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<table>
<thead>
<tr>
<th>Accessibility</th>
<th>Maneuverability</th>
<th>Door Height</th>
<th>Flexible Seating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interior Space</td>
<td>Large Wheelchairs</td>
<td>Lowered Floor</td>
<td>Seating Capacity</td>
</tr>
<tr>
<td>Max Headroom</td>
<td>Ease of Use</td>
<td>Ramp Width</td>
<td>Safety</td>
</tr>
<tr>
<td>Comfort</td>
<td>Independence</td>
<td>Floor Space</td>
<td>Reliability</td>
</tr>
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From a Kleenex tearjerker about a man and his dog to a sweet Honey Maid offering of an aunt bonding with her niece, Ad Land has never featured so many wheelchair users. ALLEN RUCKER says it’s because advertisers want real people and that means wheelchair users, too. Also, TIM GILMER catches up with one of them — Mr. Wonderful.

Cover Photo by Pascal Demeester, provided courtesy of Nordstrom
The current state of wound care is undergoing changes, in part because numerous wound care materials have fallen short. Some even bring about negative results — drying out, scabbing, or maceration (where too much moisture from a draining wound enlarges the wound perimeter). Fortunately, speaking for myself, I have found a systematic approach and two wound treatments that I can rely on.

In my March column, I reported on a shallow yet dangerous wound I discovered on my heel. I followed five critical protocols — eliminating edema, staying free of pressure and infection, having adequate circulation and eating more protein — and the wound healed in one month. I also got help from using two Unna boot wraps (see Para/Medic, Feb. 1, 2014) followed by a flexible silicon mesh dressing impregnated with petroleum jelly (ADAPTIC). I changed each Unna boot dressing after three to four days. The wound began to heal right away. Next, I applied ADAPTIC as a primary dressing, along with a secondary gauze pad to absorb moisture, and changed this every three days. Three weeks later the wound had completely closed over.

But the most serious wounds, admittedly, are more difficult. Complete wound healing often takes months or even years. Knowing this, a team of UCLA bioengineers and researchers have developed a gel made from microporous annealed particles (MAP) that promises to speed healing and reduce scarring when used to treat burns and chronic wounds.

A common problem with non-healing wounds is fragility. Too often tender new growth is either washed away, pulled off by adherent dressings, or aborted by scabbing. The wound lingers and the danger of infection persists. The MAP gel, bioengineered by UCLA post-doctoral fellows Don Griffin and Westbrook Weaver, along with researchers Dino Di Carlo and Tatiana Segura, can be injected into a wound bed and easily made to conform to its exact dimensions. The porous gel, made of microcellular spherical particles invisible to the naked eye, looks like a cream but lays down a scaffolding that encourages new skin growth and inhibits scabbing.

The soft gel hardens after being injected, then gradually degrades as new growth grows through its porous micro-spaces to knit together. “Over time the hardened gel solubilizes, falls apart and leaves the body through urine,” says Griffin. “The scaffolding is a support system for the body to do its healing work. As a result, healing happens faster because the body does not have to make its own scaffolding.” Because the gel is similar to commonly used materials and contains no biologicals, it can be approved for use by doctors or wound care specialists after large animal trials that are expected to take place in two to three years. Mice trials have already demonstrated rapid healing and less scarring.

Potential applications are many and exciting for this newly engineered product. For instance, the newly injured spinal cord attempts to heal itself, but that process is short-circuited by scarring after two weeks. Ultimately, the injectable MAP gel may be combined with stem cells or other healing agents to spur new growth and inhibit scarring in many soft tissue injuries — including the newly injured spinal cord.

— Tim Gilmer
Allen Rucker grew up in Bartlesville, Oklahoma, and went to Washington University in St. Louis and Stanford. In the '70s, he co-founded the pioneering video group, TVTV and in the '80s he wrote comedy with Martin Mull as well as others. In 1996, he became paralyzed at T10-12 via transverse myelitis. More recently, he has written three books on *The Sopranos*, and a memoir of life after paralysis, *The Best Seat in The House*. A longtime *New Mobility* contributor and columnist, he lives in Los Angeles with his wife, Ann-Marie.

Maureen Gazda remembers reading her first copy of *New Mobility* from her hospital bed in the summer of 1997. The 12-year-old competitive swimmer had just been thrown into the world of quadriplegia after diving into a friend’s backyard pool, sustaining a C5 incomplete SCI. Writing became her escape and she went on to earn a bachelor’s degree in English from The University of Massachusetts Amherst in 2007. She is beyond excited that her relationship with NM has come full circle, from avid reader to contributing writer.

Bob Vogel has a unique insider’s view of the complex rehab DME industry. A T10 para, he was a pioneer of extreme adaptive sports in the late '80s, which led to marketing a gig touring the country working with a wheelchair manufacturer’s sales reps. He was a manufacturer’s rep in the mid '90s and worked for a complex rehab DME dealer in the early 2000s. When he isn’t writing for *New Mobility*, he spends his time sharing adventures with his teenage daughter, Sarah, and Killy, his German Shepherd service dog.

In 1979, as a result of employment discrimination during a temporary disability, Tari Hartman Squire joined forces with other performers with disabilities, including Alan Toy and Christopher Templeton, to spearhead the Screen Actors Guild Committee of Performers with Disabilities. She then launched Media Access Office’s first casting clearinghouse of performers with disabilities and produced talent showcases. Squire co-chairs National Disability Leadership Alliance’s Employment Team and produces Lights! Camera! Access! 2.0 to improve disability portrayals, and increase employment in media. Her company EIN SOF Communications specializes in disability-inclusive diversity strategic marketing and employment.
Wishing them a lifetime of love.

Best Wishes
Happy for all the couples ["Weddings and Wheels," February 2016]. Wishing them a lifetime of love.
Jonnie Finley
Via newmobility.com

How Can I Get on Trials?
[Re. “Epi-Stim Opens Up Pleasure Pathways for Paras and Quads,” February 2016:] I’m a T8 complete and have been for only a year and a half. I’m a 40-year-old single dad who lost my insurance after my accident. State insurance wouldn’t pay for a wheelchair let alone this procedure [epi-stim] — or physical therapy for that matter. How can I get on a list for this or any procedure?
Kurt Lutz
Via newmobility.com

The author responds: As I write this, implanting epidural stimulators at the level of SCI is in very early stages of clinical trials. Only a few people have received these implants, which are being done via the Christopher and Dana Reeve Foundation to Cure Paralysis’ “The Big Idea” project. The next goal is to implant devices into 36 more people, analyze and publish the results, then go from there. If you are interested in becoming a participant, you can sign up and get on a list of potential volunteers by going to victoryoverparalysis.org, scrolling down to the bottom of the page and clicking the red button on the left that says “Participate in Research.”
Best of luck, and please keep us posted if you are able to receive an epi-stim implant.
— Bob Vogel

Break from Spasms
Great article ["The Ejaculation Affirmation," February 2016]. I was discussing this option with a fertility specialist who told me that many of his clients with SCI who had some version of this vibrator procedure done in his office — for in vitro fertilization purposes — reported a pleasant side effect. Their spasticity went away for 12-24 hours following ejaculation. I’m curious if anybody else has experienced this. Sure beats high doses of baclofen.
Roger Ellsworth
Berkeley, California

Spasms Complicate Collection
The Viberect has gotten the job done for me, a T6 para, with no autonomic dysreflexia complications besides flushing of the face ["The Ejaculation Affirmation"]. I was an early adopter and they sent me a new and improved model in 2014 after I pointed out the ineffectiveness of the original product. In using it at home artificial insemination, I’ve found the hardest part is one not often talked about — catching the money shot. Ejaculation causes major spasms, which make “aiming” nearly impossible. And wearing a condom decreases the likelihood of ejaculation.
Mark Demaris
Stockton, California

That Primal Feeling
I thought your information on “electro nut busting” was good ["The Ejaculation Affirmation," February 2016]. I was one of the early posters in the thread and I am glad that it has reached so many males with SCI and has seemingly helped many achieve ejaculation. It is a huge mental aspect, especially being younger (I was 25 when injured). Not only does it help bring back that primal feeling, but it is healthy for the prostate to flush the pipes out occasionally, and it’s nice to have some time off from spasms, even if for a few hours.
It does take time to “figure yourself out.” It can be extremely frustrating when you find what works, keep with it, and then all of the sudden, it stops. Usually I just need to take some time off, give it a few weeks and then try again. The dysreflexia has gotten easier over time, but it is usually still there to some degree. I can’t speak for all relationships, but I gather from others and my own experience that your partner usually wants/needs to see it [ejaculation] happen occasionally, just so that they don’t feel any sexual guilt or greediness. I think to most women, seeing it equates to sexual gratification. And while that is somewhat true, it will never be the same as it was pre-SCI.
It would be interesting to see if down the road, centers like Shepherd introduced this in their sexuality classes.
Thomas Sessions
Charleston, South Carolina

Ali’s Broadway Success
Yay, this just makes me happy ["Ali Stroker: Bright Light on the Great White Way," February 2016].
Jen Halbert
Via newmobility.com

MS Curve Ball
Your story of being diagnosed is so close to mine ["An Unexpected Plot Twist in My Life," I remember being in the neurologist’s office after having an MRI for severe and chronic migraines and having her ask me, “What types of MS symptoms have you had so far?” I think my dumbfounded reply was something like, “I came in for a headache.” I am also an educator and starting to find that I can’t really handle the demands of the job very well anymore. At 40 I am hopeful I will find some sort of new career path that will allow me to keep working. Five years later I am still struggling with accepting this curve ball.
Amy Renea
Via newmobility.com
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Greyhound Settles with DOJ over ADA Violation Claims

Greyhound Bus Lines, the nation’s largest bus company, has agreed to pay over $375,000 in compensation and penalty fines to settle claims that it repeatedly violated the Americans with Disabilities Act.

According to the Department of Justice, Greyhound routinely disregarded numerous ADA requirements, including “failing to maintain accessibility features on its bus fleet such as lifts and securement devices, failing to provide passengers with disabilities assistance boarding and exiting buses at rest stops and failing to allow customers traveling in wheelchairs to complete their reservations online.”

As part of the Feb. 8 settlement, disabled passengers who experienced discrimination or unnecessary barriers will be compensated $300,000 by Greyhound. The Department of Justice has also left that number uncapped, saying that anyone who received unfair treatment because of their disability within the past three years is eligible to submit a claim and can contact a designated DOJ claims administrator.

The bus company has also agreed to hire an ADA compliance manager to train employees and contractors on important ADA practices such as accurate management of the fleet’s accessibility features.

“The ADA guarantees people with disabilities equal access to transportation services so that they can travel freely and enjoy autonomy,” principal deputy assistant attorney general Vanita Gupta, head of the DOJ’s civil rights division, said in a statement. “Today’s agreement marks a major step toward fulfilling the promise of the ADA, and we applaud Greyhound for entering the consent decree.”

— Maureen Gazda

United Spinal Member Sues for Ferry Access to Statue of Liberty

United Spinal Association member and employee David Heard, a wheelchair user, filed a lawsuit in February against Statue Cruises, LLC, for its failure to provide safe and lawful ferry access for wheelchair users, thereby violating the Americans with Disabilities Act and New York State and New York City Human Rights Laws.

Wheelchair-using tourists from all over the world are among the 4.2 million people who visit the Statue of Liberty every year.

People in the News: Joe Stone Fights to Stay in the Race

Handcyclist Joe Stone has settled his disability discrimination complaint against Run Wild Missoula after marathon organizers agreed to allow handcycles and wheelchairs in the race with no restrictions. As part of the Jan. 22 settlement, the organization agreed to pay Stone $13,000, which includes his court costs, as well as have its staff and board members undergo two hours of training on accommodating people with disabilities.

“I’m glad the Missoula Marathon is now going to be a truly inclusive race,” says Stone, a quad who lives in Missoula. “It’s going to make a big difference in the way directors look at their races in the future. They’ll know it’s time to start including people with disabilities.”

Stone says that although he was denied access to the marathon in 2013, Run Wild allowed him to race in July 2014 — but only if he obeyed a speed limit and yielded to foot runners. He protested these requirements by participating without registering and video recording a race volunteer telling him to either get off the course or “get up and walk.” Soon after the race, Stone filed a discrimination complaint against Run Wild Missoula with the Montana Human Rights Bureau.

Stone considers the settlement to be a big step forward. “This is really the first case that’s gone this far when it comes to inclusion in races like this,” he says. He wants Run Wild Missoula to know people with disabilities are part of the community and need to be included in community events. “I hope this makes them realize that they can’t just say someone with a disability is a safety hazard,” he says.

Tony Banovich, executive director of Run Wild Missoula, declined to comment on the specifics of the case. “We’re just happy to have the issue resolved, and we are moving forward with our planning for the 2016 Missoula Marathon,” he said.

— Mark Boatman
The complaint states, “Tens of thousands of disabled Americans who depend on wheelchairs for mobility — including many military veterans who were disabled in the service of this country — cannot easily visit the Statue of Liberty or Ellis Island, because defendant Statue Cruises, LLC (“Statue Cruises”), which holds the exclusive right to operate ferry boats to the Statue of Liberty and Ellis Island, does not make its ferry boats accessible for wheelchair users.”

United Spinal President and CEO James Weisman sent a letter last December to the National Park Service that described significant and dangerous problems regarding wheelchair accessibility on the ferry and requested appropriate changes be made in order to comply with the law. These problems included transition plates and ramps that are at an unlawful slope, gangways that are too narrow with unlawful handrails, and restrooms that are inaccessible and unusable.

In a letter responding to United Spinal, the superintendent of the Statue of Liberty National Monument stated that “the National Park Service and Statue Cruises believe that the ferry is in full compliance with all applicable accessibility laws” and declined to take any steps to compel Statue Cruises to remedy the alleged violations.

United Spinal had received multiple notifications from wheelchair users identifying accessibility problems on the ferry boats. As a result, plaintiff David Heard visited the Statue of Liberty where he, too, faced the same dangerous obstacles and difficulties using the inaccessible ferry boats.

#CripTheVote Lights up the Internet

As the 2016 election process heats up, newly launched online campaign #CripTheVote is lighting up the Internet as a way to bring awareness to disability related issues in the 2016 presidential campaign. Created by disability activists Gregg Beratan, Andrew Pulrang and Alice Wong, #CripTheVote is a “nonpartisan campaign to engage both voters and politicians in a productive discussion about disability issues in the United States, with the hope that Disability takes on greater prominence within the American political landscape,” their mission statement reads.

“Our primary message is that disabled people are tired of being an afterthought to the political establishment,” explains Beratan. “We are not the last special interest you rattled off at the end of a laundry list of constituencies — we are nation’s largest minority, and it’s time the politicians at every level of our government paid attention.”

Taking place on Twitter before, during and after presidential debates, #CripTheVote conversations allow disabled voters to voice their opinions and concerns on such topics as unemployment, healthcare, housing needs and accessibility, just to name a few. “Disabled Americans deal with twice the unemployment rate that nondisabled Americans do, we are more likely to live in poverty, end up incarcerated or experience violence. And much of the nation’s housing and transportation infrastructure is inaccessible to many of us,” says Beratan. “Add to that an education system that treats us as second class citizens and we have a situation that is long past needing political action.”

— MAUREEN GAZDA
“The only difference between you and me,” says 23-year-old Eric Saunders to friends and new acquaintances, “is that you put on sneakers in the morning, and I get in my wheelchair.” This quote perfectly exemplifies how Saunders has dealt with his 2010 motocross crash that changed his entire world and introduced him to a new sport he now loves.

Saunders, from Lakeville, Indiana, was a rising motocross racer with big-name sponsors like Tony Stewart Racing and Bass Pro Shop. Then came a heartbreaking accident — he crashed on his backyard track a day before his 18th birthday. “It was a jump I had done several times before, but I somehow landed sideways.” Welcome to the world of T4-5 paraplegia.

Fortunately, being from a very active racing family, Saunders was able to try out a new style of racing — mini sprint — with his family’s support after his injury. “It’s all I know,” he says about returning to racing. Mini sprint cars are perfect to be adapted for people with spinal cord injuries. A 600cc street bike engine is put into a smaller race car chassis, and each car is custom made by its owner.

Since venturing out into the mini sprint world as a paraplegic, Saunders has noticed something very uplifting — his colleagues accept him fully. “The other racers don’t treat me any differently. They just always tell me that they could never do what I’m doing,” he says with a grin. It took a couple of years to excel at it, but in 2015 alone, he won six feature races. But that’s not why he’s racing again — he has a higher purpose.

“My goal with racing is to show people that just because you have a disability, it doesn’t mean you have to stop doing what you love.”

We all know how long it can take to get dressed when you can’t stand up, which is why Pants Up Easy is one of those products that definitely belongs in the “Why hasn’t this been thought of before?” category.

An original device not yet covered by insurance, Pants Up Easy minimizes how long it takes to get your pants up. The user backs up to either a free-standing or a wall-mounted unit and puts their arms over supports that clamp below their armpits. This allows just enough lift to elevate their body, leaving their hands free to pull up their pants.

The device reportedly shrinks the time to accomplish the task to just seconds. Pants Up Easy is best suited for paraplegics and some low-level quads. For pricing and more info, visit www.pantsupeasy.com.

Ryan Atkins was living the so-called perfect life — 21, a junior honors student on a full-ride scholarship to the University of Cincinnati — when he became paralyzed at C3-4 in a car accident. Now 27, he went on to graduate last December, works in commercial real estate and is engaged to be married in November. Read his motivational blog posts at www.flatonmyback.com.
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Dusty Grim
“How many wheelchair users have you seen on the street in the last week? How many have you seen in the last year?”

Depending on how big your city is and how often you are out and about, your answers likely vary widely. But if you live in the United States, chances are good that you’ve seen at least one — and probably many more — wheelchair users going about their daily lives in your area.

When Alexandra Kutas asked her university professors those same questions about their experience in Dnipropetrovsk in her native Ukraine, she was met with silence. In the country’s third-largest city, with almost 1 million residents, none of her professors could think of another wheelchair user they had seen.

Sadly, her experience is shared by millions of wheelchair users around the world. While progressive laws and attitudes slowly improve access and quality of life for wheelers in the United States and other countries like the United Kingdom and Australia, progress toward equality rolls more slowly in many other countries, sometimes not at all.

For Denisse Chavarria, the lack of accessibility in Costa Rica has literally slowed her roll, as the absence of accessible sidewalks forces her to regularly navigate a two-hour gauntlet of pothole-strewn roads and unfriendly drivers in her wheelchair so she can attend therapy.

For Ivan Sosa, Croatia’s physical obstacles pale in comparison to the outdated attitudes on disability that he confronts every day in his quest to become a doctor.

In their countries they may be the visible few, but by sharing their stories, they hope to give voice to the marginalized and help bring about the changes needed to empower other wheelers.

Alexandra Kutas knew that wheelchair users in Ukraine faced an uphill roll long before her professors’ silence in response to her simple question about how many wheelchair users they had seen on the streets of Dnipropetrovsk. A doctor’s mistake left her paralyzed since birth and reliant on her wheelchair. She thinks Ukraine has the potential to embrace disability and accessibility, but lacks the resources and impetus for change.

“Unfortunately on the streets of Ukraine you can rarely see people in wheelchairs,” she says. “The problem is
Poor accessibility means Kutas must rely on friends and family to carry her up stairs and curbs, but she hopes to parlay recent media attention into better infrastructure in her city and country.

mostly inaccessible infrastructure. ... If I need assistance, I can easily find people who gladly help me. But it’s annoying because even though people react nicely, if I wanted to go for a walk, I would have to ask for help for every single sidewalk, so I usually don’t walk alone.”

Growing up, Kutas relied on her parents and friends and the opportunities they provided. “I’m really blessed for my parents helping me,” she says. “The country is still not accessible at all. To get around I need my own personal driver because transportation is not accessible and the city center doesn’t have curb cuts.”

When she attended university, she relied on friends to carry her up four flights of stairs to her classes. The building had no elevators and she was the only wheelchair user asking for improvements.

Kutas had little to compare the lack of access against, but as she traveled abroad with her family, and later alone, her eyes opened. “When I started to travel around Europe, I began to realize places can be accessible,” she says. “I fell in love with all the accessible trains and buses that allowed me to get around cities independently. Obviously, accessibility in Europe differs from country to country, but it’s better than Ukraine most of the time.”

With that realization, Kutas found herself facing a stark choice. “My first thought was maybe I should move, because it’s really, really difficult to live in Ukraine since not much is accessible, but after the revolution I started to believe that it is possible for my country to change, so I decided to do my best to bring that about,” she says. “It’s my homeland.”

The revolution she speaks of, the Orange Revolution of 2004, led to a revote for the presidential election and was seen as evidence that democracy could exist in a former Soviet country. Kutas’ plan for a revolution of accessibility began to take shape as she wrapped up her undergraduate studies at Dnipropetrovsk National University. She jumped on an assigned final group project as an opportunity to devise a plan to improve access in the city center. Knee deep in the heavy winter snows, her team mapped out the locations where ramps and curb cuts were needed and then submitted a proposal for funding and applied for various European Union grants. She won best project, which helped propel her to a degree in psychology, but the project didn’t have the impact she had hoped. No one would fund the suggested improvements.

“Unfortunately we are having a war and all of our politicians, if they don’t have the money, say everything goes for the war,” she says. “The mayor would adopt her project as part of his election campaign, but they said it was too expensive.”

The war with Russia, which started two years ago, has drained resources and left many soldiers and civilians with new disabilities. Kutas is optimistic that disability and accessibility will soon find their time in the spotlight.

“Hopefully, after everything ends, politicians will do something, but right now the war is still going on, slowly,” she says. “It looks like the media and some groups are trying to change things, but the whole country is so inaccessible that it’s going to take time and lots of investments.”

Fashion Modeling for Access

Still, Kutas isn’t willing to just sit around and wait for accessibility to come. When she failed to secure any funding for her project, she decided to do things differently.

“I have wanted to be a fashion model since I was 16 and I’ve had a lot of photoshoots, so I decided to try to become a famous fashion model and get attention for people with disabilities in the Ukraine that way,” she says. “I figure it would be easier to earn money to make the country more accessible with the help of the media.”

That may sound like a fantasy, but with her natural good looks and tenacity she has made it a reality. She started out as a hostess for Ukraine’s national fashion week. On the first day she met Andrey Sarymsakov, a photographer who expressed interest in working with her. One successful session later, the two felt confident they had the makings of a good exhibition. The exhibit, entitled “Break Your Chains,” was picked up by a museum in Kiev and shown during fashion week. “It was a big deal because no one had ever had an exhibition of a fashion model who uses a wheelchair in Ukraine,” she says. The show led to an

“Break Your Chains,” a collaboration between Kutas and photographer Andrey Sarymsakov, was exhibited during fashion week in Kiev. “No one had ever had an exhibition of a fashion model who uses a wheelchair in Ukraine,” Kutas says.
Although injured more than two years ago, Chavarria just got a chair in January that she can use independently.

The absence of wheelchair users on the streets of San Jose, Costa Rica, is more than just a talking point for Denisse Chavarria. Until January, she was a prime example of the country’s often hidden wheelchair-using population, as she lacked a wheelchair she could use independently. Two and a half years ago a surgery to fix Chavarria’s aneurysms left her a C3-7 quad. She has spent the majority of her time since then in the three accessible rooms of her parents’ house, relying on others to push her around in a medical transport chair. “When I got out of the hospital, the doctors told my mom I would be able to move out after a couple of months. Those were the two longest months in my life. I’m still waiting,” she says. “When you get out of the hospital they transfer you to a rehab center for one month. If you start doing something new, they give you more therapy, but if you stay the same, they tell you that you’re not going to give you more therapy because you are not going to improve anyway.”

Chavarria says that attitude is emblematic of the Costa Rican medical community’s regressive approach to spinal cord injury. “I tried to tell them that the rehab and therapy is not necessarily for me to move or walk again, but for me to stay in shape and learn and be able to live my life to the fullest,” she says. “They treat me like garbage here.”

Prior to her injury, Chavarria taught kids with disabilities and yearns to get back to work, though she is unsure if she can logistically. Two and a half years ago a surgery to fix Chavarria’s aneurysms left her a C3-7 quad. She has spent the majority of her time since then in the three accessible rooms of her parents’ house, relying on others to push her around in a medical transport chair.

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Prior to her injury, Chavarria taught kids with disabilities and yearns to get back to work, though she is unsure if she can logistically. “Right now I can’t even write, so how am I going to teach them?” she asks. She has seen many of her friends with disabilities get repeatedly rejected from jobs and says discrimination is rampant. “It’s like people with disabilities are seen as not worthy and unable to do anything,” she says. “People see me in my wheelchair and they go up to my mom and ask, ‘Can she speak?’”

She laughs off the question. “Oh my god, I speak a lot!”

To keep her mind active, Chavarria works part time for the local university, but doesn’t even make enough to pay her phone bill. Money is a real issue.

Chavarria receives a disability pension through Costa Rica’s Social Insurance program, but says, “Social Insurance will not help me with a wheelchair, it won’t help me with my catheters, it won’t do anything. My parents have to pay for everything. That’s pretty hard because we’re not rich, and even if I was rich, there’s no way to buy all the things I need.”

With very little government support, Chavarria faces a chicken-and-egg situation; she wants to work to earn money to pay for her own needs and supplies but lacks the supplies and resources to get and hold down a job. “I just want to teach, but I need money,” she says.

This January, Chavarria’s goal grew closer when a friend’s crowdfunding efforts netted her a new Permobil F5, her dream chair and her first chair she can use independently. She traveled to Florida to pick it up and marveled at the differences in her surroundings. “I saw that everything was accessible,” she says. “It was awesome … and then I got back here to Costa Rica and it was disappointing getting back to reality.”

Chavarria’s first trip to the hospital in her new power chair provided a stark reminder of the distance Costa Rica has to go before wheelchair users can enjoy anything close to a level playing field. “When I got to the hospital, the doctors and nurses seemed surprised to see me in my big wheelchair. Power wheelchairs are pretty expensive, and without government help, very few people get them,” she explains. “It should be the other way around, where everyone who needs one has a wheelchair, and doctors and nurses are shocked when that doesn’t happen.”
Ivan Sosa: Rijeka, Croatia

Ivan Sosa has had plenty of time to think about the obstacles facing people with disabilities in Croatia in the 12 years since he suffered a cerebellum injury that affected his speech and left him using a wheelchair much of the time. When Sosa was injured, he had completed medical school in Rijeka, Croatia, and was about to start his internship. Instead he found himself in rehab at the start of a journey that would expose him to the sometimes-ugly side of a country undergoing rapid change. “It’s a pretty interesting perspective because we are a developing society, and

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human rights are something that’s really important, but often overlooked,” he says.

Located on the Adriatic Sea, with a population of about 4.5 million, Croatia has endured a turbulent 25 years since gaining its independence from Yugoslavia in 1991. In 2015, Croatia’s unemployment rate of 16.5 percent was the third-worst in the European Union.

Sosa knows his disability only complicates things. “In general, it is hard to get a job for everyone, and for people in wheelchairs it is even harder,” he says. “Employers are not good with the idea of employing people with disabilities as they’re afraid of getting less efficient work from us. If you look at the structure of Croatia’s population, most of the jobs are blue collar. So white collar jobs are exclusive for the general population and even more exclusive for people with disabilities.”

Sosa wanted to continue pursuing his medical career after finishing rehab, but like many facilities in Croatia, the hospital lacked an elevator, accessible facilities and staff willing to work around his needs. He eventually got a job as a research fellow at the same facility. His office was up a flight of stairs. “I climbed to the second floor each day for more than a year with the help of my father,” says Sosa. His complaints and requests for a new office went unheeded, something he says happens all too often in Croatia.

“Most people are not malicious,” he explains. But they still see disability as a personal problem, rather than as a social issue. “If you ask politicians for something just for your disability, they don’t see it as a great problem, but if you ask for something because you need it to be ‘normal’ and live like anyone who doesn’t use a wheelchair, that is where problems start.”

“The question that I personally face most often is, ‘How do you think you are going to make it? People most often think your disability prevents you from being able to do some ‘normal’ things.”

Sosa sees social attitudes slowly changing. “A few years ago it was easier for the public to dismiss the opinions of the disabled and do as they liked, thinking we will just have to deal with that,” he says. “That is becoming less and less possible, because we are organizing ourselves more and more efficiently.”

Sosa is a member of an active Facebook group for Croatians with disabilities and says he sees more groups coming together. “A few years back it was something that two or three people did. Now more and more people are sharing their opinions and speaking up,” he says, noting that the Internet has broadened people’s horizons and exposed them to other countries’ approaches and connected them with advocates and leaders abroad.

Still, change at home comes at a slower pace than Sosa would like. He has heard multiple politicians promise improvements in accessibility only to end up failing or apologizing for being unable to deliver. Yet, his own experience shows change is happening.

Twelve years after he was turned away, Sosa is finally doing his internship, and at the same facility he was unable to attend after his injury. The hospital still lacks many of the accessible amenities Sosa would like, but a new facilitator who was willing to work with Sosa’s needs has enabled him to take the next step on his career path. Once he becomes a board certified physician, he will be able to advocate for change from inside the medical profession, and you can bet he won’t be turning away interested candidates.
At New Mobility, we get a lot of questions about why disability equipment costs so much. A significant number of readers think that manufacturers are gouging us and that dealers are just out to make a buck. Surely wheelchair costs needn’t look like line items on a new Ford Mustang, right?

With the current climate of shrinking insurance coverage and narrowing options, we decided to follow the money as far as we could. What we found is that “complex rehab technology” is well-named: The complexity of the equipment is matched, if not surpassed, by the complexity of FDA approval, Medicare reimbursement and qualified customer service in our unique community of producers and consumers. We have also come to believe that the great majority of manufacturers and dealers are our allies. They must make a profit to stay afloat, but when you lift the curtain, you often find engineers thrilled to be designing for independence, company advocates toiling for better Medicare coverage, and technicians working overtime to uphold our quality of life. Here is a peek behind the scenes at a few of the companies who, yes, make a living, but who also make a difference in our living.

**Corpus VS Power Elevating Legrest**
- R: $3,162
- M: $2,400
- C: $600

*Medicare is inconsistent in its coverage of this component. In some cases, it may be available only if the consumer pays full price.*

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**THIS PAGE:** A glance at price tags on a complex rehab power chair. It’s not Permobil’s top-of-the-line chair, but it does have state-of-the-art components for staying healthy as a quad. There are three figures to be aware of: What the retailer charges if you don’t have insurance, how much Medicare reimburses the retailer (80 percent of the “allowable” covered charge), and what, ultimately, the end user is responsible for paying (20 percent of the “allowable” covered charge). Most private insurance companies base their rates on what Medicare covers. What we can’t see is the dealer’s cost, a price negotiated with the manufacturer based on volume of sales. And, as hard as we tried, exact manufacturer costs are nearly impossible to define (see page 20).

**PAGE 20:** A look at some of the “whys” behind wheelchair component costs, including the convoluted Medicare system.

**PAGE 23:** An in-depth view of how changes to Medicare funding are harming one crucial health product — cushions.
F3 Corpus Base
R: $7,295
M: $4,348
C: $1,087

Batteries (Group 24)
R: $945
M: $280
C: $70

Expandable Controller
(for tilt/recline functions)
R: $635
M: $372
C: $93

Wiring Harness for Expandable Controller
R: $561
M: $274
C: $68

Headrest
(10" with hardware)
R: $369
M: $155
C: $39

Corpus Ergo (or Ride Designs) Back
(designed for power recline chairs)
R: $993
M: $376
C: $94

Seat
(with 50 degrees power tilt and
175 degrees power recline to help
prevent skin breakdowns)
R: $11,355
M: $6,690
C: $1,673

Expandable Controller
(for tilt/recline functions)

THE BOTTOM LINE
Total Cost for Permobil F3
Corpus with Power Recline,
Tilt and Elevating Leg Rests
RETAIL: $25,315
MEDICARE REIMBURSEMENT to dealer: $14,894
(80 percent of allowable charge)
COST TO CONSUMER: $3,724
(20 percent of allowable charge)

NEXT: WHERE DOES THE MONEY GO?
APRIL 2016
Access to complex rehab technology — medically necessary, individually configured wheelchairs, seating systems and components — continues to be threatened by Medicare reimbursement cutbacks. Because private insurance companies tend to use Medicare policies as guidelines, this affects all wheelchair users. Yet there is a widespread misconception that complex durable medical equipment is overpriced. People sometimes compare the price of high-end power and manual chairs and components to cars and bicycles. Quite simply, these are apples-to-oranges comparisons. To clarify the issue, we looked at some of the expenses involved in bringing complex rehab DME from original concept to the end user.

Research, development and design is the first step in creating equipment that addresses the orthotic support, proper fit, and skin protection that is so important to wheelchair users every day. “Complex rehab products are not commodity items that you pull off a shelf,” says C5-6 quad Josh Anderson, vice president of marketing for Permobil and former head of product management and marketing for TiLite. “Whether it’s a manual chair custom made for an individual or a custom-fit power chair where you can dial everything in to an exact fit — like a controller or a headrest that is specific to a person’s needs — the design of each part is about maximizing ability. It has to fit the person like an orthosis.”

Most people with SCI sit in their chairs an average of 11 hours per day — ranging from five to 16 hours. Neither cars nor off-the-shelf bicycles are designed to custom fit and support a person so intimately and uniquely. Car seats, for example, do not provide the skin protection that many wheelchair users need, so we have to sit on our wheelchair cushions while driving to avoid dangerous pressure sores. As for bikes, the most appropriate comparison to complex rehab manual chairs are custom-fit bikes, which start at around $3,800.

Economy of scale is another huge difference. “Permobil U.S. and TiLite produce approximately 20,000 power chairs and 20,000 high end manual chairs respectively per year,” says Anderson. “These quantities are not enough to bring the price down.”

For comparison, in 2013 GM alone had U.S. vehicle sales of 2,700,000. That same year over 18,000,000 bicycles were sold in the U.S. Product testing and FDA approval is another costly and lengthy manufacturer expense. Wheelchairs must pass testing by the Rehab Engineering and Assistive Technology Society of North America that represents five years of use. John Goetz, government affairs manager of Permobil, says RESNA testing includes loading test chairs to maximum weight capacity and rolling 200,000 cycles on round drums with half-inch metal curbing built into them. Also, the chairs are dropped from a height of 6 inches 6,666 times. Power chairs must pass additional tests, including speed, braking, stability, obstacle-climbing and numerous electrical system trials, including battery and controller tests. Test results and design documentation are then submitted to the FDA for review. A chair can’t be marketed until it gets FDA approval.

Then there are the ongoing costs of running a business, which include — besides the usual daily overhead costs — paying accountants, attorneys, and employees like Goetz, who must stay abreast of all the

BY BOB VOGEL
latest legislation and CMS (Medicare and Medicaid) requirements.

**WHAT THE DEALER DOES TO GET YOUR CHAIR**

When a wheelchair product is ready to sell, DME dealers that specialize in complex rehab products must provide extensive customer service that goes above and beyond other types of retail stores.

An assistive technology professional must work with wheelchair customers to make certain they get the most appropriate custom rehab equipment. RESNA requires a lengthy apprenticeship before an ATP can qualify to take a four-hour 200-question test on knowledge of disabilities, complex rehab equipment, diagnosis, and funding. Continuing education is also required. “Under Medicare guidelines, basically any piece of complex rehab equipment has to be delivered by an ATP,” explains Dave Kruse, an ATP employed by Bellevue Healthcare in Portland, Oregon, who is in his 40th year supplying complex rehab DME to clients.

“It takes a huge amount of time, driving and paperwork to get a piece of equipment to a client,” says Kruse. “For each ATP, we employ three full-time office support people.” This includes a direct support specialist who knows insurance coding, how it is handled, what documents are required, and what each type of insurance will and won’t pay for. Also, a funding coordinator, and a reimbursement specialist.

"Per Medicare guidelines, if a wheelchair user needs a cushion, back, ultra-lightweight manual chair or power chair, an ATP must attend an assessment with the wheelchair user at a seating clinic done by a physical or occupational therapist," says Kruse. The average seating clinic eval is 1.5 hours plus drive time. Following the evaluation, the ATP writes up notes on the equipment that the therapist has determined, then gets price quotes from manufacturers, which all goes in a file.

“For a manual or power chair we are required to do a home assessment which means measuring to make sure the chair fits in doorways, etc.,” says Kruse. “If it is a first-time wheelchair user or they are getting a different model of chair, I take a demo to the client’s home for them to try — for anywhere from an hour to a few days — to make sure the chair fits and works in and around the home.” After this, the ATP’s documentation is turned over to the direct support specialist.

The direct support specialist checks documentation and contacts the physician — to get the client’s history and chart notes — and the therapist for their notes on why they need the specific equipment. The specialist also requests a prescription and/or letter of medical necessity explaining in specific detail why they need the equipment, then reviews the documentation, particularly the letter of medical necessity to make sure the wording is exact so insurance doesn’t deny the claim. The specialist may need to request additional documentation or a rewrite of the physician’s letter. At times follow-up calls and paperwork go back and forth between the doctor three or four times before it is right.

The funding coordinator then receives the documentation file and re-checks everything and writes up the information. If the client has private insurance, documentation is submitted along with a request for pre-authorization — to guarantee payment. If the request is denied, the reimbursement specialist reviews everything and submits paperwork to request a hearing to reconsider. “Medicare generally doesn’t do a pre-auth,” says Kruse. “It is the reimbursement specialist’s job to make sure all the documents support the coding requirements, which are kept on file in case the claim is denied. Medicare can deny payment after receiving the invoice, or years later they can audit invoices and if the documentation isn’t perfect, Medicare can make the dealer return the payment.”

After many hours of work by different full time DME specialists, including constant reviewing of all information and paperwork, the ATP goes over the order with the client, explaining any co-pays or items that aren’t covered. Documents are signed and the order is placed. “With Medicare there is a bond of trust that the client will cover the 20 percent co-pay and a leap of faith that all of the paperwork is perfect and Medicare will pay for it,” says Kruse. “But co-pays can be difficult. If the client doesn’t have the money up front, you can set up a payment plan, but other times we have done all the legwork and
paperwork to get approval, and then the client decides they can’t afford the co-pay.”

**DELIVERING THE GOODS**

When the equipment arrives at the DME dealer, it is then **set up for delivery.** Manual chairs often require minimal set up, but a power chair with a complex seating system such as power recline and/or tilt-in-space requires time-consuming assembly by a technician. The final step is **delivery of the wheelchair** to the client’s house for **final set up and adjustment** by the ATP — and getting the client’s signature before a bill for payment can be submitted.

After this lengthy, time-consuming process of customer service, jumping through hoops, and checking and re-checking documentation, it is not uncommon for payment to be denied by Medicare or private insurance. Of course this means **appeals and more paperwork.** “You can spend just as much time fitting and getting funding for a small piece of complex rehab DME, say a headrest that may cost a few hundred dollars, as you do on a wheelchair,” says Kruse. “You are probably never going to financially recoup your time, but it makes all the difference for the client, and that is what this business is all about.”

After equipment is delivered, customer service continues in the form of **maintenance.** “Clients generally don’t realize how dedicated people in the industry are,” says Kruse. “If I get a phone call from a client who needs a repair or has a flat tire on a power chair, I will go fix it after-hours or on a Saturday because I know they won’t be moving until I handle it. This usually costs me, not only time away from my family, but also because Medicare doesn’t reimburse calls to fix a flat tire. Other insurance companies require a preauthorization — how do you get a pre-auth on somebody’s broken down chair on a weekend? This is an industry you get into because you care about helping people. You aren’t going to get rich, but like any job, you have to make a living, which is becoming more difficult as funding continues to get cut.”

When you consider all of the expenses involved in getting the correct complex rehab DME to wheelchair users, prices for equipment that is so important to us are very reasonable. Continued pressure to reduce reimbursement is a very real threat to not only gaining access to wheelchairs, but also a threat to our health and mobility.

**RESOURCES**

- ATP Eligibility Requirements: www.resna.org/get-certified/exam-eligibility-requirements
- Manual Wheelchair Use: Bouts of Mobility (sitting time per day): wwwhindawi.com/journals/erp2012/753165/
- National Registry of Rehabilitation Technology Suppliers: www.nrrts.org
- What is Complex Rehab Technology (CRT)?: www.nrrts.org/pages/what-is-complex-rehab-technology-crt

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A high quality, properly fitting cushion is arguably the most crucial complex rehab DME product for people with SCI — anything less can result in a life-threatening pressure ulcer. Unfortunately, Centers for Medicare and Medicaid testing guidelines for cushions are minimal. Moreover, an outdated CMS coding system lumps a myriad of cushions made by different manufacturers into the same “skin protection” codes, which gives the illusion that all cushions in a particular code provide similar tissue protection.

This flawed system encourages “building a cushion to meet the code” (skimping on quality development) rather than investing in research, design and clinical testing — a practice that advances technology and develops superior cushions. Not all cushions provide protection against pressure ulcers even as skin becomes less tolerant with age or from previous breakdown.

“Testing procedures for cushions are insufficient in measuring design variability for skin protection,” says Tom Hetzel, CEO, chief science officer, clinical therapist and ATP for Ride Designs/Aspen Seating. “The tests can be completed by an independent lab in a couple of days at the cost of just a few hundred dollars.”

Cushion tests to qualify for Medicare funding include a Cal-117 fire safety test and a simulated immersion laboratory test, where two cylindrical devices, meant to simulate a human pelvis, must sink 40mm with a 31-pound load without bottoming out after simulated aging of 18 months (the minimum required warranty). “The current tests do not measure pressure, meaning you could end up with a cushion that passes the tests, yet puts tremendous pressure on bony areas of the pelvis and puts the user at risk of a pressure ulcer,” adds Kara Kopplin, senior director of efficacy and research for ROHO.

In order to make cushions safer for wheelchair users, ROHO — in conjunction with Sunrise Medical — invested huge sums of money and years of research to develop a better cushion testing device, one that measures “envelopment” (how well the cushion wraps and supports the pelvis to evenly distribute weight and reduce pressure on bony areas).

Called the Simulated Envelopment Laboratory, the new device is in the shape of a pelvis and has 18 pressure sensors imbedded at typical pelvic pressure points to show the actual pressure readouts on all 18 points when immersed in the cushion. The goal is equal pressure distribution on all areas without any high pressure points. “ROHO uses the new device to test all models of our cushions,” says Kopplin. “As of 2015 the International Standards Organization has published the new device as an international test specification, and in the U.S., RESNA is close to finalizing a published version as well.”

OUTDATED CODING VS. RESEARCH AND DEVELOPMENT

Outdated coding encourages poor-quality cushions. There are at least 100 cushion models made by approximately 20 or more manufacturers in Medicare codes E2622 and E2624 for the type of high-end cushions used by a majority of wheelers with SCI. In 2015, they had a Medicare reimbursement rate of 80 percent of $368 and 80 percent of $371, respectively, and that rate is trending down, not up.

“The current coding system is very dangerous because it does not differentiate between technologies,” says Hetzel. “You have manufacturers with cushions made with cheap combinations of materials and questionable degrees of science and research competing with manufacturers that have invested a great deal of time and money into thoughtful, innovative, clinically tested designs,” continues Hetzel. “Some consumers and many funding sources believe all products grouped in a single code are equal — when nothing could be further from the truth.”

Research and development is a major expense for manufacturers focused on creating a cushion for tissue protection versus “meeting the code.” Ride Designs’ most recent cushion, the Java, took four years of research and development and employed three full-time engineers to get ready for another two years of university studies and research papers. It took two studies of 10 subjects averaging 18 years post-SCI to clinically prove the efficacy of the cushion before they were ready to bring the Java to market.

ROHO has a similar approach. “We spend a tremendous amount on evidence-based research, while other companies that make similar-looking products spend little in this area,” says Dave McCausland, vice president of government affairs, ROHO. “Research costs include manufacturing a prototype mold for every research cushion — something that is very expensive with no guarantee that it will ever reach the consumer. Additional costs include laboratory studies, clinical studies and support papers for the research.”

Quality control and customer service are other fluctuating variables. “We
have three levels of inspection before a product goes out to the dealer and our warranty is at least 24 months and usually three years, when the required minimum is only 18 months,” says McCausland. “If you have a problem with a ROHO during the warranty period, we will ship a replacement right away. We could make a lot cheaper product, have it made in another country, have shorter warranties, and not do immediate warranty replacement, but is that what the wheelchair user wants?”

The goal for elite cushion manufacturers is to have CMS award a separate benefit category for complex rehab DME like the prosthetic industry has had for decades. Innovations in the prosthetic industry are funded favorably, and payment is authorized for the service component. “We don’t have that advantage,” says Hetzel. “When I present our seating concept to a room of prosthetists or orthotists, they all get it. They have been doing this concept of support to control posture and alignment for eons. So I ask them, ‘why aren’t you doing seating?’ Their answer? Insufficient reimbursement funding to cover the service.”

**ONGOING EFFECTS OF REIMBURSEMENT CUTS**

Reimbursement cuts not only jeopardize manufacturers’ ability to provide cushions with quality skin protection, it puts the financial brakes on advances in research that lead toward greater independence and mitigation of risk. “When I have a brilliant idea for seating, I have to consider minimal reimbursement versus development and research costs — without any confidence of a path towards reimbursement,” says Hetzel.

“It is important for wheelchair users to advocate for funding while they still have a chance,” says Hetzel. “Downward pressure on reimbursement is not only causing access issues to correct technologies, it is actually putting roadblocks up to further innovation. Access to quality seating is very tenuous right now. It may take the loss of this access for consumers to say, gosh, I should have advocated a few years ago.”

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**GET INVOLVED**

- Write down your DME reimbursement story. Share it with your families, friends, social media networks, health care professionals and most importantly, your congressional representatives. Find contact info for your elected official here: www.unitedspinal.org/action-center/.
- Get to know your senators and representatives. The most effective strategy to make an impact on any elected official is to build a relationship with that person. Write to them, call their office, schedule appointments to talk with them about this issue and show up at community events they’re speaking at, such as town halls. By spending time getting to know them, you may get their vote in support of your issue today or in the future.
- Join the Advocacy Alliance (www.unitedspinal.org/advocacy-alliance/). To learn more, contact Jenn Wolff, United Spinal’s Advocacy Alliance Manager, at jwolff@unitedspinal.org. Look for Wolff at the Advocacy Alliance’s “Sound Off — Selfies and Stories” booth at Abilities Expos and consider sharing your story on video.

— Jenn Wolff

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OK, every year can’t be great. But big-time commercials can also be seen as cultural road signs that often precede other media in spotting and exploiting social trends. For example, recently both television and print advertising featuring people with disabilities is on the rise and decidedly more prevalent than the inclusion of people with disabilities in television programming itself. Every expert I talked to, from advertising journalists to Hollywood talent agents, agreed. It’s somewhere between more than occasional to a trend.

Advertising has to break through the clutter and get your attention. These days it is being done with what Hollywood talent agent Gail Williamson calls “vanilla — the friendly black doctor, the overwhelmed soccer mom, that vivacious young woman trying to sell you a phone plan.” And what is more vanilla than Honey Maid Graham Crackers? That’s about as close to “Leave It To Beaver” ’50s blandness as you can get.

The Honey Maid people, knowing that no one will notice an all-vanilla cracker ad, decided to take a chance and appeal to real American families. They launched a campaign called “This is Wholesome,” featuring same-sex couples, single dads with tattoos, and a mixed-race military family, all eating delicious graham crackers. The result? Hate mail galore from those who thought same-sex couples were shameful, with comments like “this is an attempt to normalize sin.”

The company’s response was to take all of those nasty letters and mesh them into a huge sculpture in the shape of the word “LOVE.” When the response came out, it was reportedly the most shared online message on the face of the earth. According to Honey Maid, “In one month, Honey Maid went from a graham cracker that people loved to a brand that people loved.” This appears to be the near future of product advertising in America, or a big part of it — a turn toward reality. And it’s a trend where people with disabilities can be a potent part of the mix.

The ad agency reached out to disability media expert, Tari Hartman-Squire, to assist with authenticity and outreach. The very next “wholesome family” ad that Honey Maid released was called “Apple & Cheese Melts,” featuring a woman who uses a wheelchair helping her niece make graham cracker melts. You don’t notice the wheelchair until

It’s a national pastime to hate commercials. Only during the Super Bowl are commercials given any respect. That’s when the best of the best show up, or so they say. This year, the best of the best was a troupe of wiener dogs dressed in hot dog buns.
COOL PEOPLE IN WHEELCHAIRS ARE DECIDEDLY NEW CONTENT, RIGHT ALONG WITH HEAVILY TATTOOED DADS AND MIXED RACE COUPLES.

Clockwise from top left: Kroger grocery stores, Toni&Guy hair salons, Kleenex tissues, Honey Maid graham crackers, Target stores, Axe men’s products.
Online videos can be longer than TV ad spots and often tell stories with high "social currency."

So, why are things in Ad Land so different from 10-15 years ago? Josh Loebner, director of strategy at ad agency Design-sensory in Knoxville, Tennessee, writes a popular blog about advertising and disability, www.advertisinganddisability.com. He has a clear-eyed view of both subjects. "Advertisers," explains Loebner, "can no longer advertise a product’s features and benefits. Everyone knows what a Coke is. To make an impact, they have to make social and emotional connections with potential buyers. Honey Maid isn’t selling crackers. They’re selling a social trend that real buyers can relate to.” “Nowadays,” he says, “ad makers don’t want just financial currency. They also want social currency. The latter brings more visibility and more engagement and can last a lot longer than just one impulsive purchase.” And in Loebner’s view, “Social media now means everyone is an advertiser.” Buick ads or Dollar Shave Club ads — same potential exposure. It’s a level playing field with the most remarkable material, from Funny or Die to the women-centric blog, Jezebel, rises above the endless mind-numbing GIFs. This limitless platform is as new to advertisers as it is to the rest of us, and when something like the Honey Maid campaign attracts millions of eyeballs, virtually for free, the whole industry starts buzzing.

WHAT HAS CHANGED?

So, great, the airwaves, both analog and digital, are now crawling with disability-centric ads? Not exactly.

Perhaps the country’s leading authority on this matter, at least in terms of quantitative analysis, is Olan Farnall, Ph.D., a communication and media scholar at Texas Tech University. In 2012, Farnall conducted an exhaustive survey of what he called “ability-integrated” TV advertising (AIA) and compared it to a similar study done in 2001. In a sampling of over 1,600 commercials, Farnall found that 29 made the grade. Doesn’t sound like much, does it? In 2001, the number was 15, i.e., half as many. Extrapolated from his sampling, there are far more ads out there than 1,600 and far more AIA ads than 29. Today is a huge ad universe. Counting in multiple repeats, there may be as many as 1,500 30-second spots airing a day!

Farnall estimates that the frequency of ability-integrated ads is about 1.7 percent. By comparison, in the last study published, the frequency of actors with disabilities in speaking parts in a given television programming season was .5 percent. Get out your calculator — that’s more than three times greater.

It has been four years since Farnall canvassed the TV commercial landscape, so the uptick from then to now is largely anecdotal. Farnall himself sees two ongoing trends. First, the increasing presence of AIA ads on cable television as opposed to traditional broadcast outlets. Cable shows, at least the good ones, try to break every barrier known to man, so seeing an AIA ad during Breaking Bad or Transparent doesn’t seem risky at all. To the demographic watching such cable offerings, these ads fit right in.

The second trend Farnell notes is a marked spike in the quality of such ads and their depiction of people with disabilities. In the past, commercials would normally paint someone in a chair as one of those two hoary clichés — superhuman or needy. Now, more often, they are presented like Stephanie Woodward in the Honey Maid ad — just normal people going about their daily lives [see sidebar].

Barbara Lippert, a prominent advertising journalist who wrote the award-winning “Critique” column for ADWEEK for years and now has her own blog, MediaPost.com, says that she is “encouraged by the difference now in the level of awareness and sensitivity ad makers have for people with disabilities. It gives the ads both texture and reality.”

Lippert points to a recent ad as an example — Swiffer, maker of nifty new mops and the like. The ad, called “The Ru-kavina Family,” features a single-armed Caucasian amputee who boasts about his ability to “out clean” his African-American wife as their mixed-race kid cheers them on. This is the advertising version of a hat trick: a white-guy amp in a mixed marriage proudly doing housework. He could have been in a wheelchair and still got across the same message.

WHEELCHAIRS IN YOUR LIVING ROOM

There are dozens of other examples of this rise in the portrayal of people with disabilities, specifically in wheelchairs, entering your living room. The first such commercial of 2016 is for the youth-market deodorant for men, Axe. In a campaign called “Find Your Magic,” we hear the announcer say, “You don’t need heels when you ride those wheels” — and we see a cool guy in a chair whirling his date on the dance floor at the high school prom.
It’s the holiday season and the doorbell rings. Nick Magistrale, 35, T7-8 para, goes to the door in his manual wheelchair, opens it and an animated woman, mid-30s, instantly hugs him with a big “Hi!” Nick responds, “It’s wonderful to see you.” A man, Asian-American perhaps, follows closely on her heels, and Nick greets him warmly. It’s a party, a gathering, and one by one the guests connect, exchanging pleasantries, mostly about how “wonderful” everything is — the prime rib, a gift someone received, a sliced ham. And then comes the dinner toast. Sitting at the head of the table, Nick raises his wine glass with the others. “And to all of you,” he proclaims, “and the most wonderful time of the year. Cheers.” The room is filled with the clinking of wine glasses and voices raised in unison. “Cheers!”

What a spontaneous feel-good moment! — and it’s all carefully scripted, cast, rehearsed, and filmed for airing around the nation by Kroger, one of the world’s largest grocery retailers, with 2,600 stores in 34 states and annual sales of $108 billion.

The call for a 30-ish man who uses a wheelchair went out last September. Magistrale’s mother saw the newspaper ad in the Portland, Oregon, area. She called her son in Tucson and bugged him until he finally made arrangements to fly to Portland to audition. Nick was hesitant at first, never having acted before. But he was perfect for the role, just the type of warm, diverse Millennial that Susan Ramsay, director of creative services for Kroger, and Julie Patterson Holland, head of production, wanted for Kroger’s in-house-produced TV commercial. “Our goal was threefold,” says Ramsay. “We wanted authenticity, connection and emotion, and we wanted to use actors and people who come across as real people gathering for a holiday dinner.” She wanted the cast to represent the kinds of people who might live in a city but be apart from family. The message would be warm, uplifting and real, without overselling.

Thirty-plus cast members showed up in Portland for the all-day shoot, meeting and greeting. “Nicholas emerged right away as someone who could act as a congenial host and leader,” says Holland. “He had a way of putting everyone at ease.”

When you think about it, he had just the right background and experience. “It goes back to my injury,” says Magistrale. “I always tried to make others comfortable around me. That feels good. That’s rewarding,” he says. It is not an uncommon experience for those of us who must adapt to such a sudden and unremitting change in our lives — instant disability, wheelchair awkwardness, unspoken assumptions of others. Gradually we learn to put people at ease. “I was fortunate to work with such a great group,” says Magistrale. “It was a lot of fun. At first I was nervous, but I did a little research on how to keep calm. Basically the best advice was to just be myself. Don’t act.”

Magistrale was a 17-year-old senior at Lake Oswego High just south of Portland — a star football player bound for the University of Arizona on a full athletic scholarship — at the time of his 1997 accident. Besides his SCI, he sustained broken ribs, a punctured lung, pulmonary edema and was life-flighted to Oregon Health Sciences University. “It was a nasty accident. I had to be resuscitated, was pretty much dead. They brought me back, cleared my lungs of fluid, put me into a drug-induced coma and on a respirator. But I had tons of community support, that was the key,” he says, still grateful. Not only was he fortunate to live, he still received that full-ride scholarship — even though he would never play football again.

So now what? Will he try to capitalize on his 30 seconds of fame and go into acting? “I just need to look into it. I’m fresh meat. No idea what I’m doing. But it’s been a lot of fun,” he says. “In hindsight I’m so glad I did it.”

Perhaps the best part happened during the holiday season when the commercial was airing all over the nation. “I was in an airport, and you know how it takes longer for wheelchair users to go through security. One of the TSA attendants comes up to me, a mature lady, sweet and friendly. I was tired from traveling, had my head down. ‘I know who you are,’ she says. ‘You’re the guy from the commercial. Mr. Wonderful.’”

“Yeah. That’s me,” he says. — Tim Gilmer
If you watched Super Bowl 50, only one ad featured a wheelchair — for SunTrust Bank — and "featured" here means the man in a chair showed up for a second or two, but a second or two in front of 167,000,000 viewers. A pre-game Toyota "Fathers and Sons" ad featured a football star talking about his double-amputee dad, and last year, Toyota and Microsoft ran powerful ads featuring double amputees using state of the art prosthetics. Double amps, I guess, make for arresting images.

Here are a few other current, wheelchair-referenced spots to check out: a Petco ad opens with quad actor Toby Forrest whizzing down the block being pulled by his frisky dog. Lego is about to launch a campaign that features a Lego-made kid in a wheelchair with a service dog. Target now runs both print and TV back-to-school ads with kids in wheelchairs and on crutches playing around in bright colored clothes like all their classmates.

And there are more: Nordstrom has ads and catalog photos featuring a series of people with disabilities, including quad beauty and Push Girl, Angela Rockwood. J.C. Penney has a guy in a chair getting married. A longer version of the Toyota "Fathers and Sons" spot features an off-camera interviewer asking a child in a wheelchair what he likes most about his dad. His answer: "He takes me everywhere!"

When these ads are masterful, they stay in your brain forever. Remember the Guinness Beer "Wheelchair Basketball" ad of a couple of years back, where only one guy in the game is an actual wheelchair user? Of course you do. It's an instant classic.

Now some might see that spot, and many others, as "inspiration porn," with the elbow-throwing guy in the chair being the inspiration. Adman Loebner points to another spot that might draw the same reaction. Made for Kimberly-Clark, aka, Kleenex, it is called "Unlikely Best Friends" and features a paralyzed dog and a paralyzed man and their man-dog camaraderie. "Chance," the dog, hit by a car and close to euthanasia, is an ever-present reminder that, back legs or no back legs, life is good. Kleenex is never mentioned until the final graphic.

"Ah," you're saying, "isn't that an overly sentimental scene?" Not really. These are real people, in their real home, wearing their real clothes, with real sentiments. As the man's wife says about the para-dog, "It's so nice when you come home, he's running at you at the door, going so fast, his butt slides into the wall ... it makes you appreciate life." If you've ever been around dogs using a wagon for legs, you know what she's talking about. They couldn't care less that they are impaired. Chasing a bone is chasing a bone. Maybe there is good inspiration porn and bad inspiration porn. Put this one in the good column.

Williamson, who just happens to be the leading agent for actors with disabilities in Hollywood, has a unique vantage point on this phenomenon. Dealing only with performers, she, too, has seen a lot more business in the last three years. Before, she says, "the requests from the ad world were for a generic 'disabled person.' Now the breakdowns (i.e., casting sheets for actors) are getting both more specific and more real, to the point of wanting actual family members.”

"The difference between commercials and TV shows," she adds, "is that commercials don't require a lot of acting. Ads are about image, not acting." The image has to be unquestionably believable. Today's commercial makers don't want a nondisabled person, no matter how famous, playing a disabled person. That would ruin the message.

NEW MONEY ON THE BLOCK
Even if they are only image-enhancers, performers with disabilities were nonexistent for most of TV advertising's history. Hartman-Squire, one of the principals behind the "Lights! Camera! Access! 2.0" think tank, traces the emergence of ads featuring people with disabilities to the 1984 Olympics in Los Angeles. Levi's ran a bold spot featuring a youthful couple on a walk when the camera pulls back to show the guy doing a wheelie. The same year a Paralympic wheelchair user, George Murray, was the face on a box of Wheaties. "For decades," says Hartman-Squire, "a spot with a family with a member with a disability was a rarity. But the zeitgeist changed.”

Beyond the changing style of advertising, two other factors add to the current, and hopefully ongoing, growth in disability-related ads: Millennials and
money. Millennials, according to *Forbes*, will make up half of the workforce by 2020 and are now the target audience for thousands of marketers like Axe or Dollar Shave Club — they have disposable cash and are not yet brand-loyal. To get to these youngsters, you have to go where they are watching, and that ain’t the CBS Evening News. It’s cable and social media, and the ads better have new style and new content.

Cool people in wheelchairs are decidedly new content, right along with heavily tattooed dads and mixed race couples. Seeing a wheelchair user dancing is something Millennials have seen over and over again at Coachella or Bonnaroo. In their minds, ads like this are simply catching up with their everyday reality.

But the Honey Maid or Kleenex people weren’t targeting just Millennials. They were going after you and me. You may have heard these mind-boggling statistics before, but the disability demographic in America, all 50-plus millions of us, has about $200 billion in yearly purchasing power. That seems like a lot, but there is more. What is often overlooked is that an ad featuring a disabled person is also trying to hook in all those close to that person with a disability, and when you add up all those uncles, aunts, and close friends, you are now looking at purchasing power of an awesome $3 trillion. That’s a lot of Toyotas and Lego bricks. It’s an ever-widening circle. One expert summed it up nicely. “It’s not a niche — it’s a blockbuster.”

Lippert points out that unlike certain politicians running for president, ad makers can’t afford to be exclusionary in a wildly heterogeneous culture like contemporary America. Demographics don’t lie. They need every Muslim, Millennial, same-sex-married wheelchair user they can find. Like that big Honey Maid sculpture constructed from hate mail, they preach love and acceptance of all people, an almost dissident message in such a fragmented, hate-filled society.

Well, that’s my pitch — did you buy it? The truth is, we shouldn’t get carried away here. The potential is great, but the number of ads showing people with disabilities is still infinitesimally small. As Loebner points out, “Ads featuring people with disabilities are still a novelty — that’s why good ones get talked about on morning TV shows and in *Time* magazine. The day they become widespread, they’ll lose their gee-whiz quality, which might be a good thing.”

In the meanwhile, we should all support the sponsors who support us by posting and sharing these spots on line, the fastest rumor mill known to man. Also, make the ad men happy and buy the stuff. I have never bought a graham cracker in my life, but if I ever get the hankering, Honey Maid is the ticket. I’ll get to the grocery store to buy it driving my new Toyota and stopping at Petco, Target, Nordstrom and J.C. Penney along the way.

I’m a sucker for a good ad.

**MAYBE THERE IS GOOD INSPIRATION PORN AND BAD INSPIRATION PORN. PUT THIS ONE IN THE GOOD COLUMN.**

Muniba Mazari is proof that the trend to include wheelchair users in ads is going global. She appears in a campaign for Toni&Guy, a London-based international chain of upscale hair salons.

In addition to being known for modeling, Mazari, 29, who lives and works in Pakistan, is an anchor for National Television of Pakistan and was named one of BBC’s 100 most inspirational women of 2015. She is also a singer, motivational speaker and education advocate.

Fittingly, Mazari, who was injured in a car accident at 21, wasn’t just showcasing her beauty and style in the Toni&Guy campaign, which was titled “Women of Substance.” Recognized for her intelligence and resilience, she was featured alongside a nondisabled architect, professor and school director, among others. Learn more at www.munibamazari.com.

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*Kleenex navigated a fine line with its TV-magazine-style story about an active wheelchair user who adopts a paralyzed dog. It does tug at the heart (keep the Kleenex handy) yet it feels dignified and true to life.*
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MY TAKE
After 18 years living here as a wheelchair user, I’ve adapted to the gray, overcast weather and I’ve learned to appreciate the “sun breaks” (as our weather forecasters so proudly call the respites of sun). I am not alone. The Portland metropolitan area has a good-sized wheelchair-using community — people who tolerate the drizzle and gray in return for the accessible bounty offered by one of our country’s lushest regions.

If you are worried about washing away in a deluge, know that Portland averages 43.5 inches of rain per year. That is less than New York (49.9), Boston (43.8) and Atlanta (49.7) and on par with places not associated with rain, like Cincinnati (41.9) and Washington, D.C. (39.7). That said, Portland has the third-most rainy days of any big city in the nation (164), trailing only Buffalo and Rochester, New York. It rarely rains hard, but we do have lots of gray, drizzly days. But summers are perfect and, as long as you don’t mind cloud watching, the rest of the year is pretty mild. I have had great success avoiding the rain. My chair has only died from waterlog twice.

PLACES TO GO
One of my favorite places to go in Portland is Council Crest, a park that doubles as the highest point in the city. On a clear day, you can easily see the looming majesty of Mount Hood, a decapitated Mount St. Helens, the peaks of Mount Adams and Mount Rainier and a huge swath of the fertile Willamette Valley. Literally, you find yourself surrounded by beauty and easily accessible destinations for a hike, picnic or simple outing. It’s easy to understand why a former governor here famously said, “Come visit us again and again. This is a state of excitement. But for heaven’s sake, don’t move here to live.”

Another accessible highlight is the Springwater Corridor Trail, a 20-plus mile paved path that runs along the Willamette River through downtown and into the country. Start your wheeling or handcycling adventure on the brand new Tilikum Crossing (in photo), the first major bridge in the United States designed to allow access to transit vehicles, cyclists and pedestrians, but not cars. Keep your eyes open for bald eagles and other wildlife as you swing by Oaks Bottom Refuge and decide just how far you want to push yourself.

GETTING AROUND
Thanks to an intricate network of fully-accessible buses, light rail, and street cars, getting around town is a snap. A wheelchair van makes ramping around town easy, as parking is free downtown and in any metered spots for wheelchair users. Portland also has a decent number of accessible cabs, should you need a late night ride or something else out of the ordinary. While Portland’s western edge is bounded by hills, the downtown and eastside are mostly flat and easily rollable.

AVAILABLE HEALTH CARE
With three large hospital systems (Legacy, Providence, Kaiser) and internationally renowned Oregon Health Sciences University, there is an abundance of medical expertise around. I did my rehab at the Rehabilitation Institute of Oregon, part of the Legacy system, and have been impressed by the care I’ve had access to. Befitting its alternative image, Portland also boasts a number of alternative medicine options, including the National College of Natural Medicine, the oldest accredited naturopathic medical college in North America.

MUST SEE, MUST DO

RESTAURANTS: Portland City Grill’s views from 30 floors up are too good to pass up, as are the steaks and fresh Northwest seafood. Or try Departure, with a modern, fusion-Asian menu and cocktails from around the world — also with a view.

VENUE: Powell’s City of Books is the biggest and best bookstore you will ever go to. Seriously. It takes up an entire city block and houses over a million books.

MOVIES: Across the street from Powell’s, enjoy the ultimate comfort in a movie house. Living Room Theaters has small, HD screens, hard-to-find flicks, and wine and beer delivered to your recliner.

SKINNY ON THE CITY
Portland offers much more for wheelchair users than the incessant rain and surplus of hipsters that popular media present. An amazingly accessible transit system, easy access to year-round skiing and beautiful beaches and one of the country’s most vibrant music and food scenes ensure that Portland has something accessible and amazing for just about everyone.
Pizzas are sizzling in the oven, specialty beers are flowing from the tap, and lively tunes are blasting throughout the bar. It’s just a typical, crowded last Monday at The Lucky Lab Brew Pub in Portland, Oregon. And although the atmosphere is already rocking, when West Livaudais and his crew arrive around 6:30 p.m., the place really gets rolling. Livaudais is the founder of The Oregon Spinal Cord Injury Connection and the monthly Wheel Connect gathering, which brings the local SCI community together for a social evening to gather support and share experiences.

“When we started a little over a year ago, we only had five people show up. Now the group has grown to 35, with family and friends sometimes making it 50,” Livaudais says. “We have become close and have developed a camaraderie and strength together through our relatable stories.”

For Livaudais, that story began back in 2013. Having always possessed a deep desire to help people, Livaudais was living in Guatemala working for Medical Teams International as the maternal and child health program coordinator when he was hit by a truck and sustained a severe hip injury.

Livaudais returned to Portland immediately. Complications followed and he developed a dangerous infection and abscess, which ultimately pinched his spinal cord, paralyzing him at the C7 level.

Livaudais says the idea for Wheel Connect came to him on a whim while having a drink after therapy with a friend who was also a wheelchair user. “I thought, why can’t we make this a group thing?” he says. “We started to invite a few more people, and the whole idea kind of blossomed from there.”

Wheel Connect was the first step, and from that Livaudais created the Oregon Spinal Cord Injury Connection to help those with spinal cord injuries throughout the state of Oregon. “Oregon SCI Connection is a group for all those affected by spinal cord injury, new and veterans alike,” Livaudais explains.

In addition to Wheel Connect, The Oregon SCI connection has also created a forum to open dialogue between people with spinal cord injury and health care professionals to help transition to life after rehab. The forum covers a variety of issues, including emotional, physical and psychological obstacles that the SCI community faces. The meetings typically take place at the Rehabilitation Institute of Oregon in Portland. Recent workshops and discussions have included dating and relationships after SCI, regaining independence through transportation, and a discussion among women with SCI, just to name a few.

The Oregon SCI Connection recently became an affiliated chapter of United Spinal Association, a big step in furthering the reach of the organization beyond Portland and throughout the entire state, according to Livaudais.

He plans to launch an SCI peer mentoring program, which would train experienced people with SCI to help individuals with new injuries. “I imagine developing a community health outreach program that would improve the health outcomes and social and emotional adjustment of those recently discharged with SCI. Veteran wheelers with SCI are qualified to be community health coordinators because they have knowledge of the difficult adjustment to this new life,” he says. “As community health coordinators, they would collaborate with local SCI rehab programs and home health to outreach to newly-discharged people with SCIs and their families.”

Although his path may have suddenly changed, Livaudais says he is still fulfilling his desire to help people, but just in a different way.

“It was through my work with Mayan mothers in rural, indigenous communities in Guatemala that I learned how to utilize the dynamics of community engagement to leverage a community’s strengths to promote health,” he says. “Ultimately, I want to strengthen and engage others to promote their own health and well-being. Now, finding myself in the SCI community, I want to use my experience and training to build this community to promote its own strength.

We’ll learn as we go.”

Wheel Connect meets on the last Monday of the month from 6:30 p.m. to close at the Lucky Lab Brew Pub, 1495 NW Quimby Street, in Portland. For more information on The Oregon Spinal Cord Injury Connection, visit www.oregonsci.org.

— MAUREEN GAZDA
Getting to Know the United Spinal Resource Center Team

Bill Fertig doesn’t shine a wheelchair-shaped distress symbol into the night sky every time a call comes in to the United Spinal Resource Center, but for callers in need, the team of experts he assembles may be the closest thing to SCI/D superheroes out there. Every month, they use their unique skills and expertise to resolve hundreds of inquiries about spinal cord injuries and disorders. Here’s a quick look at the (super)heroes who make up the team.

Bill Fertig, Director
Superhero he resembles: Captain America
Every team of superheroes needs a leader with vision who devises brilliant plans. That’s Fertig. “One of the greatest things Bill brings is an ability to see everything and connect the dots,” says Jane Wierbicky, the Resource Center’s nurse information specialist. “He’s super compassionate and tireless, and he’s great at bringing people together.”

Lindsey Elliott, Director of Member Initiatives
Superhero she resembles: Wonder Woman
With laser-like focus and a big heart, Elliott is a problem solver who strives to improve and help everything she touches. Her background as a social worker gives her unique insight and makes her well suited to lead programs like United Spinal’s Peer Mentor Training. “She has built her programs to be much larger and deeper than when she took over,” says Fertig. “She brings drive, energy and enthusiasm to everything she does.”

Jane Wierbicky, Nurse Information Specialist
Superhero she resembles: Jean Grey
As the only team member with a background in nursing, Wierbicky is the go-to team member for tough medical cases, but she brings much more. “She has a great background and experience in different SCI experiences,” says Fertig. Elliott calls her the “heart and soul” of the team: “She always finds that personal human connection.”

Daniela Castagnino, Information Specialist
Superhero she resembles: Beast
Castagnino is “the brains” according to her teammates. “She’s great at finding the right resources,” says Wierbicky. “She loves to dig deep and find things that can help people.” That passion makes her perfectly suited to the Herculean task of updating United Spinal’s voluminous resource guides. And she’s got a wicked sense of humor.

David Heard, Membership Coordinator
Superhero he resembles: Deadpool
Without Heard, inquiries might fall through the cracks or end up on the wrong person’s desk. He doesn’t let that happen. “He keeps things going behind the scenes,” says Fertig. “Living with SCI himself, he recognizes the needs people have, even in a routine email.”

Power-assisted arm support GoWing
GoWing provides a stable support for precise activities. GoWing supports the execution of numerous daily activities.

Assistive robotic arm JACO
JACO was created to be user friendly and intuitive, allowing performance of daily tasks, objects manipulation and interaction with environment.

Front row: Nick LiBassi, director, chapter relations; Bill Fertig, director, resource center; Daniela Castagnino, information specialist; Back row: Jane Wierbicky, nurse information specialist; Abby Fitzsimmons, COO; Lindsey Elliott, director, member initiatives.

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Assistive robotic arm JACO
JACO was created to be user friendly and intuitive, allowing performance of daily tasks, objects manipulation and interaction with environment.

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Same Friends, Different Reality

Almost inevitably, there are social fears after the trauma of a spinal cord injury.

Megan, injured at age 18 in 1995, says that beyond the physical changes she faced after her T5-L1 injury, she felt certain she was going to lose all her friends — and that was terrifying. “My greatest fear was that all of my friends would abandon me and that I would never have a family or a husband or children or anything like that,” she says. “That I would have to give up any thought of ever having a normal life.”

Luckily, none of that came to pass. “I had enormous support from friends, a very close circle of friends, that were always there and said, ‘no matter what, we’ll be there for you,’ which was very helpful because I went back to school three months after my accident.”
Today when Megan addresses her friends on the subject of her life with a disability, she always tells them, “It’s not easy to live with any kind of disability, it’s a hard life, but at the same time you can be happy and fulfilled.”

For Vicki, a C5-6 quad, today the biggest problem with her friendships is reminding them of the more concrete realities of using a wheelchair. “With my friends, it’s really funny, because they forget I use a wheelchair,” she says. “They make plans to go somewhere, and I say, ‘what’s the parking like?’ Or, ‘am I going to be able to go to the bathroom at this place?’ and they suddenly gasp, ‘Oh! I forgot! We’ll have to reconsider.’ It happens.”

After Vicki’s diving accident, the then-22-year-old quickly realized that in addition to handling all the physical changes of her injury, she also had to take the lead on helping her friends deal with her injury. This is a strategy she employs today as well.

“When I meet someone new, it is my job to make them feel comfortable with my wheelchair,” Vicki says. “It’s still true nearly 30 years later. I meet people who are uncomfortable with my injury and the way my body looks, and I have to help them understand that I’m OK.”

This is especially important during those times when she’s really not all that OK. “Sometimes I’ll have a change in my health status. Things like a bout with autonomic dysreflexia or a broken bone from a fall,” she says. “When I can see the worry on my friends’ faces — that’s when I know I have to get back to reassuring them it’s all part of living with paralysis.”

After all, nondisabled friends have no idea what it’s like to live with an SCI unless they’re told — as uncomfortable as telling them might be. Chase has lived with T11-12 paraplegia since age 17, and says that although it took a while for his friends to become comfortable with him again after his 2007 injury, they got through it. “I’m closer with my friends now, definitely very close with all my friends. I’d say I’m with them probably every day,” he says. His secret? Being open and honest about all that his injury entails, and showing he’s OK with it. “I
came out and just said, you know, 'Hey guys, I wear diapers sometimes, I pee my pants sometimes, and I’m going to need help doing this — help doing that,’ and they just kind of accepted it. And, it’s normal now.”

The key is to remember things are different for everyone post-injury, including our friends, says Tony, a C5-7 quad injured 25 years ago when he was 27 — but that most situations improve with time. “Just understand that this is a learning experience,” he says. “Everything is going to change because the person in the wheelchair is going to get better at some things. And the person in the wheelchair is probably not going to need some of the things that they used to need [right after their injury], they’re going to end up needing new things. Everything is going to evolve and change — but for the better.”

It may sound hard to believe that life can get better after a spinal cord injury, but Michelle, a C6-7 quad injured at the age of 21 in 2002, says it’s true for her as well. “I am very happy,” she says. “I always say it’s kind of strange, it took this tragedy to happen to me to put my life in perspective. Like, before I was injured, I didn’t go to concerts, I didn’t go to plays, I really didn’t go out of my comfort zone, but now it’s like I push myself to do things like that.”

Perhaps having wonderful, supportive friends has helped her recovery? “My friends have been great,” she says. They were very supportive while she was in rehab and that continued when she was released. “Before we got the lift in the house, if I needed someone to help me with stairs, they would.”

And she is supportive to them in turn. “You know how there’s that one friend in every bunch who everybody needs to get advice from? Well, that’s me! So now everybody’s always at my house — ‘Oh Michelle, I need to talk,’” she says. “So they’re great, I love them! And if I ever need a ride, I always have one.”

The Pain of Friendship Lost

Giving yourself some time to adjust, and your friends’ as well, is often all that’s needed for most relationships to get back on track and feel comfortable again. But for some friends, nothing seems to work.

At age 62, in 2008, Nova had a fall that resulted in T6 paraplegia. She says her greatest fear was losing her deeply loved, longtime friends. Not only did that partially come true, but she was shocked by how easy it was for some of them to detach.

“I have written emails to people who didn’t know what happened to me, or heard back from people who did know what happened to me, and tried to touch

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bases, and no response,” Nova recalls. “And I remember writing to this one woman whom I’ve known for 25 years, saying: ‘I don’t want to pressure you, and I don’t want to impose upon you, but I’m hurt, and we have such history with each other. I love you, what’s wrong?’ One friend didn’t reply at all. Another wrote back: ‘I feel like an awful person, I just don’t know how to handle it.’ And I responded, ‘I’m totally willing to help you handle it because I don’t want you out of my life. I’m not embarrassed to answer anything, feel free to ask.’"

The friend who wrote she felt like an awful person is much younger than Nova and they had become friends while working together on setting up commercials and personal appearances for professional athletes. Nova was an important mentor and as the friendship grew, Nova recalls, “She even began to call me her mother. Her own mother had been dead for a long while.”

In my mind there are two types of people who leave a friendship, and they are very distinct,” says Dr. Lester Butt, rehabilitation psychologist at Craig Hospital, in Denver, Colorado. “It’s important for people with a spinal cord injury to appreciate the difference.”

“The first set of people who leave are those with whom your relationship was predicated upon fragile kinds of parameters, things like, ‘all we did is party;’ ‘all we did was go out and hunt.’ These are activity-based relationships,” he explains, and “if the person with a disability can no longer engage in those activities, the friendship might not have as much power for the non-disabled person, and they can leave.”

The second subgroup of friends who can detach, withdraw or potentially leave is very different from the first network. “These are people who care so deeply, care so much, or feel that they have such little skills in terms of understanding that they pull away,” he says. “The person with the injury has to appreciate or discriminate between those two, to be able to reach out to the latter group. It is vital not to leave friends behind who are really caring.”

Johnathan, who became paraplegic at age 19, tells how he was able to preserve friendships that fell in the second subgroup. In the beginning, his friends came to the hospital every day. “But once I was home, my friends would visit and say, ‘We’re just stopping by, and we’re going to get something to eat.’ And I would think after they left, ‘Why won’t you just come and get me, and take me to get something to eat with you, instead of only just stopping by?’”

So he let them know how he felt. “And once my friends understood that I wanted to hang out, and come out, and do different things, we started to actually go do those different things.”

Butt says Johnathan’s experience is typical of the way strong friendships can begin to grow after a spinal cord injury — and of how the person with the disability usually must take the lead.

“It is very important to be able to educate friends that even though how someone with a spinal cord injury gets from A to B might be transformed, and how they access social or work activities may change, their heart and their brain remains the same,” says Butt. “And usually, so do their values, dreams, goals and humanity.”
Nova’s husband Don called this friend the day after her surgery to inform her about the fall and her diagnosis. “Don said she could hardly speak because she was crying so hard. He tried to console her and called her a few times after that to give her updates on my progress,” she says. “She sent a huge box of presents to the hospital that I received a week after she heard the news.”

“Almost six weeks after my surgery — when I was not drugged so deeply that I could not talk — I did the best I could to write her a thank you note, and to call her. For weeks, I only got her voice mail and left countless messages. She never called back.”

“It’s been almost eight years now since Don reached out to her to give her the news about what had happened to me. My heart is broken, and I have tried every way to give her reassurances about how much progress I have been making. I also want to let her know I will still answer any questions she has and try anything to help her feel more comfortable with me.”

Nova says that though she was not able to recover that particular painful loss, she has learned to focus on those who journey with her. “I am totally blessed with relationships that actually grew and intensified in the love expressed in friendships both new and old,” she says. “So, I have chosen to focus on those relationships and put all of my energy into honoring them with reciprocal love and friendship.”

**Breaking Free of the Friend Zone**

Nick was 17 and still in high school when he was injured at the C5-6 level in 1995. He says it was hard finding genuine friends at first.

“Some friends were great, they were there taking all the blows with me, and really supportive of everything going on and wanted to help with whatever they could,” Nick remembers. “Other friends just kind of disappeared, or started avoiding me in the hallways and not returning phone calls. So, I pretty quickly realized who my true friends were, and people who were just there for their own selfish reasons. It was a great learning experience for me, as it kind of gave me a good crash course on true friendship, and the friends that stuck with me are still around me today.”

One of those friends who stuck with Nick was Suzzi. And over time that friendship bloomed into romance and then marriage.

“My wife and I were friends in high school and ended up going to the same community college, and during that time, our friendship turned into a relationship,” says Nick. “We dated for six years, all through college, and then we were married the summer after I graduated.”

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Suzzi says she’s a very strong woman and her marriage has only enhanced that strength. “I believe that our relationship has only made me a stronger person both individually and together. I know that friends and family had questions at first about our commitment, but once they got to know Nick, they understood why we worked so well.”

As with any successful relationship, Nick says a big part of theirs is communication. “We can’t avoid the fact that I’m in a wheelchair, I have a spinal cord injury, and there is stuff that comes along with that,” he says. “Early on, we really had to talk about how that had an effect on the relationship and how it could slow things down, or kind of hinder activities. But, we did a really good job of communicating, we’re very open with each other, very open about how she felt and also very open about how I felt, and it’s worked, it’s worked out really well.”


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Q. I’m 57 years old, in my 40th year as a T12 complete para. Five weeks ago I was in my chair getting dressed with my left leg crossed and resting on my right knee while I put on my shoe. When I leaned forward to tie the shoe, I heard a dull pop and my left knee dropped. Within moments my mouth went dry and my heart started racing — I knew I had broken my left hip.

At the emergency room, X-rays confirmed I had broken my left trochanter (the bone that leads from the femur to the ball that fits in the socket) in two places. An orthopedist said my fracture would heal on its own if I wore an orthotic brace and kept my leg quiet for three to four months. Another orthopedist came in later and said he could stabilize it by inserting a “long intramedullary nail” (long rod) the length of my femur and running a sliding hip screw through an angled hole near the top of the IM nail to secure the trochanter and hip ball.

I opted for surgery and was up in my chair and home, albeit slow and careful, in five days. Unfortunately, within a month the sliding hip screw pulled out of the hip ball and the surgeon had to remove it. The good news is he says everything is lined up and lots of new bone has already grown in. The plan now is to keep the hip supported with pillows while lying down and carefully supported while transferring — he is hopeful it will finish healing on its own within a month. With SCI, how does one know which route to choose when healing a fracture?

— Darren

D arren, excellent question. According to a 2005 research publication, “Pathologic Extremity Fracture Care in Spinal Cord Injury,” people with SCI have a 40 percent incidence of fractures to the lower extremities (hip and leg). The article explains that the rate is probably much higher because fractures treated at non-SCI centers are not reported.

The high fracture rate stems from osteoporosis caused by chronic SCI, says Dr. Douglas Garland, an orthopedic surgeon and former director of neurotrauma at Rancho Los Amigos Rehab Center. Garland, who has researched SCI and osteoporosis for the past 25 years, explains that the longer you have had SCI, the more fragile the bones in your lower extremities become. He has created a formula to determine the estimated bone strength — measured in bone mineral density — in your lower extremities based on your age and how long you have been injured (see Resources). The average person with SCI loses 28 percent of their BMD within the first 16 months of injury. Around that point, BMD loss slows down but continues at a rate of 1 percent per year. However, the good news is BMD in the lumbar spine rebuilds, reaching normal within 10 years of injury. In addition, for reasons unknown at this time, 30 percent of people with SCI gain back much of their BMD in other areas as well.

Osteoporosis is diagnosed when you’ve lost 32 percent BMD, which puts you in the “fracture threshold” (where a minor fall or missed transfer can cause a break). A 50 percent loss of BMD is considered the “fracture breakpoint,” where minor incidents like stretching or even getting a limb caught in the covers while rolling over in bed can cause a fracture.

It is important for a person to have a basic knowledge of fracture management with SCI because this is an unfamiliar area for many doctors and orthopedists, says Garland. In the event of a fracture, referring the treating physician to “Pathologic Extremity Fracture Care [in SCI]” is a good idea, says Garland.

Although every fracture is unique, Garland says most non-displaced fractures (when the bone is still lined up) can be treated non-operatively with pillow splints, immobilizers or careful bracing, sometimes custom made. Also, he says it is important to be sure they are well padded and can be opened for skin inspection. “In the case of femur and some tibial fractures, intramedullary nails can often surgically fix the fracture. This is preferred over screws and plates because screws can pull out of osteoporotic bone.”

For a broken hip, the first line of treatment is still non-surgical. If the fracture stays in alignment, it can be supported with an orthopedic brace and/or pillows while healing. The next option is securing the fracture with surgical screws — if this is done, it is crucial to avoid stress on the
hip, especially any pulling, like letting the leg hang during a transfer. Not only can this pull screws out of osteoporotic bone, but muscle spasticity can stress screws and cause the same result. Spasms can sometimes be quieted by injecting Botox into the spastic muscles.

Treatment for a failed attempt at healing a hip fracture has changed. “The old fashioned rule has been don’t do a hip prosthesis (artificial hip) because the risk of post-op dislocations was too high,” says Garland. A girdlestone surgery — removing the ball, smoothing the trochanter, and pulling muscle around the end of the femur to create a cushion of scar tissue — was the only option left. This is a serious surgery best done by a surgeon experienced in the procedure.

However, improved technique and prosthetics have now made artificial hips an option for people with SCI. “A prosthetic hip in a person with SCI is now an option, assuming the hip capsule is in good condition,” says Garland. “You can do two types of repair — the cup and ball, or just the ball. The ideal way to do a prosthetic in a person with SCI is just the ball, (endoprosthesis — where the ball and stem go into the femur).” Surgeons are now doing the hip anteriorly (through the front of the hip capsule) versus posteriorly (through the rear of it.) This makes such a big difference because the incision in the hip capsule, even after it has healed, is an area of weak scar tissue that can stretch, and when that happens, the hip can dislocate. The usual area of stress for an artificial hip is on the posterior part of the capsule. By doing an anterior incision, the area of the capsule (posterior) that is under the most stress is not compromised.

“Another improvement is larger endoprosthesis balls,” says Garland. A larger head means a tighter fit in the socket, which makes it more difficult to dislocate. The combination of anterior incision and larger prosthetic head means good range of motion and reduced incidence of dislocation.

An option that is frequently discussed in SCI chat rooms is an artificial hip with an artificial socket that has a ‘retaining’ ring to prevent dislocation. Garland recommends an in-depth discussion with an orthopedic surgeon before doing this option because the retaining ring limits range of motion. Be sure to ask how much range of motion your leg will have with a retaining ring, especially because without sensation, if the leg moves beyond the built-in stop, it can rip out the entire cup.

In the case of repairing a hip fracture, Garland reiterates the options in order of preference:
1. Manage with pillows and or splinting.
2. Repair with surgical screws.
3. Prosthetic hip (endoprosthesis) only. “If the endoprosthesis fails, you can always go back and add a prosthetic cup. And if all of that fails, you still have the option of a girdlestone.”

**Resources**

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When it comes to traveling with complex mobility needs, it can be, well, complex. After all, power chairs and shower chairs can be exceptionally cumbersome when it comes to destination travel. How do we transport such necessities, and how do they fit into the logistics of where we’re traveling?

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The KD Smart Chair is revolutionizing travel mobility for many, including complex rehab power chair users. No, it doesn’t have power seating or such, but it’s a remarkably highly-adaptable, well-performing power chair specifically made for travel.

The key to the 50-pound KD Smart Chair is its integration of state-of-the-art technology to create a balance of portability without sacrificing performance. The power chair begins with an ultralight aluminum frame that folds like a lawn chair. From there, an impressively supportive integrated seat — which accepts a rehab cushion — and a supportive footplate provide meaningful positioning for a range of needs. Also, a conventional joystick is used.

Now, here’s where the real technology to the KD Smart Chair comes in. Instead of heavy, conventional batteries, it uses 10 amp-hour lithium ion battery technology, offering compact, ultralight power up to 15 miles. To complement the lithium ion technology, small but powerful brushless motors are used on the drive wheels, allowing impressive torque and a top speed of 5 mph.

When you add it all up, the KD Smart Chair offers phenomenal travel power mobility. In certain situations where one might be limited to using a manual chair, the KD Smart chair may be used instead, which then becomes an independence-game changer for many power chair users.

FDA-approved, the KD Smart Chair meets the safety, operation, and durability standards of conventional power chairs and is available in two models. The standard 50-pound model features a 16.75-inch by 15.25-inch seat size with a weight capacity of 265 pounds and a price of $1,995. Ordered online and delivered to your door, the KD Smart Chair is well within the budget of most travelers.

The HD model features a 17.25-inch by 17.25-inch seat size with a weight capacity of 396 pounds. Weighing just 9 pounds more than the standard model, the sturdier HD comes at a higher price point.

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For those with more complex needs, Nuprodx has introduced its tilt series, including the MULTICHAIR 4000Tilt. Like all others in the series, the 4000Tilt serves as both a portable shower and commode chair, but with the extraordinary feature of up to 45 degrees of tilt. Complete with user-adjustable positioning components — including leg rests, headrest, and seat-to-floor height — the entire chair weighs a scant 38 pounds and has a weight capacity of 300 pounds. Caster wheels allow for easy maneuvering.
With an MSRP of $2,495, the MULTICHAIR 4000Tilt is expensive, but it is so well built that for some it’s a good investment for both home and travel.

**Have Ramp, Will Travel**

There’s nothing new about folding, portable aluminum ramps. And if you’ve used one, you know that while they’re effective, there’s also nothing new about their drawbacks — they can be heavy, cumbersome and noisy.

EZ-Access, a leader in aluminum portable ramps, recently introduced its Suitcase Singlefold GF series. The Suitcase Singlefold GF is short for “graphite fiber,” a super-strong, ultralight composite material. The result is a ramp that’s half the weight of most aluminum ramps, along with equal or greater strength.

For example, the 34.75-inch long ramp weighs only 9 pounds and has a weight capacity of 660 pounds.

The Suitcase Singlefold GF ramp is ergonomically designed, featuring a non-protruding hinge, sleek carrying handle, and smooth edges. The grip-textured surface provides excellent traction. The Suitcase Singlefold GF ramp is available in five sizes ranging from lengths from 29 inches to 81.75 inches, all with the impressive 660-pound weight capacity.

Where the Suitcase Singlefold GF ramps become especially useful for travelers is in the smaller sizes. The 29-inch version folds to 29 by 14.5 inches by 2 inches and weighs only 7.75 pounds.

Both the 29 and 34.75-inch long versions can easily stow on the back of a power chair. Often when traveling, it’s a single step or two that prevents access, so having such a portable, compact ramp is a vital tool.

The Suitcase Singlefold GF ramps aren’t inexpensive, and the price increases with length. However, through reputable online sites, you can get the smaller sizes for around $500.

**Ready to Go!**

With a portable power chair, a shower-commode chair and a handy ramp, you’re ready to hit the friendly skies — off to your dream destination. However, I do have one last tip: if you’re going somewhere tropical, take me with you!

**Resources**

- EZ-Access, 800/451-1903; www.ezaccess.com
- KD Healthcare, 877/827-6278; www.kdsmartchair.com
- Nuprodx, 707/934-8266; www.nuprodx.com

The Suitcase Singlefold GF series uses graphite fiber to make very sturdy ramps that are lighter than aluminum.
I had no idea that Mary Tyler Moore is crippled. But apparently she is. It says so on the Internet, so it must be true.

You can Google up one of those lists of famous people who are or were crippled, and there she is. It says she has diabetes and that counts as crippled, so we’re claiming her as one of our own, whether she likes it or not. And there is also Lucille Ball. According to one of the famous cripple lists, she had rheumatoid arthritis as a young woman and was unable to walk for two years. So we’re claiming her, too, dammit! Sorry, Lucy, but you’ve been outed as a cripple. There’s no going back in the closet. It doesn’t matter if you got better. Being crippled is like being Catholic. Once you’re crippled, you’re always crippled, no matter how much you try to insist that it’s a dark episode from your past. It says so in the Americans with Disabilities Act.

In fact, according to these lists, there have been so many famous crippled humans that it’s impossible to create an inspiring crippled Mount Rushmore honoring the top four crippled role models of all time. There’s no way to narrow it down. So we have no choice but to construct several crippled Mount Rushmores representing the role models of the many many subspecies of cripples.

Like for instance, there could be a One-eyed Mount Rushmore. It would feature Sammy Davis Jr., actors Sandy Duncan and Peter Falk and glass sculptor Dale Chihuly. Chihuly lost an eye in a car accident. I imagine his first project after that was to sculpt himself a new eye. Another candidate for the One-eyed Mount Rushmore could be Quintus Sertorius, the ruthless Roman general who died in 72 B.C. Who says Mount Rushmore has to be limited to four heads?

On the other hand, when it comes to the One-armed Mount Rushmore, there aren’t a whole lot of candidates. U.S. Senator Daniel Inouye lost an arm in a war, as did American geologist and ethnologist John Wesley Powell. I suppose you could throw in Bob Dole. He didn’t actually lose his arm in a war, but what was left of his arm wasn’t much good. A fourth popular choice might be The Fugitive’s nemesis, The One-Armed Man, but he’d probably be tossed out by the selection committee on the picky technicality that he’s fictional.

We have the same problem with the Mount Rushmore stutterers. There’s only singer Mel Tillis, actor James Earl Jones and that British king they made a movie about. We could complete the stutterers Mount Rushmore by throwing Julius Caesar up there. He doesn’t actually appear on any lists of famous stutterers, but so what. Who’s counting?

But wow, when it comes to the Learning Disabilities Mount Rushmore, there are enough famous people with learning disabilities to make three or four of them. They include Albert Einstein, Whoopi Goldberg, Leonardo da Vinci, Woodrow Wilson, Thomas Edison, sculptor Auguste Rodin and fairy tale guy Hans Christian Andersen.

And who could forget Diane Swonk, chief economist and a senior vice-president at Bank One Corporation and author of The Passionate Economist: Finding the Power and Humanity Behind the Numbers?

And when it comes to the Depression Mount Rushmore, don’t even get me started. There have been tons and tons of famous people who were depressed. Poet Theodore Roethke was depressed, as is every poet. Playwright Eugene O’Neill was depressed, too, as is every playwright. Some other role models for the depressed are funnyman Rodney Dangerfield, actress Vivien Leigh, composer Robert Schumann, Winston Churchill and Abraham Lincoln.

Some famous cripples are double dippers. Composer George Frideric Handel was both blind and depressed, Ludwig van Beethoven was deaf and depressed, and Olympic diver Greg Louganis is HIV positive and learning disabled. Poet John Milton is listed as blind and only blind, but you can’t tell me that guy wasn’t also depressed as hell.
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Wellspect HealthCare believes a good start to CIC is crucial for a good life. For FREE samples of LoFric catheters, proven to improve short- and long-term urethral health. 855/456-3742 or www.wellspect.us

Allergan: The LLS (Lower Limb Spasticity) Approval press release is at the link: www.allergan.com/NEWS/News/Thomson-Reuters/U-S-FDA-Approves-BOTOX-onabotulinumtoxinA-for-the

Astellas Pharmaceuticals, www.astellas.us, 800/888-7704
Asterias Biotherapeutics: SciStar study is now recruiting, www.scistar-study.com

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For more information on how you can support United Spinal and become a business member, please contact Megan Lee at mlee@unitedspinal.org or 718/803-3782, ext. 7253.
Acknowledgements on our website, in New Mobility, in United Spinal e-news or any other United Spinal publication should not be considered as endorsements of any product or service.

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TINY DESK COUP
Irish fiddler and singer Gaelynn Lea beat out 6,000 other artists who submitted videos of themselves playing an original song to win NPR’s second annual Tiny Desk contest. Lea, who has osteogenesis imperfect and teaches music in Duluth, Minnesota. The March 11 concert is online at www.npr.org/2016/03/10/469966998/gaelynn-lea-tiny-desk-concert.

WHEN YOUR MEME IS IN BRAILLE
“We need to make every single thing accessible to every single person with a disability,” proclaimed Stevie Wonder, as he awarded the song of the year at the Grammys. His co-presenters expressed surprise that the announcement was in Braille, and Wonder teased them about not being able to read it, and then got serious, using the moment to highlight the importance of universal access. Disability employment advocacy group #RespectTheAbility turned Wonder’s words into a widely-shared meme.

BOLIVIA BLOWS UP THE INTERNET
Bolivian disability rights activists blew up the Internet when they took their protests to a new level by suspending themselves from the Viaduct Bridge in Cochabamba. They want the government to raise their monthly pension to 500 bolivianos (that’s $70 a month in U.S. dollars).
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