to access. The bill does not contain a definition of "substantial progress."

Supporters claim the bill is designed to stop so-called "drive-by lawsuits," in which serial litigants make a profit by suing businesses for ADA violations. Opponents of the bill, including nearly every major civil and disability rights organization in the country, say it will have limited effect on such lawsuits, while further placing the burden of compliance on those who are being discriminated against.

"I am saddened and angered by the congressional effort to undermine the well-established rights of Americans

CHAPTER NEWS

TENNESSEE CHAPTER HOSTS SECOND ANNUAL CAMP UNITED

Last year the United Spinal chapter of Tennessee hosted Camp United, an outdoor adaptive sports day held at the Joe E. Davis Outdoor Center in Nashville. After a successful first run, they are upping the stakes with the second annual Camp United on May 20.

Last year’s event featured a wide variety of sports from adaptive kayaking to wheelchair tennis, adaptive sailing, wheelchair basketball, and even fishing. There were Paralympians giving tennis instruction and a youth group demonstrating basketball. Chapter leader Alison Harris says that despite the August heat, they had an impressive inaugural showing, "Last year we had over 300 people attend the event, with over 100 people launching kayaks and over 50 zip liners fulfilling a bucket list dream. It was very liberating for everyone who participated and very humbling for all the volunteers and staff! Great bonding event for our disabled community. And everyone had a blast."

This year, Harris is looking for more of the same, with an expanded array of sponsors' booths and the addition of adaptive badminton to everything they had going on last year. Everything will be set up for wheelchair users to make the most of the day, with fully accessible rest rooms, and a separate room so that people have a private area to change clothes, important with so many water sports going on. For more information, please contact unitedspinaltn@gmail.com.

FROM UNITED SPINAL
with disabilities. Most of those who supported this misguided legislation would not have abridged the rights of women, racial or religious minorities,” says James Weisman, CEO of United Spinal Association. “They were attempting to stop abuse of the ADA by a few unscrupulous attorneys with cooperative clients who shake down businesses by filing a barrier removal ADA suit but take legal fees to dismiss the case without forcing barrier removal. The bill passed by the House will not prevent this practice or even slow it down. It will keep legitimate cases from being filed, however.”

The disability rights organization ADAPT was active in protesting the bill, and even had several members removed from the chamber and arrested during the House vote.

Democrat Sen. Tammy Duckworth of Illinois, who had both legs amputated as a result of a combat injury in Iraq, said in a Twitter thread following the vote: “Being unable to independently enter a movie theater, store, hotel or restaurant is not only humiliating, it limits the freedom to pursue certain jobs, access necessary services and enjoy basic conveniences that most Americans don’t think twice about. I understand that not everyone thinks about these things because for most of my adult life I didn’t either. But the truth is that everyone is just one bad day away from needing accessible options the #ADA requires to help them get around.”

The fight now moves to the Senate, where there is currently no companion bill to HR 620. A number of Democratic senators have vowed to fight passage of any similar bill in their chamber, including Sen. Bob Casey of Pennsylvania.

“Today the House passed HR 620, which guts the Americans with Disabilities Act and strips away the rights of people with disabilities. We will fight to protect those rights in the Senate #DisabilityRightsAreCivilRights #HandsOffMyADA,” tweeted Sen. Casey after the vote.

If no companion bill is passed in the Senate by the end of the year, the House will have to start the process over and re-introduce the legislation. Advocacy organizations are now implored the disability community to make their opposition heard at the ballot box.

“There must be consequences for elected officials who vote to rip away disabled people’s right to access public accommodations,” said Colleen Flanagan, co-founder and executive director for Disability Action for America, and also an ADAPT organizer in Massachusetts. “It’s our time to defeat and unseat elected officials who refuse to promote disability rights and repeatedly commit disability wrongs.”

**Member Benefits**

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

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- Ongoing Educational Webinars

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

United Spinal has over 70 years of experience educating and empowering individuals with SCI/D to achieve and maintain the highest levels of independence, health and personal fulfillment. We have 50+ local chapters and 190+ support groups nationwide, connecting our members to their peers and fostering an expansive grassroots network that enriches lives.
Quite literally following a vivid dream she had one night, Kristina Rhoades and her husband quit their jobs, sold their Georgia home and moved to a little canyon about 20 miles from Truth or Consequences, New Mexico. After a career as a seasoned sales professional, she turned her focus to creating desert retreat experiences for people with disabilities and other groups.

“In this very vivid dream I could see the people there, the landscape, and I knew it was in the Southwest. It felt like I dreamed for a week,” says Rhoades, a T5 para. “So I woke up and wrote down four pages of notes of what I dreamed about and started looking at properties on Zillow.”

This led to what appeared to be the perfect spot in New Mexico, but someone else had already purchased the property.

Rhoades reflects that since the community is perfect, the right venue will arrive. Plus, it’s giving her time to nurture relationships with locals who provide the types of experiences she wishes to offer. “This area is what the healing is about, the people here, and the culture of this community,” she says. “We’ve been identifying practitioners, musicians, healers, acupressurists, energy workers, crystal healing, adaptive yoga … all sorts of people who want to be a part of this and help serve our clients.”

Her next big event is a women’s empowerment retreat planned for October in conjunction with thought leaders from the disability community. “I’m working with all the lodging downtown to find the max number of accessible rooms before we advertise,” says Rhoades. “And I will also have my own retreats based in spirituality and personal empowerment to help support people in creating the life they want by discovering all these techniques.” She is available for life coaching in person, by phone or on Skype. For more information, visit her website: kristinarhoades.com

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“Yoga is not one size fits all,” says Mindy Eisenberg, author of Adaptive Yoga Moves Any Body. “Every body is unique and each individual’s practice is different. However those with movement challenges associated with MS or other neuromuscular conditions require a more creative approach to traditional postures.”

Eisenberg’s mother had progressive multiple sclerosis. After volunteering to teach yoga to an MS support group, she realized how the practice could help others with her mom’s condition. She started a nonprofit called Yoga Moves MS that offers classes in the Detroit area and has $5 videos as well as the book available on her organization’s website.

Like the best how-to yoga books, this one lies flat so the pages stay put. It shows and explains traditional poses, as well as how they can be adapted using chairs, walls or the mat on the floor. Visit yogamovesms.org to learn more.

Those of us who live with fatigue-causing conditions like multiple sclerosis know that sometimes pushing ourselves to be more active can create big problems. This is where tools like Fitbits come in handy. Just as they can be used to challenge ourselves to be more active, they can also be used to figure out how much activity we can safely handle before fatigue or other symptoms are triggered. Using a Fitbit this way is especially useful when we feel fine, and may be unaware of how hard we’ve pushed ourselves until it’s too late and we’re doomed to be an exhausted puddle of incoherence in a day or two’s time.

Try keeping a log or otherwise being aware of how many steps you took on the day or two before your bad day and then set your goal significantly below that amount. When your Fitbit goes off, that’s a sign that it’s now time to slow down and have less physical activity. In a week or so you’ll have a sense of how much you can do before your symptoms are aggravated — that’s your baseline. Once you have a handle on what you can do without triggering symptoms, you’ll have a better idea on how to safely challenge yourself.
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Q. Do you happen to know if it’s legal or OK to supply your own portable hand controls for use when renting cars? I have heard of people saying that’s what they do, but I have tried more than once and was refused the car rental — they said I could not use my own hand controls. I wonder if not letting them know and using them anyway is a good idea. This is an important issue to me because I use a manual wheelchair and can transfer into most types of vehicles without assistance. But I do need hand controls to drive, and I have them installed in my personal vehicle. I am also independent in other aspects of my life, so running into these roadblocks is especially frustrating. I travel across the continent quite frequently as part of my job, and this is just one of many problems I have encountered with rental car agencies when I arrive at my destinations. Even though that may seem like no big deal to some folks, it can completely take away my independence and ability to visit our rural offices or attend important meetings without renting an Uber or similar rideshare, limousine service or some other form of paid transportation.

Lately the list of excuses that rental car companies use to explain away their inability to supply me with an accessible vehicle has gotten even longer, as many new models of cars supposedly will not accommodate standard hand controls. On a couple of occasions the rental car agencies have claimed that, even though they had the hand controls at that office, they had to wait for a vehicle that would work with their hand controls. In the meantime I was stranded at the airport, searching for other alternatives. All of that occurs despite the fact that I always make advance reservations and make it clear what type of vehicle with hand controls I require. Are there any laws covering these failures to provide hand controls? Am I expecting too much? What can I do about it?

— Stuck at another airport

It is probably not a wise idea to install your own hand controls without the knowledge of the rental car company — I can envision a potential problem if you simply rented the car, then had someone drive it around the corner out of sight where you could install hand controls yourself, but got in an accident later. That would probably negate whatever coverage you had from either your private insurance policy or what the car rental company supplies. The rental car agencies have gotten very careful about what they will and won’t do when it comes to renters who have disabilities, especially if they need hand controls. Making an advance request to use your own, installed by their technicians, is always a possibility, but the major car rental chains likely have policies against using anything but the equipment they supply. They might argue that their company could face some type of legal liability if you supplied hand controls that later failed while you were driving, even if they had been installed by the rental car agency.

New Mobility and our parent organization, United Spinal, have heard from several other travelers who use wheelchairs and require hand controls in the vehicles that they rent. They have also faced similar problems with new vehicles that will not accommodate hand controls due to the required knee bolster air bags; there is a shroud where the hand control rods would normally run to the foot pedals.

The type of hand controls that many car rental companies use has two metal rods extending from the hand control mechanism to the gas and brake pedals on the floor of the vehicle, and there is no clear space
remaining for those rods to fit in newer automobiles. There are other types of hand controls that might work, even with that configuration, but they can be more expensive or require more technical knowledge to install than the rental car agency technicians currently receive in their training.

Rental car companies are classified as public accommodations since they sell or rent goods and services to the public. They must comply with Title III of the Americans with Disabilities Act, and in some states there are also similar state civil rights laws that mirror the ADA. Since new vehicles will continue to be equipped with air bag assemblies under the steering wheel, it appears that rental car agencies and others who install hand controls will need to take whatever steps are necessary to make vehicles with hand controls available to the customers who request them. That might include purchasing the type of hand controls that are compatible with those vehicles and training their technicians in the proper installation of them.

As you might imagine, there have been several complaints filed with the Department of Justice regarding rental vehicles and customers with disabilities. The DOJ can take action against subjects of ADA violation complaints, which may include civil action in a federal court, but its primary goal is to eliminate the recurrence of those violations through arbitration or mediation. For information on settlements reached and how they may apply throughout the industry, visit the DOJ’s ADA website. In some cases, settlement agreements have specified that the companies may require advance notice, and longer notice at smaller locations, but they still need to supply a vehicle with hand controls upon request. Situations which might excuse them from that obligation are also listed in the settlements.

If you continue to encounter problems, it is important that you file a DOJ complaint. Without a record of multiple complaints, DOJ cannot assume that these violations are a pattern or practice within the industry. You may also be able to, in those instances where there is an applicable state law, hire an attorney and sue in a state court. State civil rights laws may allow the payment of an award to the plaintiff and attorneys’ fees. You can check that out through the state’s National Disability Rights Network office or a knowledgeable attorney. I hope this helps, and that your next trip has no delays related to hand controls.

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

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José Hernandez may be the happiest driver in New York City. The image of a smiling New York driver may be hard to fathom, but when you hear why Hernandez is so happy, it makes perfect sense.

Behind the Wheel in NYC

To understand Hernandez’s cheery mood, let’s go back to last year — before he had a van — and his return from a visit to Washington, D.C. On the heels of a four-hour train trip, Hernandez rode the subway for another 40 minutes to the stop nearest his house. He got off, ready to be home, only to find the elevator was broken. He sent his aide home with his luggage and rode to the next accessible station — five stops away — and got off, only to find out the elevator was broken there, too. He rode to the next accessible stop, another five stations away, got off, turned around and rode downtown. He eventually got home, but the subway breakdowns added almost three hours onto an already tiring travel day.

For the first 19 years after he was paralyzed, that was the daily reality facing Hernandez any time he wanted to venture out of his Bronx residence. With no accessible vehicle, his only option was New York’s famed subway.

“It’s one of the largest systems in the world and if I was nondisabled, I would love it. You get on in one location and you can get out 20 miles away for $2.75. There’s nowhere else in the U.S. you are able to do that. Unfortunately, if you’re disabled, there’s only a handful of train stops that are accessible, and you have to plan your routes accordingly.”

Hernandez’s planning got easier last year when he purchased an accessible 2016 Dodge Caravan. “It’s the best thing since sliced bread,” he says. “The best part is now I can actually do stuff like drive down to Philadelphia and take my nieces and nephews out for ice cream, whereas I couldn’t do that before. That world was completely shut out to me. Yes, family came to see me, but I didn’t have the freedom to go where I wanted when I wanted.”

Instead of mapping out a complicated plan to attack the inaccessible subway, or relying on others, Hernandez now drives himself all over the city and the Northeast. “I’ve put on close to 8,000 miles since I purchased it,” he says. “I

ADVICE FOR NEWBIES: Don’t get hung up on your disability. Focus on your ability and what you can do, and stop focusing on what you cannot do.

CAN’T LIVE WITHOUT: I hacked my Amazon Echo Dot so I can control my amplifier, bed, and a few other devices using nothing but my voice.
drive to the office a couple days a week, and I run errands. I drive it a lot."

Injured at 15, driving his new van was Hernandez’s first experience behind the wheel outside of driver’s ed. As a C5 quad, he relies on the Scott Driving System. "It’s an older system, but it works so well," he says. "Steering is minimal effort, gas and brake is forward and back, respectively, and all of your secondary controllers, whether it’s shifting, lowering your windows, turning on the radio, changing the stations, they are all on the control panel to my left." Asked if it was stressful learning to drive in one of the country’s most notorious driving cities, Hernandez shrugged it off. "I’m a typical New Yorker, and I don’t know anything else," he says. "I find it fine. You know, there are a lot of people that are idiots, but you need to just be aware. You drive your vehicle and don’t worry about what everyone else is doing. Just make sure that you’re safe, and you don’t hit anyone else and no one else hits you."

ON DATING SOMEONE IN A WHEELCHAIR:
I thought it was gonna be difficult, but she’s been in a wheelchair her entire life, and she thinks differently. She has opened my eyes to a whole new world, and I love her to death for it.

ON SKYDIVING:
You go from zero to terminal velocity in 1.2 seconds. I didn’t expect that speed. The air pressure rushed into my lungs and chest and made it hard to breathe.
When I first started to think about fitness and nutrition 13 years ago, there was frustratingly little information to follow when it came to workout and nutrition advice specific to wheelchair users. I was an early-20s college student with C7-8 complete quadriplegia, twiggy arms and a quad belly, who also fancied himself a wheelchair rugby player. I was self-aware enough to realize that I had neither the relative function nor the natural talent to excel at a high level in rugby with my present (lack of) musculature and fitness, so I set about trying to change that.

Today, I can say that was the best decision I ever made. Learning how to maximize my body’s function was a sometimes painful, often frustrating process, but it took me further than I’d ever dreamed in terms of athletic pursuits. More importantly than that, it improved my day-to-day functionality, allowing me to enjoy my world in a way I hadn’t been able to immediately after my accident.

A few things I learned in my decade-long refining of my body’s capabilities turned out to be backed up by the latest in scientific research on health and fitness. First, when it comes to being in a wheelchair, being as strong as your particular body is capable of is beneficial in a multitude of ways. Second, consistent physical activity is the key to long-term health. And third, at least in terms of body composition, nutrition should only be
High-level Injuries Get Screwed Again, Sort Of

Outside of infection and skin breakdown, the two biggest health concerns for wheelchair users are cardiovascular disease and obesity, which operate hand in hand. Cardiovascular health and weight management are tied to diet and activity level. The two operate together, but even for a trained professional like Elizabeth Broad, a senior sports dietician with the U.S. Olympic Committee, the typical emphasis is often too much on the food side of things. In rehab centers, she says, people are often told they need to keep their weight down, but “I think the natural instinct in most people is to say, ‘Well, don’t eat as much,’ as opposed to, ‘I’ve got to stay as active as I can and maintain as much muscle mass as I can.’ Obviously, there are two related ways of keeping your weight under control, aren’t there? There’s energy uptake and energy expenditure. I think the focus is not so much on activity, and it needs to be more so.”

Broad works on both the Olympic and Paralympic side of things. It was thanks to her that I underwent a round of innovative metabolic testing with USA Wheelchair Rugby in 2015 that measured our individual resting metabolisms, as well as our individual energy expenditure while playing rugby. At that time, I had upped my metabolism to the point where my body would burn 2,000 calories a day without ever getting out of bed. This number is higher than clinical studies would suggest for my injury level, but still below nondisabled averages. But, estimates based on the testing showed that when I was in a heavy training day, I needed some 3,300-3,400 calories just to be energy neutral, and even more if I was trying to put on muscle.

Clinical testing has shown that people with spinal cord injuries have a lower resting metabolism than nondisabled control groups (see sidebar). This is primarily due to people with physical disabilities having fewer active, functioning muscles than the nondisabled. Muscles are our bodies’ engines, and as a group, we have smaller engines that burn less fuel. Logic follows, and research confirms, that the less function you have, the lower your resting metabolic rate. So, as a group, T10 complete paras are going to have a higher resting metabolic rate than C7 complete quads.

But things start to get surprising when you look at total daily energy expenditure. A study evaluated people with varying levels of spinal cord injury and compared them with a nondisabled control group on both active and inactive days. As might be expected, the authors found that on inactive days the nondisabled group burned more energy than the SCI group. Perhaps less expected was the finding that on active days there was no difference in energy expenditure between the two groups.

Broad says the difference on inactive days is “a function of the amount of muscle mass that [the non-disabled group] has.” But on active days, the heart rates of the SCI group were higher than the nondisabled group, a sign that their smaller engines were having to work harder to do a similar amount of activity. This is simply confirmation of what wheelers already know: Doing most anything is just more difficult if you use a wheelchair.

Take vacuuming. It’s hardly a workout, but still, it requires some measure of energy to do. If my wife, Kelly, vacuums the house, she certainly wouldn’t consider that a strenuous physical activity. Her body can accomplish the task without raising her heart rate more than a few beats. But when I vacuum, within five minutes my right deltid is starting to burn and I’m having to take a break and regather myself. Vacuuming the house noticeably raises my heart rate, and it takes at least twice as long to do as it does Kelly. I can think of a hundred other examples: Just last week I found my arms burning while washing some pots and pans. This sucks for a slew of reasons, but in terms of overall health,
No Gym? No Problem.

Strength training doesn’t have to be complicated or expensive. If you have access to a gym, and want to go, great. But if that isn’t a realistic option, you can still get a quality, functional strength workout without ever leaving your house or buying a bunch of dedicated equipment. (See “7 Budget-Friendly Products for a High-Performance Home Gym,” New Mobility, November 2017).

A basic strength routine for a wheelchair user can start with a pair of adjustable wrist weights or even just some Therabands. The Shepherd Center has an easy-to-use app for smart phones called SCI-Ex that shows wheelchair users how to do different types of exercises based on your level of function, from low para to power chair user.

Ed Suhr, a C5 quad since 1984 who uses a manual wheelchair, tries to go for a dedicated push four times a week as well as a strength routine two or three times a week. “It’s hard to vary the workout, it’s mostly arm raises and circles,” he says. “I just use wrist weights, up to 5 pounds. Pretty lame, but it works for me.”

Former USA Wheelchair Rugby strength and conditioning coach Steve Pate, himself a Paralympian, recommends starting with a simple program of four sets of 12 reps for four weeks, and then going to four sets of 10 reps, updating the weight as your body adapts.

Finding whatever works for you is the key. It doesn’t matter if you can transfer onto a bench and press 200 pounds, or if you’re doing weighted arm circles. What’s important is maximizing whatever musculature you do have.

The Tao of Strength

A key factor for keeping your body composition healthy and boosting your metabolism is doing some sort of strength training to build muscle. “Muscle mass is such a functional thing in so many ways that you’re better off having the higher end of your own capacity,” says Broad.

This was undoubtedly the case for me. Before I started playing wheelchair rugby and strength training, not only did vari-
Food as Fuel

At its base, food is fuel for our body's activity, and in respect to metabolism and body composition, that's a good way to view it. Even with our lower resting metabolisms, Broad says wheelchair users often underestimate the amount of nutrition it takes to properly fuel our bodies. "People often think, 'If I eat fewer calories than what I burn, I should lose weight,' but there's a point you go too far, and the body will actually fight it," she says. “That’s where a lot of people get stuck. If they keep trying to drop their energy intake, trying to lose weight, they don’t succeed. And then they think they’re just not working hard enough, or they’re just not trying hard enough, and they get salty with the situation, where all they do is suppress their metabolism and their body becomes very conservative. This happens with people who yo-yo with their weight.”

This is why dieting often doesn’t work in the long term. By significantly reducing your caloric intake, you put yourself at an energy deficit, which initially helps you lose weight. But being in a constant energy deficit stresses your body out, and it tries to protect itself by slowing your metabolism. When you stop dieting and return to normal eating, or even slightly reduced eating, your metabolism is now slower as well and you quickly start putting back on all the weight you just lost, sometimes more.

Increasing your strength and total energy expenditure while improving the quality of the food you’re eating is more sustainable than worrying about reducing calories, volume, or removing things from your diet.

Eating processed foods — full of refined carbohydrates, saturated fats, and the like — it’s easy to consume more calories than your body can process without ever feeling satisfied. If you’re focused on putting quality food into your body, it’s much easier to satisfy your appetite and fuel your energy needs while staying within a healthy calorie range. “For the same volume of food, you can have lower calories by improving the quality of that food,” Broad says. Adding lots of fruits and vegetables to their diets help people feel more full, and “using more whole grain food products makes it more filling, but it also delivers a lot more micro-nutrients.”

Also important is when you eat. In terms of maintaining and promoting muscle mass, as well as appetite regulation, having breakfast is essential. Muscles don’t respond well to long periods of an energy deficit. “You’re already, by being asleep for eight hours or longer, in a long period of energy deficit because your body’s still metabolizing,” says Broad. "It’s still burning energy in that period of time, but you haven’t delivered any fuel to it. If you wait until noon instead of, say, 7:30 a.m. to eat, you’ve then extended that by another four hours.”

If you are never hungry for breakfast, don’t worry — Broad says habits can be changed. Like Pate does for weight lifting, she recommends starting slowly. “If you start eating break-

fast, even small amounts like just a granola bar or a piece of fruit, you can actually create situations where your appetite will shift, and you will start being hungry for breakfast.”

Along with eating breakfast, Broad is a proponent of eating frequently — spreading your food intake more evenly across the day rather than consuming the majority of your calories in one or two big meals, which she says “lends itself nicely to holding muscle mass.”

Being proactive about fueling your body means looking to put good food in, rather than taking large components out of your diet. Skewing your diet away from one type of macronutrient — whether protein, fat, or carbohydrates — makes it difficult to deliver all of the micro-nutrients that are going to keep you healthy over the long term. An easy way to keep things balanced is by dividing your plate into thirds at meal time. One third can be fruits and veggies — the more color the better, one third can be relatively lean proteins such as chicken or fish, and the other carbs such as whole grains or sweet potatoes.

And remember, nobody’s perfect. If you feel the need to eat some really delicious and glutonously unhealthy food every so often, I promise I won’t tell anyone. By keeping your metabolism and energy expenditure up, your body can handle occasional energy excesses a lot better than someone who’s been suppressing their metabolism with a diet. When you go big, instead of feeling bad about it or skipping a subsequent meal, go out for a push, strap the wrist weights on, do some yard work, or get out the dreaded vacuum. If you put too much fuel in your body, rev that little engine up and burn it off.

By focusing on a more global picture of your body that includes strength, daily activity, and sustainable nutrition, you can boost your overall metabolism and mitigate some of the typical health concerns of living with a disability. It’s no “seven-minute abs,” but I’ll take what I can get.
In the six years since Van Brooks founded SAFE Alternative Foundation for Education, a free education-centered nonprofit for kids in the underserved West Baltimore neighborhood where he grew up, he has learned never to take anything for granted. As an example, he shares the story of a trip he led to Loyola Blakefield High School just outside Baltimore. In 2004 Brooks, then a junior, sustained a C5-6 injury playing football for Loyola Blakefield. Over a decade later, he was introducing his alma mater’s picturesque campus to a group of kids from SAFE. One of the kids, seeing the stark contrast between the private school’s state-of-the-art facilities and the two-story public school they attended, told Brooks he wanted to go to college there.

“I told him, ‘You can’t go to college here because it’s a high school and middle school.’ It completely blew his mind. His reaction was, ‘Then I want to go to high school here,’” Brooks says. With the help of Brooks and SAFE, that student, Corey Bowden, went from knowing nothing about private school to being accepted into three private schools.

Bowden calls Brooks his role model. “I can go to him with any problem I have because I know he’ll have the answer I need. He is 100 percent supportive of wherever [I’m going]. I really needed that because I don’t have a father in my life. Him stepping up and doing that for me — I really appreciate it.”

Now a freshman at private Cristo Rey High School, Bowden credits SAFE with changing his life. “SAFE has exposed me to a lot that I didn’t know,” he says. “SAFE provided the exposure that I needed to get through the world. Kids don’t have a lot of exposure to things not in front of them. Van did that for me.”

In the last five years, SAFE has served over 100 students, created numerous programs to serve the community, and it even opened its own youth center. Brooks’ work has not gone unnoticed. He has received numerous awards, including one from President Obama, as well as the adulation of his community.

Brooks humbly plays down his role.
Choosing to Deal

Imagining a world without SAFE might be difficult for Brooks now, but on the fall 2004 night when he injured his neck, a future in community service was not even in his mind. "When it first happened, I was devastated because my dream was to be a NFL player. I was on my way to being a collegiate athlete," he says. "I didn't really have a backup plan."

Still unsure of his next step, Brooks resolved to keep moving forward. "I realized I had two choices. One was to deal with it. One was to not. I chose to deal with it."

With the support of his family and friends, and the stubborn persistence that made him a good football player, he made steady progress in rehab while graduating from Loyola Blakefield on time. Brooks went on to get a degree in communications from Townsend University.

With a few more years under his belt and his education progressing, he finally understood the advice his father had given him all along. "My father used to always tell me, 'Never put all your eggs in one basket.' He wanted me to focus on my education, not entirely on football. He knew I was a good athlete, but he encouraged me to hit the books."

Brooks developed a deeper appreciation of the lengths his parents had gone to in order to ensure he got the best education possible. The youngest of five siblings, Brooks was the only one in his family to attend private school. "They sacrificed a ton to provide for me and my siblings and give us things that they didn't have growing up, which is why I ended up in private school and why they kept me signed up for organized sports," he says.

Still, there was no escaping the police sirens, helicopters and gunshots that were a part of life in his neighborhood. Parts of HBO's documentary about the 2015 death of Freddie Gray and the ensuing riots were actually filmed in his backyard — but thanks in part to his parents, Brooks never lived in fear.

"I was a little sheltered from violence. I was aware of it, but I was always kept active with sports and other extracurricular activities, and I didn't have any free time to explore any of that," says Brooks. "I can't quite say the same for some of my friends. Some of us took different paths."

Instead of bemoaning his new reality, Brooks focused on the advantages his hard work and his parents' sacrifices had given him. "I realized my education could never be taken away, no matter my physical mobility. The things that I was exposed to could never be taken away."

The Great Equalizer

As Brooks contemplated the importance of education and the needs of his community, he got his "marching orders" in a dream. "I woke up from a dream and started a nonprofit," he says. "I had no clue what it was going to do or how I was going to make it work, but I thought there was a purpose. It was God's way of telling me this is what he had planned for my life."

Brooks wanted to do for the kids of his West Baltimore neighborhood what his parents had done for him — broaden their norms and inspire the students to think big through education and exposure. "I had a wide variety of free programs I could take advantage of, but that's not the same for all of these kids," says Brooks. "The organizations I had exposure to have closed up, or now charge. Parents have to weigh whether they pay for food or for an after-school program."

Brooks envisioned SAFE as a way to take that burden off parents, provide a safe place for kids to be kids and give them the educational resources they need to succeed. "They go to public schools and are doing the best they can, but it doesn't add up. I wanted to bring a private school education to after-school. I wanted to bring the programs and resources I had," he says. "I believe the key to success is through an education. I believe the great equalizer is through an education. Once you get a good education, you can compete with the best of people in the world. For the kids who come to SAFE, it's harder to get to that level," he says.

Brooks made his dream a reality by reaching out to similar nonprofit organizations, sharing his vision through social media, making connections through those networks and cold calls, creating a business plan, finding mentors, and sacrificing both sleep and social time.

After six to eight months of his research, outreach and networking, Brooks was able to get SAFE and one after-school program started for sixth to eighth grade middle school students. "The whole mission behind SAFE was to teach kids from my community, which is an undeserved community, the importance of having an education and a backup plan, and learning how to deal with adversity along that path to success. Life is going to happen. It may not be in the form of an injury, but no matter who you are, you are going to go through some sort of adversity. You must stay the course in order to attain the success."
Since its 2012 launch, SAFE has helped several students, like Bowden, get accepted into private schools and has helped improve the lives of many of the students and their families.

“The things these kids see and go through seem normal for them. As an adult who has experienced a lot of things, I know that is not normal,” he says. “We have some single-parent households. For some of the kids that come to us, [the meal we provide] will be the last one they have that night. It may be the last time someone gives them a hug or asks them if they’re OK until they come back to us the next day. That may be the last time they’re allowed to be a kid, knowing as soon as they step in their door, they have to become an adult and take care of their siblings or themselves. That’s normal to them.”

Theodore, a freshman at Cristo Rey Jesuit High School, is one of the many success stories. He attended SAFE for two years and credits Brooks for helping him reach his potential. “Van helped me personally,” says Theodore. “I used to stay outside and go to the basketball court … not do anything dealing with education after school. He told me about the center. I started coming and learning and doing more.”

Theodore appreciates the doors SAFE helped him open. “[Private school] will benefit me in the future and help me be ready to interview or run a business and be professional.”

Brooks’ nonprofit focuses on providing educational opportunities and exposing his students to the world beyond their community. A typical day at the youth center begins at 3 p.m. and lasts until 6 or 7 p.m. During that time, there’s a specific schedule for homework, free time, the program of the day and dinner. The programs take what the kids are learning in school and teach those topics in a hands-on way.

“Kids think they only need to know dollars and cents, a little multiplication here and there — they don’t think fractions are important,” says Brooks. “We teach the kids in a fun way, and why it’s important, with a baking class.”

A lesson on pancakes asks the kids to write down the ingredient measurements and directions and then made their own pancakes. According to Brooks, “They were some of the best-looking pancakes I’ve ever seen, but they tasted absolutely horrible. Someone didn’t do the math right. When we troubleshooted, we found the issue came back to the math and the fractions.”

SAFE also exposes the students to potential careers, showing them there’s plenty out there to choose from and strive to be. “A lot of the kids want to be an entertainer or athlete. We like to focus on sports they may not know about, like fencing. Many of them have never even heard of it before this. And now they’ve tried it. We expose them to something totally different … something that could be another career path,” Brooks says.

In 2017, SAFE’s vocational exposure focused on the medical and construction fields. Hospital visits allowed the kids to see various functions and healthcare pathways. And they got to dig into several construction specialties, too, including concrete, masonry, drywall and flooring.
A Strong Vision

Brooks’ commitment and the impact of SAFE on his community have earned some high-level attention. He received the President’s Volunteer Service Award from President Obama. In October 2017, Maryland Governor Larry Hogan named Brooks the Director of the Governor’s Office of Service and Volunteerism. The Office on Service and Volunteerism oversees $4.2 million in AmeriCorps grants from the Corporation for National and Community Service.

“Brooks’ story is one of perseverance through great personal adversity. His background in youth outreach, as well as his commitment to public service, is a tremendous asset in his work to bring communities together to help others,” says Hogan. “Our administration is fortunate to have someone with Van’s passion and experience leading the Governor’s Office of Service and Volunteerism.”

In celebration of Black History Month, Brooks is using this role to introduce the Black History Month Community Leaders Awards, recognizing Maryland-based, African American-founded organizations that provide volunteer service to improve local communities. Also, he has been working with the Banneker-Douglass Museum — Maryland’s official museum of African American heritage — to encourage Marylanders to visit this free museum and inspire them to continue on the work of their predecessors.

Brooks still oversees SAFE but isn’t as involved in the day-to-day operations as he had been for the last few years. He reflects on the transition and the future of the foundation. “I knew I wanted the foundation to be much bigger than me. To achieve that status, I knew at some point I would have to no longer be a full part of it and to step away.”

The hectic schedule, balancing of roles and living his life on wheels haven’t slowed Brooks down or let him lose sight of what really matters.

“The kids keep me going. This is the purpose of my life. That is enough motivation,” he says. “We’re helping kids that so many people count out. Having these kids get into private schools, bring in straight As, and feel more confident in themselves is one of the most fulfilling things one could ever ask for.”

Fueled by the people he serves, and dedicated to philanthropic efforts, Brooks’ drive and vision carry him through the ups, downs and in-betweens—and ultimately into the future.

“Van’s message is that whatever you want to do, you can do. There’s no one that gets that message and inspiration out there better than he does,” says Steve McAdams, executive director of the Governor’s Office of Community Initiatives. “And his vision is always forward-looking. It’s always about where we need to go and what we need to do.”

With his focus and determination, Brooks has made an impact in his immediate Baltimore community and now in the greater state of Maryland. The results have been life-changing for himself and those he serves.

“My life forced me to grow up very fast. But looking where I’m at now, it was part of the process. I’m part of something that’s larger than myself,” he says.

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When the creators of The Jetsons imagined the automated world of the year 2062, they assumed robot technology would take care of life’s drudgery — shopping, washing dishes, vacuuming. We still hold on to that fantasy, even as we embrace a time in which microcomputers enhance our lives in countless invisible ways. Who wouldn’t want a robot that could change diapers? Admittedly today’s reality is subtler, but it’s no less exciting. Autonomous vehicle technology. Self-compensating drive control. Predictive maintenance apps. A virtual seating coach. All of these things are happening now in wheelchair technology — and they’re transforming our mobility, health and independence in this lifetime.
Two sleek, futuristic wheelchairs drove themselves through Tokyo’s Haneda International Airport this past August, one obediently following the other like a friendly robotic dog. They smoothly navigated a turn, traversed bumpy grates and sedately pulled up alongside a group of reporters who were there to record the future.

Their short journey is a promising sign of where the future of power wheelchair design is headed. Why? Because the first chair autonomously traveled to a woman standing nearby who summoned it using her cellphone, and the second followed independently.

The chairs were part of a demonstration of a new project to shuttle passengers through the airport when Japan hosts the 2020 Olympics. While these specific chairs will likely be of little use for most wheelchair users, the underlying technology — state-of-the-art mapping software and built-in sensors to avoid running into obstacles — could change the way you drive your power wheelchair, or … the way it drives you.

With all the similarities between driverless chairs and driverless cars, it makes sense that the autonomous chairs are made by WHILL, a company founded by former Japanese auto designers. They are not the only auto industry players getting involved in the mobility world. In 2016, Japanese car maker Nissan showcased the ProPilot, a self-driving chair designed for customers to sit on while waiting in line at restaurants. When the first person in line leaves their chair to go inside, the chair goes to the back of the line and the other chairs move forward.

And if you watched even a fraction of the recent Olympics, you probably saw at least five ads for Toyota’s “Start Your Impossible” campaign. Instead of just featuring Toyota’s traditional vehicles, each ad ended with quick shots of disabled athletes and an array of non-traditional mobility devices, including a peek at the long-promised iBot II. That didn’t happen by chance.

“Toyota believes that ‘mobility’ goes well beyond cars and that movement is a human right. This campaign, and our partnership with The Olympic and Paralympic Games, are a reflection of our commitment to providing freedom of movement for all,” said Ed Laukes, group vice president, Toyota Division Marketing, Toyota Motor North America, in an interview with CNET.

This overlap between the auto industry and the mobility industry is not new. It turns out many varieties of self-driving chairs are already being tested, and power chairs have had some of the “smart” features we might more readily associate with autonomous cars for quite a while.

Some of the similarities are obvious, like the integration of hands-free wireless technology, but you may not even know of others you’ve been taking advantage of every time you roll out. The impact is already huge, and will continue to grow, touching every aspect of chairs — from the drive systems, to how they navigate, to maintenance, to actually helping you monitor your health. It won’t happen overnight, and there are real challenges involving funding and regulations, but it is coming.

WHAT’S NEXT
Dubbed the WHILL NEXT, the aforementioned driverless chairs look almost identical to WHILL’s better-known models, the Model A and the Model M. But unlike the A and M, NEXT — which WHILL and co-designer Panasonic refer to as a “mobility robot” — was designed specifically to transport ambulatory people who have difficulty walking long distances.

Airport visitors will be able to summon a WHILL NEXT by tapping on a smartphone app. The chair self-drives to their location, picks them up and delivers them to their destination.
The app will even tell them how long it will take to get to their gate. With the aging population, it is easy to envision a growing market for similar mobility devices at resorts, malls, parks and other expansive destinations.

Ted Fagenson, former vice president of sales and marketing at WHILL, explains the simple economic incentive behind the chairs. “It costs X amount of dollars to pay an employee to push a person from the check-in terminal to the boarding area of the airplane. If you are doing that a thousand times a day, that adds up to a lot of money in labor. It is going to be economical for the airline, and for the user it will be a much better experience,” says Fagenson.

Testing of the NEXT at Haneda is expected to have been completed by March 2018.

While cool, the NEXT technology isn’t quite what full-time chair users need. “We would love an autonomous power chair that could navigate any sidewalk, and/or chairs that can perform obstacle avoidance for people using sip-and-puff or head array controls, but the technology isn’t there yet,” says Mark Smith, general manager of public relations for Pride Mobility/Quantum Rehab. "Obstacle avoidance and autonomous technology is moving into the power chair market for indoor use in the coming years because it’s easy for sensors to avoid vertical objects on a flat indoor surface, but outdoors is another story. Current technology can’t tell a puddle from a dark patch from a pot hole. And current sensors aren’t capable of distinguishing between curb angles, or if a curb is shaded by a tree.”

For now, the closest manifestation of this technology lies in the WHILL Model A’s iPhone app, which allows users to summon and drive their Model A. Imagine being able to easily move your chair away from a sofa or bed after transferring or being able to call it to you in a crowded room.

Emily Oakley, of Campbell, California, takes full advantage of the app whenever she is out with her WHILL. Oakley, 44, is able to walk, but has multiple sclerosis and uses the Model A to do what her body won’t always let her. The Model A is called a personal electric vehicle rather than a power wheelchair because it has not been submitted to the FDA for review and is typically not covered under insurance.

“I’ve always been very active and having four-wheel drive on the Model A enables me to go hiking again,” she says. The app comes in handy when she and her husband, Ken, are out and about. Oakley prefers to transfer into a regular seat at restaurants. She can then use the remote to drive the chair out of the way, usually into a corner. And when she transfers into the front seat of their van, she uses the remote to drive the Model A around the back of the van and onto the rear lift.

STICKING TO THE STRAIGHT AND NARROW
The idea of software that keeps your wheelchair going in a straight line may not be quite as sexy as the possibility of ghost-driving your chair via remote, but for many users, such software is invaluable. Self-compensating drive control is one of the earliest smartchair systems, and it is so seamlessly integrated that most wheelers aren’t even aware it is on their chair.

It’s basically the wheelchair equivalent of the lane centering technology that is being rolled out on many high-end automobiles. Just like lane centering technology keeps your car in the lane, self-compensating drive control autonomously corrects a chair’s direction, keeping it going where controller input intended by compensating for uneven or bumpy surfaces. This makes driving with a joystick easier because you don’t have to make constant corrections while cruising down a sidewalk, path or off-camber surface.

Self-compensating drive makes a huge difference for those who use a switch control, like sip-and-puff or a head switch, to drive. Before self-compensating systems existed, a driver using switch input would have to make continuous adjustments to keep a chair going straight. Wheeling on sidewalks and streets required so much input to control the chair that it was difficult to carry on a conversation or enjoy the scenery. Self-compensating drive enables a switch driver to give an input and the
Enjoy driving with both hands on the wheel

Enjoy driving with both hands on the wheel

Chair stays in the intended direction until another input is given, which enables the driver to relax, talk and enjoy their surroundings.

Kenny Salvini, a C3-4 quad and frequent New Mobility contributor, drives an Invacare TDX SP using an ASL head array switch input control. He taps his head on a switch to his right or left to turn, while a switch at the back of his head controls forward, speed, stop and reverse inputs. He is a believer in G-TRAC, Invacare’s self-compensating drive system. “For a brief time, I didn’t have G-TRAC, and wow, it really gave me an appreciation for it. The road I wheel on in front of my house has a mild arc for water drainage and I had to constantly re-hit the switch input to course correct. It was fairly maddening to say the least and really gave me an appreciation of how important self-compensating drive control is.”

All the major power chair manufacturers now offer some sort of self-compensating drive control. Invacare has G-TRAC, Quickie has SureTrac, Quantum Rehab has Accu-Trac and Permobil has the boldly named Enhanced Steering Performance. Iterations of self-compensating drive control have been around since 2001, but manufacturers are continually working to improve it, resulting in new additions like Invacare’s Adaptive Load Compensation. It provides autonomous adjustments for consistent low speed driving on different surfaces from concrete, to padded carpet to grass. In addition, ALC adjusts motors as they wear so the ride stays consistent. For the wheelchair user, this means that ALC keeps the chair at a steady speed over changing surface textures, in addition to staying on the intended course.

**FIX PROBLEMS BEFORE THEY START**

You can’t keep on course if your chair isn’t working. Thankfully, a new wave of predictive maintenance apps is aiming to make it easier to keep your wheels on the road and not in the shop. Car drivers have grown so used to oil check warnings, tire pressure lights and other built-in warning systems that they take them for granted. But put similar systems on a power wheelchair and they could make the difference between getting out of the house and waiting weeks to months for someone to service what is often a minor problem.

Predictive maintenance apps continuously monitor the systems in your power
They allow you to see the basics, like battery status, driving habits and distance traveled, while also enabling real-time troubleshooting of error codes on your smartphone and sending complex information about systems on your chair to your dealer. This can make it easier to solve minor problems, like a joystick that suddenly isn’t working because a wheel-lock or attendant control is engaged.

A quick look at the predictive maintenance app on your phone will either show the problem or bring up a phone link to your dealer, who can look at your chair on their computer screen and diagnose the problem live. This would save the user down time and the dealer a service call. Sharing detailed information about your chair’s status with the dealer also allows you both to see if maintenance is coming up and plan for it well before parts fail.

Research done at Human Engineering Research Laboratories at University of Pittsburgh shows that waiting for parts can leave a power chair user without access to their chair for an average of three months.

“With predictive maintenance, a dealer’s computer and the wheelchair user’s smart phone will say, ‘based on wear patterns you’re going to need a new battery or certain part within so many months, now is a good time to set up an appointment to have the part changed,’ and the dealer has time to order the part and you have a fast turnaround,” says Rory Cooper, founder and director of HERL [see “Rory Cooper: The Man Behind the Technology, May 2017].

“For the consumer, it means they won’t be stuck with a broken chair sitting in the shop waiting for parts.”

Cooper, a wheelchair user himself, helped oversee development of Permobil’s predictive maintenance app at HERL, and thinks it can help reduce the frustrating waits for service that many power wheelchair users deal with. “It benefits the user and the wheelchair dealer,” he says. “The dealer monitors the chair and can order parts in advance, before they wear to the point of failure. This means fewer trips for the technician, one trip to swap out the battery or replace a part, rather than one trip to troubleshoot and another to fix the chair.”

Permobil launched its predictive maintenance technology, Permobil Connect, in December 2017 and it now comes standard on all Corpus model chairs. The system has a Connect module that uploads chair information to the web via an AT&T Global SIM card. Dealers access the information via a portal, with chairs needing attention showing at the top of the list. Permobil users can log into the My Permobil app on their smartphone to view graphs that show battery charge status, seat function usage summaries, mileage, and any error codes, which also send an automatic alert to their dealer.

If a Permobil user’s app does show an error code, or they have a chair issue, they can call their dealer and the technician can log into the portal and troubleshoot the problem. “The goal is to reduce the amount of service calls that are simply done to diagnose a problem,” says Brandon Edmondson, director of clinical sales at Permobil.

“Although the system can’t see things like when your armrest pad needs to be replaced, we can mine the data, tracking parts, order history and chair usage and in time, know on average how often our users are changing their arm pads or other mechanical parts and be able to make suggestions to consumer and dealers. The data from all the chairs can be aggregated to help us predict problems, see trends, update electronics remotely and ultimately design a better chair that is in tune with how our clients actually use them.”

As a self-professed technology geek, Todd Stabelfeldt is already enjoying the benefits of the My Permobil app after less than a month of using it with his Permobil F5 Corpus. “I forgot to plug in my battery one night. I logged into my Connect app later that morning and saw I didn’t charge the battery last night,” says Stabelfeldt, 39, in his 31st year as a C4 quad. [See “Todd Stabelfeldt: Titan of Tech,” October 2017.]

Invacare also launched its own predictive maintenance app last year. Called MyLiNX, it’s available on the TDX SP2 power chair. MyLiNX sends information about the chair through the web to the cloud, allowing dealers to monitor systems on chairs they have sold through a dashboard program on their computer.
In addition to monitoring systems and electronics, the dashboard tracks driving and battery charging habits and flags technicians to potential issues. Invacare customers can use the MyLiNX app to view graphs showing battery information including charge, usage, and drive time remaining as well as any fault codes, which automatically send an alert to their dealer.

“This data can give more insight into their chair and empower them to spot issues before they become a larger problem,” says Brad Peterson, vice president of professional affairs and clinical education for Invacare. “The whole key is to reduce the number of tech visits, and when they do occur, make them more efficient with the goal of more time with the technology and less time in the shop.”

AUTOMATED BUTT PROTECTION
Every wheeler wants their chair to spend less time in the shop, but what if your chair could actually keep you out of the hospital? A new app from Permobil promises to help do just that by

Bluetooth Technology: Not New But So Powerful
Bluetooth technology has been connecting people wirelessly with their beloved gadgets since the 1990s and was first introduced on power chairs in 2005 by Quantum Rehab. “Our philosophy has been that that complex rehab power chairs should interface with the user’s environment,” says Mark Smith, general manager of public relations for Pride Mobility/Quantum Rehab.

For users like Tim Gaynord, 35, an accountant from Scranton, Pennsylvania, Bluetooth is a game changer. “Q-Logic controls give me independence and control over my environment,” he says. “I have SMA 2, a form of muscular dystrophy, and have very little arm and hand mobility and have my joystick mounted on my lap tray.” Gaynord lives in an apartment in his parent’s house. Before Q-Logic, he would frequently have to call them to help with various controllers. “With Q-Logic I’m able to control the television, computer and mouse, iphone and even the fireplace. A screen shows the mode I’m in and part of the system includes micro buttons to switch from various modes, seat control, computer, television, etc.”

Quantum’s newest Bluetooth software, standard on the Q-Logic controls, can control up to 16 devices ranging from televisions, computers, and phones to lights, fans and door locks through the power chair’s drive control. Permobil, Invacare and Sunrise-Quickie all now have Bluetooth offerings as well.
providing management and motivation for your pressure releases. Permobil’s Virtual Seating Coach is a weight shift coach built into the Permobil Connect module and available on the Corpus line of power chairs. Ideally, a user with VSC will work with a therapist to program a custom seating regimen for their needs that includes optimal tilt angles, recline and leg rest height, as well as frequency and duration of weight shift. VSC users also have the option of choosing one of 10 pre-programmed weight shift schedules.

Stabelfeldt hasn’t had his virtual coach for too long, but he is loving the immediate impact it has had.

“I’ve had a lot of skin problems and multiple skin flaps,” says Stabelfeldt. “I’ve been hoping for something like VSC for a long time … it has already been a huge blessing. I’m setting up an appointment with a therapist to design a custom program.”

For now, he has his VSC set on one of the pre-programmed settings — tilt and recline for three minutes every hour — which are called exercises. “When the app on my phone gives me a notification, I hit Memory 3 on my Permobil, which takes me to the exact amount of tilt and recline I’m supposed to have. I call it ‘super-chill mode.’ At that point, a timer and a green light starts, and after three minutes my phone says ‘Good Job!’ which is like an ‘atta boy’ that you get on
a Fitbit. I really like the reward because it makes me feel normal — it’s the first time I’ve been able to receive the ‘congratulations’ from a smart device, and I like getting my ‘Good Job!’ stars.”

The value of positive reinforcement should not be underestimated. Keeping track of weight shifts has been shown to keep users motivated to shift or stand on schedule.

“In our studies with Virtual Seating Coach at HERL, we saw a four-fold increase in compliance in weight shifts,” says Cooper, whose HERL team helped design the program. “We estimate that this will drastically reduce the number of people who develop pressure ulcers, which could add up to a savings of $1 billion a year in hospital costs in the U.S.”

VSC can also be used to coach standing programs on Permobil standing chairs. Once programmed, the app alerts the user when “It’s time to reposition your chair” or “Time to stand.” At that point, the user starts moving the seat and a graph appears showing seating angles.

When the proper angles have been reached, a countdown clock appears and starts. When the weight shift or stand is finished, the app shows “Good Job!” The VSC app can also share info to the wheelchair user’s therapist so they can see how their client is doing and make adjustments online as needed. An anticipated bonus of VSC is that it will generate information that clinicians and researchers can use to improve optimal weight shift angles and times, and/or standing times.

ON THE HORIZON
Looking toward the future, it’s a good bet the parallels between cars and power chairs will continue to grow. Whether this means that the long-promised arrival of flying cars also brings flying wheelchairs, or perhaps something cooler, remains to be seen. The folks at HERL are already looking beyond self-driving chairs and obstacle avoidance. “Rather than avoiding obstacles like curbs and grass, we are working on a chair that says, ‘You are driving up to a curb, do you want to climb it? Yes? OK,’” says Cooper. “Our idea is to build a cool chair that not only recognizes different types of surfaces and obstacles, it enables you to travel over them.”

RESOURCES
• Invacare LiNX, rehab.invacare.com/rehab-redefined-home
• Permobil, permobilus.com/products/power-wheelchairs-by-permobil
• Quantum Rehab, quantumrehab.com
• Sunrise Medical, sunrisemedical.com
• WHILL, whill.us
My need for a wheelchair came on slowly over the course of 10 years, due to the progression of multiple sclerosis. Over the past 15 years, I have used a cane, a walker, a scooter, and finally, about seven years ago, my insurance covered my first power wheelchair. Now I’m on my third insurance-covered power wheelchair as the more disabled I become, the more advanced my wheelchair needs to be.

As I waited out a year-long exchange between my healthcare advocates and my insurance, I envisioned the chair would be everything “state-of-the-art” implied — light, slick and sleek. Certainly not a 400-pound, clunky, industrial machine. What I received was my most advanced wheelchair yet — offering more power, a head array, parts that adjust with more precision, longer battery life — everything I need to live a full and happy life.

Sort of.

Despite the new technology and functions, the “cosmetic” design leaves much room for improvement. The term “cosmetic” makes me feel like I am being vain. Like it’s the cherry on top, the last minute add on by engineers who have labored over the more complex, more essential parts of the wheelchair. But as an artist sensitive to design and visual impact, the external parts of my wheelchair inform how I am perceived, how I take up space … so this piece is essential. It’s not an afterthought for me, rather it is the very first thing I feel every time I interact with another person. I want my chair to be elegant and innovative — a conversation starter instead of an intimidating machine.

Yet my chair is intimidating — it is a complex medical device. People seem to be simultaneously wary that it is destructive (afraid to drive it) as well as nervous that it is fragile (afraid to touch it or me). My chair is a fortress, impenetrable and unwelcoming. This impacts my daily life, and the burden of overcompensating is draining. Trying to be friendlier, more welcoming, more outgoing, is exhausting. I dream of a power wheelchair that works well and invites intrigue, conversation, and fascination. A chair that allows me to be seen as a complex, interesting professional, a member of the community.

While designers in far off incubators are rising to the task, insurance companies are dragging their feet. Nevertheless, startups are moving forward without the guarantee that their designs will be accepted by the insurance industry, which is critical for the majority of us who rely on insurance. The new generation of chairs may far surpass my state-of-the-art behemoth, but many of them are financially out of reach.

My assistant and I recently wrote an article about self-driving technology (see Resources), wheelchairs, and how people like me might benefit from the combination. We realized that the wheelchair market is waiting to explode — what with a current base of 6 million wheelchair users in the U.S. alone, and the global aging population, as well as an increase in illness and disability. More people will be in need of wheelchairs, and rapid advances in technology can meet these needs better than ever before. The technology to create user-friendly power wheelchairs is already in existence.

Discovering this got me interested not only in the tech side of wheelchair design, but also the exterior elements — the cultural, societal implications of design choices or lack thereof. With a little digging, I discovered beautiful wheelchairs designed by Scewo and WHILL. I was delighted. I wanted one. But as I dug deeper, I discovered every person depending on a wheelchair for mobility has a diagnosis, has medical needs, has a story. In turn, every chair has a story, with pros, cons and most importantly, insurance issues.

Scewo, an innovative, stair-climbing chair initially prototyped in 2014, is still in the incubator phase, without a price tag — but a utopian video they posted gives me hope of technological advances in the future. Yet without cooperation from the insurance industry, who can use this?

I was excited to learn that WHILL has three wheelchairs on the market that are user-friendly, beautifully designed and innovative. They are Bluetooth integrated for instant tech support, able to ride on rough surfaces, compact and, in some cases, collapsible and portable. Unfortunately, only one model — the Model M — has been FDA approved. WHILL is very upfront about the difficulties and obstacles to getting insurance coverage. As representative Jeff Yoshioka commented, even though private insurances such as Blue Cross Blue Shield have covered as much as 60 percent of the Model M, “in our opinion, it is always worth trying to obtain Medicare reimbursement. Although WHILL customers have had success receiving reimbursement through private insurance, a high level of persistence will be required … be prepared to insist on additional funds; it will require your unwavering effort.”

When we asked why the other two models were not submitted to the FDA for approval yet, Yoshioka stated there is
a reluctance of insurance companies to authorize the devices.

As someone who came to rely on a wheelchair later in life, I had the benefit of interviewing Mark Smith of Pride Mobility/Quantum Rehab for this article. As a lifelong wheelchair user who has chronicled the industry for New Mobility and on his personal website, powerchairdiaries.com, Smith’s perspective is completely different from mine. From his viewpoint, the industry has evolved over the past several decades from a mere medical model to one that is more focused on the needs and desires of its customers, of which the most important is enhanced independence. In regards to wheelchair design, Smith admitted that “there’s still a long way to go with the further evolution of power chairs for those with disabilities.”

Wheelchair design has been a historically neglected afterthought, but the current generation of designers are more disability conscious than their predecessors, and more innovative design has just recently begun to gain traction.

If we could take the design process a step further and convince insurance companies to recognize the critical importance of the exterior parts of the chair, then the very same engineers who designed my fortress could transform it into a user-friendly and approachable device, and could vastly improve the health of those of us who depend on wheelchairs.

While we should celebrate the strides made in the industry, we should not overlook design flaws in current, insurance-approved wheelchairs. Combining form and function is not a perk or a luxury, but rather a medically necessary strategy that is crucial to our mental health. Well-designed wheelchairs transform lives and redefine society’s perception of illness and disability. If insurance companies can get on the bandwagon, it will help enable people with disabilities to live fuller lives.

**RESOURCES**

- WHILL, whill.us
- Scewo, scewo.ch
- Scewo video, youtube.com/watch?v=CzsBByh9c7w

The author loves the look of WHILL mobility devices. “Well-designed wheelchairs transform lives and redefine society’s perception of illness and disability.”

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If you are a person with a disability, you know all too well that “stuff happens” that can wreck your schedule. Your bowel routine runs long, your transportation is delayed, you spill coffee on your lap and need to change clothes, your caregiver doesn’t show … the list could go on, and the daily adventures seem endless. All these little adventures can make the prospect of holding down a full-time job seem out of reach. The traditional idea of working 9-to-5 in an office doesn’t offer the flexibility that our lives so often demand. But, what if you could have a job you liked, get paid well and work around your schedule? Thanks to advances in technology, more and more jobs like this are opening up, making the prospect of getting and keeping a fulfilling career more real than ever for people with disabilities.
HOME ALONE …
AND LOVING IT
As telecommuting has grown easier with faster internet speeds, better software and cheaper hardware, some smart companies have moved to allow employees or whole departments to work remotely from home — or a beach that has Wi-Fi. These companies offer at-home support to employees, opportunity to advance and benefits.

If coordinating transportation to work or caregiver schedules is an issue, working from home could be the solution you’ve been looking for. It has been just that for Adam Cale, a C5 quad. Cale lives in a small town in Illinois where disability-friendly jobs are few and far between, but he has worked from home for many years, first for Direct TV, and currently with Apple.

His success shows you don’t have to have a degree in computer science to be able to find a flexible tech job. Before starting at Apple, Cale, whose degree is in graphic arts, went through six weeks of online training in a virtual classroom with other trainees. After only two weeks of mentoring, he was ready to work independently in the company’s tech support department. “It wasn’t until the last week of my training that the instructor realized I had a disability, because I mentioned it,” he says. “I was interviewed and hired remotely.”

Cale now works eight-hour shifts and relies on personal care attendants for much of the day. Working from home has made managing his attendants much easier and increased his independence. “If I worked at an office, it could be really awkward having my PCA just hanging out there,” he says. “They’d get bored too. At home, they can go to the other room and work on other tasks or watch TV in the living room.”

Working from home, no extensive accommodations are needed because Cale already has things just how he needs them. “I didn’t really get any special accommodations,” he says. “I do get extended break time. I use my typing stick with a regular keyboard, and I asked for a touchpad mouse, but everyone does. The company provides all sorts of ergonomic equipment for their employees who work from home if they request it. So my request wasn’t a ‘special’ accommodation.”

Working from the comforts of home has been invaluable for Cale. “I’m an introvert and like being alone. I often have music playing or Netflix in the background. And when I crave human interaction, I can video chat with my other teammates who work at home too.”

BEAM ME UP
But what if plain-old telecommuting won’t cut it? What if you need — or want — more than just a video or audio connection? What if you need more of a physical presence, but you can’t commute or travel where you need to be? The BEAM from Suitable Technologies is a new option that virtually allows you to be in two places at once. Imagine a video tablet mounted on a 4-foot-tall pedestal on wheels, and you’re pretty close to visualizing the BEAM. BEAM displays your face on the screen and transmits your voice to wherever it is, while record-

LEVELING THE PLAYING FIELD
As principal development lead for Microsoft Research, Jay Beavers approaches BEAM and telecommuting from a different perspective: that of the employer. Still, like Krishnaswamy and Cale, he sees limitless potential. He has been thrilled with the results of using BEAM. He is able to manage the team remotely and team members are able to attend conferences and collaborate on projects. “BEAMs have increased the diversity of our team and we have had access to many people with disabilities,” he says. “It puts everyone on an equal level. I worked with one team member for four to five months before realizing he had a disability. All I saw was the brilliant person he is.”
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Andre Johnson pitches his business idea at Campus 1871.

Spinal Association’s board of directors, is one of those people. He’s a vocal leader when it comes to getting people with disabilities into tech jobs and building the infrastructure to support them.

“There is a lot of demand in tech jobs, but on the supply side we need to strengthen the pool of candidates with disabilities. They need to be equipped for the professional setting so they can be competitive in the field,” says Maher, a T7 paraplegic himself.

He has been a part of boards and task forces where he has had the opportunity to develop multiple programs related to a disability-centric mission and currently serves as the director of civic engagement for SPR Consulting, a leading provider of information technology, staffing, and consulting services for Fortune 1000 and mid-market companies. He suggests creating “an atmosphere for candidates where they have a network in the tech industry. Go to hacks, participate in civic efforts, go online, and get educated.”

Andre Johnson’s journey into the tech world followed this exact route. It started when Johnson, a T6-7 paraplegic, dropped his water bottle and decided he needed a cup holder on his new wheelchair. He thought finding the right cup holder would be an easy task but quickly discovered it to be harder than he had anticipated. His struggle became the spark to his business idea.

Johnson had graduated with an electronic engineering degree and anticipated the 9-to-5 job, but his journey went in a different direction. “I hadn't fully grasped the fact that a lot of engineering jobs in Chicagoland are in the north and west suburbs, and how was I going to make that work?” With doctor appointments and physical therapy, he was unsure how he would manage a traditional work schedule, transportation, a commute to the suburbs, and his health.

As he approached graduation, he was invited to Campus 1871, an intense weekend competition where students team up to simulate launching a startup business. The annual event is sponsored by 1871, a Chicago-based tech incubator, and provides students with extensive coaching and mentoring. The weekend concludes with a pitch competition in front of a panel of top leaders in Chicago’s tech community.

“It was a unique opportunity to network with other technology students from other schools,” says Johnson. “Once there I saw the premise of the event was to become more than a worker in tech, but be an entrepreneur and innovator.” At the end of the weekend, Johnson pitched his business idea. He placed third in the competition and won a scholarship and membership to 1871. “This wasn’t my planned route, but it has helped vastly in my personal life and has positioned me to connect with so many people in technology.”

Two years later, Johnson is a young entrepreneur and the brains behind LiveEquipd, an online platform that he hopes will empower people with paralysis and related disabilities to find the medical equipment, supplies and resources they need, while providing health professionals with a unique channel to better equip those they serve.

Johnson’s story is exactly what Maher is advocating for and working toward. To help others find similar success, Maher started the IT Knowledge and Abilities Network. “I launched ITKAN with a few colleagues and the support of the Illinois Technology Association,” he says. “They hosted our meetings for first couple of years to target getting people with disabilities into the tech industry. I wanted people with disabilities to know where the bar was to be a professional in tech, and to drive their passion.”

Programs like ITKAN and Campus 1871 can provide the push that gets deserving job candidates with disabilities over the hill and into the jobs they seek. Through his network at the tech incubator, Johnson is able to gain access to financial and strategic planning for his business and connect with a diverse group of people in technology, like designers and programmers, that continue to help him build his company. “Their mentor resource is large and covers all the needed areas of entrepreneurship,” he says. “Being at 1871 is an opportunity to network and collaborate with the best in Chicago tech, but you also don’t have to be there every day. It pro-vides great flexibility.”

That flexibility has made all the difference for Johnson and could make the difference for other job seekers trying to balance the time constraints and logistical hassles that come with disability.

“Being an entrepreneur allows for me to become successful and still address my health currently,” says Johnson. “I’ve had therapy and several physicians’ appointments during a good portion of this journey. I’m better health-wise now so I can put focus on this venture. Now I can pursue others means of income to help in life and pursuit of my business.”
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With spring arriving in most of the northern hemisphere, people are putting away their winter gear and looking forward to getting outdoors and traveling to areas that might have been covered in snow a short time before. Many people also shop for new vehicles or make improvements to those they own at this time of year, but shopping for an accessible vehicle has changed over the last few years. Mergers and consolidations seem to be the trend when it comes to mobility equipment. Many of the companies that sold or modified vehicles in the past have given up their independent status and now share a corporate name and identity with their peers across the country.

Unfortunately, some smaller independent companies have also gone out of business, forcing some consumers to travel farther in order to find a selection of models that they may have been able to find locally in the past. Additionally, some popular models — like the full-sized Ford Econoline vans that were approved for drop-floor conversions, and the Honda Element, with doors that worked great for anyone who wanted to transfer into the driver’s seat and then load a wheelchair behind that seat — have been discontinued.

Despite that, the National Mobility Equipment Dealers Association points out it has more than 600 members in the United States and Canada, and that manufacturers continue to improve the safety and convenience of accessible vehicles and accessories that have been around for years. In 2018, they are also introducing accessibility in some new vehicles that have not previously been modified.

Larger lift-equipped vans now available include the Dodge Promaster and the Mercedes-Benz Sprinter. Several modification companies are advertising their efforts to create more interior room in minivans, which are slightly smaller but will accommodate power wheelchairs. There are also several vehicles on the market that are described as “caregiver” vehicles because they are accessed by manual ramps or may not accommodate drivers who want to remain seated in a wheelchair to drive.

BraunAbility recently introduced two new vehicles: the Toyota XL van and the MXV Ford Explorer SUV with “Tilt N’Go” seating. The Tilt N’Go feature allows either front seat to be tilted forward, which expands the maneuvering space needed for positioning a power wheelchair or other mobility device in any location in the vehicle. The Toyota XL extends the van’s length by 6 inches to provide more wheelchair maneuvering space and room for additional passengers in the rear seat. BraunAbility is also offering a Chrysler Pacifica van, pointing out that it has features and interior space that will accommodate larger wheelchairs; unlike some other caregiver vehicles, it also has a power ramp available.

Vantage Mobility International launched a new accessible Honda Pilot SUV this spring. The VMI Honda Pilot Northstar E has a manual in-floor ramp, removable front passenger seat and ample storage space according to the manufacturer.

Other Options

Those seeking a smaller vehicle have some options in the resale market as well. Freedom Motors is advertising the availability of a Fiat 500L “Wheelchair Accessible Car” equipped with a rear ramp. Despite the small size, the 30-inch-wide ramp and 53 inches of headroom should accommodate a variety of mobility devices and their passengers. Freedom Motors also sells a Kia Soul and Kia Sorrento that are equipped with rear ramps.

There are still lift-equipped pickup trucks and a variety of SUVs available for those who are looking for a ride with more ground clearance or hauling capacity. All
Terrain Conversions continues to focus on accommodating larger wheelchairs than previously possible with their unique lift design. A larger lift pan allows the vehicle to handle heavier equipment, and serves as the means for securing the wheelchair while driving.

The front of the ATC lift swings farther away from the vehicle when extended to the ground, which prevents the wheelchair from rubbing against the vehicle or tires while entering or leaving the lift. The unique gull-wing door also provides protection from the weather while loading or unloading, and has been modified to close by the force of gravity to remove the threat of crushing as the door closes.

ATC advertises that it modifies full-size trucks and SUVs as well as midsize vehicles such as the Traverse, Acadia and Enclave. The company will also modify a customer’s used vehicle, equipping it with modifications that allow the company to offer a three-year, 36,000 mile warranty. AMS Vans also modifies customer’s vans. If someone owns a vehicle that they love, but needs it to be accessible, AMS offers a means to improve it without the cost of a new vehicle.

The availability of so many different types of vehicles and features can be confusing, so take advantage of professionals in the mobility equipment industry who are qualified to evaluate customers’ needs and recommend solutions that work best.

**Trends to Watch**

Accessible vehicles are part of the move to put more environmentally-friendly vehicles on our highways: Revability is now manufacturing the first hybrid-electric Chrysler Pacifica wheelchair van, equipped with a rear ramp and four-wheel drive.

Another healthy trend that has had an impact on at least one company is the need for transit agencies and taxi fleet operators to improve the number of accessible vehicles available to their customers. Sales of the Mobility Ventures MV-1 increased 35 percent in 2016; these vehicles have been purchased in bulk by New York City and Chicago paratransit providers, as well as taxi or rideshare companies in those cities and others that want to avoid violations of the Americans with Disabilities Act or related state laws. Unfortunately, the company has been sold and the MV-1 is not being manufactured at this time.

People who drive sedans with hand controls but transfer onto the original manufacturer’s driver’s seat to do so are also encountering problems because of a requirement that all new vehicles be outfitted with knee bolster air bags located beneath the steering wheel in front of the knees; that knee bag positioning blocks much of the space required for routing of the rods that are part of several types of manual hand controls. This feature has limited the selection of vehicles for hand control users and will likely have a negative impact on the availability of rental vehicles that will accommodate the installation of hand controls for customers who request them (see Everyday Advocacy, page 12). Look for the next Motovation column to cover hand controls and other vehicle “peripherals” in greater detail.

**Resources**

- All Terrain Conversions, atconversions.com
- AMS Vans, amsvans.com/wheelchair-van-conversions
- BraunAbility, braunability.com
- Freedom Motors USA, freedommotors.com
- Mobility Ventures MV-1, mv-1.us
- NMEDA, nmeda.com
- Revability, revability.com
- Vantage Mobility International, vantagemobility.com

**VMI**'s Honda Pilot SUV offers 360 degrees of maneuverability.

BraunAbility’s MXV Ford Explorer has “Tilt N’Go” seating.
In December, I received a forwarded email that originated in Thailand and was first sent to a young Californian with quadriplegia. He was so excited that he forwarded it to everyone he could think of, and eventually it found its way to me. Here’s how it began:

I am very pleased to inform you that you have been accepted for Unique Access’ innovative Spinal Cord Injury Epidural Stimulation and stem cell treatment protocol.

A couple of weeks later, I heard this in a private conversation with Kathy Allen, a T8 complete para from Minnesota:

I have the [epidural stimulator] device ... while the feet/toe movement is not all that fantastic, my core area is unreal. I can get dressed, shower, wheel up and down ramps like I am not paralyzed at all. When I ride in the van, my core and legs are very happy. My balance is so good. I sit straight in the chair.

There’s a lot going on in the world of epidural stimulation. Like many of you, I’ve been watching the ES news since Rob Summers’ groundbreaking successful implant first appeared online: May 19, 2011. At long last, a genuine breakthrough! A man with a chronic, motor-complete spinal cord injury had been able to move his feet by willing them to move.

In 2015, I wrote dozens of pages in Don’t Call it a Miracle about what ES is and isn’t. In brief, the stimulator is really four things:

• A small, flat array of electrodes.
• A pulse generator, a gizmo about half the size of a deck of cards.
• A wire that snakes the short distance through the body between the electrode array and the pulse generator.
• A hand-held remote control.

The electrode array is surgically implanted into the epidural space — the super-narrow gap between the dura, a membrane that protects the fragile cord and the bones of the spine. The pulse generator is sewn into the fleshy pad under the skin of the hip. The hand-held remote for the stimulator is how you give the pulse generator instructions on how much juice to pump out through the electrode array.

The ES delivers a tiny stream of electrons to the general region of the lumbar cord, where networks of healthy intact neurons seem to be just waiting for a little boost. The implantation is an outpatient procedure that takes less than 45 minutes. Three models of epidural stimulators are on the market in the United States, all FDA-approved and covered by Medicaid, Medicare, and private insurers as indicated for pain (not as a therapy or intervention for spinal cord injury). Since the 2011 success, we have two parallel storylines about ES, each of which is suggested by the quotes above.

The first story is about the research effort underway to better understand how ES works in people with SCI and do the work needed to get it on the market. The second is about a group overseas that is offering to implant the device right now, for a price. Kathy Allen is part of the research effort, while the Californian is hoping to take advantage of the immediate opportunity in Thailand.

Domestic Research

As of today, dozens of motor-complete volunteers at half a dozen labs have been implanted with these stimulators, and every one of them has reported some sort of measurable improvement with zero adverse side effects. You can find the current efforts by going to clinicaltrials.gov and typing “epidural stimulation” into the search box.

Improvements range from regained sexual function to temperature regulation through sweating to ease of bowel management to — yes — the ability to move feet, toes and legs. Allen got her stimulator in December 2017, at 11 years post-injury. She is one of what will be 100 people in a trial called E-STAND that’s being managed out of
the Hennepin County Medical Center in Minneapolis. That trial is different in scope and aim from all the others.

Dr. David Darrow, one of the E-STAND principal investigators, says that optimization, or knowing how to program the stimulators, is all-important. The E-STAND trial is unique in that subjects get the stimulators implanted then go home to live their usual lives, with one difference. Darrow’s team has built an app that allows two-way Bluetooth communication to reset the controls on the device. Every one of the electrodes in the array has a huge range of settings: 160 different frequencies, 100 pulse widths, and 256 possible amplitudes, meaning there are millions of ways to configure the whole set.

Which setting is best?
Nobody knows. Darrow’s team is randomly choosing a launch set of parameters, and then using feedback in real time from the subjects to adjust them. They’re building out what they call a “clinical decision support system” — an impressive name for a tool doctors everywhere will be able to use as easily as a phone.

International Sales
What about the Californian and his Thailand adventure? I did some digging to find out more about Unique Access Medical. The businesses that call themselves Global Stem Cells and Epidural Stimulation Now are both owned by Unique Access Medical. Based in Singapore, UAM doesn’t provide any treatment or care themselves; its role is to recruit subjects and sell them on products that are then delivered by its professional partners in Bangkok. Before ES came on the scene, UAM mostly focused on persuading potential customers on the effectiveness of its stem cell treatments, claiming to cure everything from tinnitus to ALS.

They’re still offering those stem cell treatments. In fact, they’ve created a sort of package deal for people with spinal cord injury.

You can have an ES plus 30 days of rehab for $72,000. You have to pay $40,000 of that up front, with the balance due when you get to the hospital.

Or you can get the device, and they’ll throw in stem cell injections and another 10 days of rehab for an extra $20,000, making the total package $92,000.

The stem cells are mesenchymal cells, collected from umbilical cord blood and/or amniotic fluid. To my knowledge, there is not yet any reason to believe that injecting these cells into a damaged human cord will do anything to restore function, especially if they’re delivered long after injury. Less than a year ago, Stem Cells International published an article that says: “Mesenchymal Stem Cell transplantation is not an effective and reliable therapy for spinal cord injury so far...”

In other words, that science is in the early stages of development. To me, it seems unethical to charge people so much money for what is still not much more than a hope. The stimulator is different. We know that it helps, and sometimes a lot.

But there are a number of other practical things I struggle with when it comes to the idea of going to Bangkok for an ES that’s manufactured by an American company (Medtronic) headquartered in Minnesota:

• There is zero ability for follow up to adjust the settings on the device. That’s huge.
• In case of complications like infection at the implantation site or failure of the device, the person with SCI is on his own once he’s back home. There are no warranties or do-overs.
• The price is outrageous and beyond the reach of most of us.
• The data is lost to the community, which matters because data is what will make the ES widely available.

All that said, there are obviously people who are willing to do anything to get some functional return right now, and I’m not about to judge them. Speaking only for myself, it’s important to keep the larger goal front and center. I want to do the things that will speed up the process of getting these stimulators approved and insured and accessible to every last one of us. That’s what matters to me.

Making that happen more quickly means supporting the researchers with money or by helping them spread the information about what they’re doing in the labs. It means writing to the people at the FDA to let them know how important this is to us, and how impatiently we’re waiting to use it. It means joining others, like Unite 2 Fight Paralysis and the Christopher and Dana Reeve Foundation, in their efforts to get this done.

There’s so much work to do, and so many reasons to be hopeful. We’re just getting started.

Resources
• Christopher and Dana Reeve Foundation, christopherreeve.org
• E-STAND trial, estand.org
• Global Stem Cells, globalstemcells.com
• Stem Cells International article, ncbi.nlm.nih.gov/pmc/articles/PMC5467343
• Unite 2 Fight Paralysis, u2fp.org

Kathy Allen, a current epidural stimulation research participant, reports greatly improved core control that benefits daily activities like bathing, dressing, wheeling and driving.
This is about the time, every other year, when the various campaigns to get cripples registered to vote start cranking it up big time. I’m always hesitant to get too involved in these efforts. Don’t get me wrong. I’m all for turning cripples out at their polling places by the truckloads, as long as I know they are going to vote for the people I want them to vote for. But if not, then I just as soon they stay home. I don’t care if they are my crippled brothers and sisters. I won’t enable their anti-social behavior.

There’s a group that started in 2011 called She Should Run. Its mission is “to expand the talent pool of women running for office in the United States by providing community, resources, and growth opportunities for aspiring political leaders.” She Should Run has a goal of getting 250,000 women to run for elected office by the year 2030. This sounds like a smashing idea, as long as these candidates don’t include any Margaret Thatchers or Sarah Palins.

What if there was a similar initiative designed to recruit and groom crippled candidates? I know I’d get 100 percent behind any effort to support 250,000 crippled candidates who agree with me. Otherwise, forget it.

Hey, whenever a cripple tries to break new ground, I try my best to cheer them on. I really do. But I can only go so far. I have a hard time getting on their side if they’re not on my side.

Who out there remembers Jim Abbott, the crippled major league baseball pitcher? He was born without a right hand, but he was always hell-bent on being a pitcher so he pitched lefty. He fielded lefty, too. He balanced the glove on his right stub, and after he threw a pitch, quickly stuck his hand into the glove and was ready to field. He had a respectable career in the 1990s and even threw a no-hitter. I always wished Jim Abbott well, except when he pitched against my favorite team. When he pitched against my favorite team, I rooted for him to get his butt kicked as hard as I would for any two-handed pitcher to get their butt kicked. I don’t discriminate.

And now there’s another famous crippled Abbott. He’s Greg Abbott, the wheelchair-riding governor of Texas. He became a paraplegic in 1984, when he was jogging through a park in Houston and a tree fell on him. I suppose that means I should hope he rises to the political pinnacle and beyond. But in case you didn’t know it already, Greg Abbott ain’t no FDR. He pretty much stands for the same fascist crap that Trump stands for. As attorney general of Texas, he vigorously argued in court that Texas had “sovereign immunity” and should thus be exempt from complying with the Americans with Disabilities Act. Thank God he lost that case.

Cripples like Greg Abbott baffle me. You would think that if someone becomes crippled for life because a tree falls on their head, it couldn’t help but knock some empathy and wisdom into them and thus knock all the Abbott-like meanness out of them. There’s not room in the same value system for both. Abbott must’ve built up an impenetrable immunity to such things. It’s a tragic waste of a perfectly good disability.

So, there’s no way I would want to provide any sort of “community, resources, and growth opportunities for aspiring political leaders” who might someday be another Greg Abbott, just because they’re crippled. If it turned out that I was in any way responsible for one of them actually getting elected, I couldn’t live with the guilt. I hope candidates like Greg Abbott crash and burn spectacularly on Election Day, crippled or not. I don’t discriminate.

If anybody asks me if they can use my wheelchair-accessible van to drive a crippled voter to their polling place, I’ll be more than happy to oblige. But first that cripple will have to answer a few questions.

“...that I was in any way responsible for one of them actually getting elected, I couldn’t live with the guilt.”
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If it’s time for the Paralympics, it’s time for Wheelchair Sports Federation Media’s crack team of volunteer journalists and photographers to post the best of the games for those of us following from home. Enjoy these selections from the first day of the Pyeongchang Games, which ran from March 9-18, and visit wheelchairsportsfederation.org or follow WSF on Facebook, Twitter and Instagram for more.

An injury almost prevented Paralympic veteran Oksana Masters from competing in the biathlon sitting women’s 6km, an event in which she won the silver. “I dug as deep as I could for my team, and I’m happy to be on the podium.”

Team USA’s Andrew Kurka (center) celebrates winning the gold in men’s downhill skiing. After injuries kept him out of the Sochi Games, Kurka, 26 and a T10 para, said: “I didn’t know if I was going continue to ski again, to chase this dream.” Dream chased, dream caught.

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