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Our annual cover story on sexuality and relationships gives us a peek into the public world of love and romance as well as what goes on behind closed doors. ROXANNE FURLONG profiles couples and their wedding ceremony plans; BOB VOGEL reveals sexual performance gains for paras and quads in epidural stimulation trials; and MITCH TEPPER exposes the sometimes risky world of erotic electro-ejaculation.

Cover and Contents Photos by Eric Stampflii
A long time ago, 1985 to be exact, my wife and I decided to make use of the latest techniques for extracting sperm from a para and inseminating it into the para’s wife. So began a period in our combined lives in which everything other than our sexual organs became of secondary importance. Now that can be a fun time, yes. But it can also be stressful, mainly because those “latest techniques” usually involve white-coated hospital technicians treating your genitals as if they belong to the public domain, not the pubic domain.

Another thing that happens — in the male’s case, at least — is that you can become fixated on “practicing” in order to boost those sperm counts. As a young teen, it goes by the name of masturbation. As a paralyzed adult, it’s called “research.” And as every budding scientist knows, reputable research involves looking through a microscope.

So I went to a local science store and bought one and began scrutinizing whatever could be coaxed from my damaged testicles. Not only did they not work properly due to my spinal cord injury, they most likely had internal scar tissue due to a painful bout with epididymitis when I was in rehab. My balls at that time, summer of 1965, swelled to near balloon size and got all shiny and pink, then — thank God — gradually deflated. But I digress.

You would not believe the diversity of spermatozoa that escaped those damaged orbs during my practice sessions. To appreciate this, let me tell you what a healthy bull’s sperm looks like under a microscope. That’s right, bull’s sperm. His name was Bud. He was the curly-topped master progenitor of a small herd of cattle on our farm. A vet took a sample of Bud’s semen, put it under his microscope, and we looked at it. Millions of tiny tadpole-tailed swimmers writhed in a teeming frenzy. I was truly impressed, even astounded, at the thrashing spectacle within a single drop of semen.

Curious, I captured one of my own specimens and scrutinized it under my new microscope. It looked like it had been skimmed from a nuclear waste holding pond. Most of the sperm were shrunken, twisted, and malformed, many dead. A small percentage moved slowly about, looking like they had eaten too much cake at the birthday party.

I am happy to report that, with practice, the quality and numbers of sperm improved respectably. My wife and I flew to a hospital in Cleveland and underwent three inseminations during one of her fertile cycles. Here’s how they got the sperm. I was anesthetized on an operating table, and a female doctor with a British accent donned a plastic glove that had electrodes attached to her middle finger. She inserted her finger into my poop chute, found my prostate, and flipped a switch. Zowie! Somehow the British accent made everything seem sophisticated.

As it turned out, we did not get pregnant. But it did make up our minds to adopt, which — one daughter and two grandsons later — seems like a godsend.
Lynn Jorgenson has held positions as a senior high teacher, college professor and elementary principal. She retired early to spend time caring for her multiple sclerosis. She loves spending her days at the gym swimming, at home gardening or writing. She is also a speaker, ambassador and activist with the National Multiple Sclerosis Society and a regular volunteer with her church and the local blood bank.

Robert Samuels came to *New Mobility* in its infancy and served as travel editor for many years. Besides travel stories, he has written profiles, service articles, advocacy-related stories and first-person accounts of disability-related events and happenings. His acclaimed book, *Blue Water, White Water*, which chronicles his battle with the onset of Guillain-Barré syndrome, is excerpted and reviewed in NM’s August 2012 issue and is available in various formats from Amazon, Barnes and Noble online, and iTunes.

Kara Aiello has lived in the suburbs of Philadelphia for over 30 years, but loves to spend as much time as possible in the hustle and bustle of the city. Born with osteogenesis imperfecta, Aiello is a licensed social worker, holds a certificate in therapeutic recreation, and enjoys working with older adults. She studies dance with American DanceWheels Foundation, in which she performs modern dance for a wider audience. She also sings with the Academy Chorale and writes for MobileWOMEN.org, a website geared toward women with disabilities.

Deborah Davis, speaker, entrepreneur, writer and founder/owner of lifestyle enterprise Push Living, graduated from the University of Miami in 1991 with a bachelor’s in finance. As part of Push Living, she created PhotoAbility.net, which makes available disability-inclusive stock images for advertising, marketing and editorial uses. Push Living also promotes and enables accessible travel, features an online magazine that focuses on health, and provides an online store. A C6-7 quad, she is most passionate about building a network of people with disabilities dedicated to creating a more inclusive world. She resides in South Florida and is the proud mother of “two beautiful, wise and exceptionally bright young women.”
LETTERS

Really enjoyed the article.

Our Moms Are Thrilled
Josephine and I want to say, thank you [for featuring us in “What Makes Us Happy,” December 2015]. Best thing, our moms are thrilled!
Randy Alexander
Tubby Creek Farm, Ashland, Mississippi

New Visitability Law
“Buying a First Home” [December 2015] was a great read. It underscores the need to bring visitability principles and related basic access issues into the home builders market. Even those of us who have accessible homes and have experienced modification hardships, financial challenges and related obstacles are still unable to visit our neighbors. I hope NEW MOBILITY will follow the new federal Eleanor Smith bill regarding home accessibility standards. This is a critical need as the population continues to age and more people are needing basic access within their homes.
JR Harding
Tallahassee, Florida

Caregiver Economics
There’s simply no way to get around the issue of “family income” [“The Great Caregiver Quest,” December 2015]. If a spouse is employed or the person with a disability is employed, there’s a whole chunk of money to be paid just, for example, to get your butt out of bed and maybe take a shower a couple of times a week. It’s worse in rural areas. I live 10 miles from a town of 15,000 and 25 miles from a city of 150,000. I’m forced to pay more simply to get the caregiver here.
Shall we talk about being an “employer?” Every caregiver is paid, and the best we can hope for is to dodge a bullet by saying they’re contract employees. Yeah, but did you report that expenditure? I never have. I’d need an accountant to figure out how. Being a crip is an expensive hobby.
Gary Presley
Via newmobility.com

New Info Helpful
This is a fantastic article by Bob Vogel [“Adaptive Outdoor Adventure Sports,” August 2015]. Over the years I have become more and more impressed with NEW MOBILITY and all it offers. As an adaptive recreation program coordinator, I was thrilled to see this article provide information on seven adventure activities beyond my expertise.
Marcy Marchello
Amherst, Massachusetts

Kudos: Doug Davis
I am a new subscriber and am writing to send some well-deserved compliments to all the writers in the two issues I’ve received thus far. The timely topics are presented clearly and concisely and could certainly be described by an extensive list of superlatives. A special pat on the back to Doug Davis for his extraordinary cover artwork, too [November 2015 Buyer’s Guide]. We often take that part of publications for granted. This is one of my favorite pieces of mail; I read it from cover to cover.
Dolores Carron
Newington, Connecticut

Bladder Control Poster Boy
I’m a male T4 para 32 years post-injury. I started using the Neosporin/saline irrigant while in rehab [“Bladder Irrigant Solutions for UTI Reduction,” December 2015]. I cath four to six times a day but am not especially “clean” with my technique. But I do use hand sanitizer or a benzalkonium chloride towelette when I’m in a public restroom. I even reuse my catheters for about a week, just rinsing and drying them after use. I’ve had about four UTIs in 32 years and two of those were a result of urological procedures done in the hospital. I use 30cc of G.U. irrigant [gentamycin] once a day and every other day do a flush with 60cc that I leave in for about two hours. My urologist says I should be the poster boy for SCI bladder control.
Chuck McAvoy
Via newmobility.com

Mycrocyn Flush Successful
I have been using Microcyn to flush my bladder for about four years, and it has been a life-changer for me. I’m now 23 years post-injury, and most of that time fighting chronic UTIs and bladder stones has left me Cipro-resistant. Flushing my bladder daily with Mycrocyn is keeping me nearly UTI-free. Although my urologist was unaware of this, after research, she endorses it.
Karen Miner
Roseville, California

UTIs Be Gone!
I’ve been a T12-L1 para since 1981 and have cathed four times a day for 35 years. The first 12 years I fought UTIs constantly and ended up in a study. The only participant who didn’t get a UTI through the year used Betadyne to keep his fingers and “other areas” swiped clean as he cathed. I copied that system and have had hardly any UTIs that require antibiotics in more than 20 years now. I use povidone iodine 10 percent solution and pour just enough on the corner of a wet rag to completely coat the tips of my fingers and those “other areas.” My last UTI that I took antibiotics for was about five years ago.
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Single-Aisle Airplanes May Soon Have Accessible Bathrooms

Accessible bathrooms may soon become a fixture on newer single-aisle airplanes as the U.S. Department of Transportation announced in early December that it is considering changes to the Air Carrier Access Act.

Being able to use the bathroom when flying would definitely make travel more comfortable, says Minna Hong, a paraplegic from Atlanta, Ga. "If bathrooms are available to wheelchair users, it would make it so much easier to fly." Hong, a member of Delta’s Advisory board on disability, also supervises Shepherd Center’s SCI peer support program. On long flights she catheterizes under a blanket. "I know a lot of women as well as men with SCI who put in a Foley catheter to travel so they don’t have to deal with the lack of an accessible bathroom.”

Other possible changes include clearer definitions for service animals, greater access to in-flight oxygen and requiring airlines to report yearly to DOT the number of requests for disability assistance and when the assistance was provided.

Chicago Sets Goal to Make Rail System 100 Percent Accessible

On Jan. 7, Chicago Transit Authority announced an initiative to make 100 percent of its rail system accessible within 20 years. Part of the CTA Strategic Accessibility Program will be fixing or replacing broken elevators and lifts in the nation’s second largest transit agency.

“We’re proud of the progress we’ve made in the last 25 years, which has only been possible thanks to the strong commitment from Mayor Emanuel and the City of Chicago, as well as the involvement of the disability rights community,” said CTA President Dorval Carter. “We do recognize there is still more work to do, and the creation of this new program will help map out a path for CTA to deliver on this commitment two decades from now.”

CTA’s track record on accessibility is dismal, as 70 percent of its 145 rail stations are not wheelchair accessible. Also, 46 of its stations are not equipped with elevators. To turn this around, CTA has pulled together a working group of key city officials, people with disabilities and architects charged with outlining a cost estimate and schedule for making all stations accessible.

People in the News: Kelli Sem Denied Pharmacy School

Kelli Sem wanted to be a pharmacist since high school, but the 22-year-old says the North Dakota State University Pharmacy School is standing in her way. Her admission scores exceeded the school’s average, but her request to be allowed to ask fellow students to assist her in completing required physical tasks was denied.

Sem, who has cerebral palsy, knew years ago that needing assistance with some tasks might be an issue, so she visited the North Dakota Board of Pharmacy in 2012. “The board felt that accommodations could be made for me to get through schooling,” says Sem. But in spring of 2014, as Sem prepared to apply, the university changed the pharmacy program’s technical standards for students to include new physical requirements.

“I obviously was a little hurt but at the same time expected it,” says Sem. “I just kind of got the feeling that while they were open in the beginning, the doors were beginning to close.”

Undeterred, Sem plans to apply to the School of Pharmacy in early 2016 and has consulted with a lawyer in case her accommodation request is turned down again. “At the end of the day, all we want is for Kelli to be given a fair shot,” her lawyer, Scott Haider, told the Fargo Forum.

NDSU declined to comment for this story, citing student privacy concerns.
Disability Integration Act Introduced
ADAPT’s Disability Integration Act, which protects the right of people with disabilities to live in their own homes and not nursing homes, was introduced on Dec. 18 by Sen. Charles Schumer, D-N.Y., as S. 2427. “This is an all-inclusive bill that says if you have a right to long-term supports and services in an institution, then you have that same right in the community,” says ADAPT activist Stephanie Woodward, who is also director of advocacy at the Center for Disability Rights, an advocacy organization in Rochester, N.Y.

The DIA, a civil rights bill structured on the ADA, requires public entities and insurance companies that provide long term supports to serve eligible people in the community. Waiting lists, capping services, under-paying workers or taking other actions that restrict access to community-based services would be illegal.

“When you’re forced to live in an institution and segregated from the community, your civil rights are being violated,” says ADAPT activist Jensen Carabello, who is also vice chairman of the Center for Disability Rights. “The DIA will ensure this doesn’t continue to happen to people with disabilities.”

ADAPT organizer Bruce Darling adds that unlike earlier attempts at similar legislation, the DIA does not depend upon Medicaid. “It’s about having the supports we need to not just live in the community but to lead full and independent lives,” says Darling, who is also CEO at the Center for Disability Rights. “The failure to provide that assistance would constitute a form of discrimination.”

For more information on the Disability Integration Act, visit ADAPT at www.adapt.org/main/diamain.

Medicare Coverage for Wheelchair Components Safe for a Year
Medicare coverage for wheelchair components such as seat and back cushions is safe for another year, thanks to a lightning-quick act that was introduced into Congress Dec. 17 and passed Dec. 18. “The average time for a bill to pass is seven years,” says Alexandra Bennewith, vice president of government relations for United Spinal Association. “This shows that advocacy does work. You have to be persistent and committed like crazy, but it works.”

The Patient Access and Medicare Protection Act was expedited through the Senate using the “hot line” process, meaning each senator had 24 hours to object. If there were no objections, it automatically passed. “United Spinal activated many advocacy groups over the course of a year, and it got down to the wire, but finally Sen. Rob Portman, R-Ohio, and others introduced the act. It went so quickly. We were pushing, making sure everyone’s questions were answered so they wouldn’t object,” says Bennewith. “We had already set it up so Speaker Ryan and others on the House side were ready to accept it once it passed the Senate, and then it passed in the House in a matter of minutes.

“Our voice is strong and our voice was heard,” adds Bennewith. “This law is critical for our members because it helps folks get the access to customized wheelchair components that they otherwise may not be able to get.”
Going back to work after a spinal cord injury may seem daunting, but for Jeff Colton, a T3-6 paraplegic from Chanute, Kan., it has been standard protocol since the start. Injured from spine cancer when he was 18 years old, he figured out right away things could’ve been much worse. “I thought my life was over,” he says. “But as I was going through PT, OT and rehab, I soon realized there were people in similar situations, but they were much worse off than I was.”

Realizing he was beginning a new life, Colton, now 38, embraced it. “There is not much I can’t do anymore, other than walk,” he laughs. When he returned home, his first goal was to graduate from high school on-time, which he did. “Luckily I had enough credits to graduate,” he says. “In fact, when I went down the aisle during graduation, I received a standing ovation.”

After high school, Colton entered the workforce as soon as he could. Instead of going back to McDonald’s where he worked pre-injury, he gave customer service a try. “My first job was working in Kansas City, Mo., working for H&R Block doing tech support,” he says, and he loved it. After this job, Colton went on to vocational school for computer repair, then majored in computer programming at an area community college.

Armed with his new degrees, he went back to work, this time in the call center world doing tech support, a job he currently does and thinks is great for wheelchair users. “It offers a flexible schedule and nowadays, more and more companies are hiring people with disabilities to work from their homes.” Colton’s next career goal — earning his bachelor’s in computer engineering. “This was always something I wanted. It’s never too late to go back to school.”

Get Ready to Rip

In the last few years we’ve seen some exciting outdoor four-wheel drive track wheelchairs, and the Track Chair Ripchair 3.0, “an extreme off-road chair,” may be one of the beefiest practical designs we’ve seen yet.

Created by Howe and Howe Technologies, a brother duo from Maine hired by the U.S. government to build a variety of technologies, the Ripchair 3.0 is an invention that is made specifically for those with disabilities — the only outdoor track wheelchair available that lets you stay in your wheelchair. It has a ramp in the front that flips out, allowing the user to roll right in and lock their chair in.

Also, the hand controls for this device are much like those found in an adapted vehicle, with a lever for each hand for gas and brake. It can even come with a gun rack and fishing rod holder. Cost is high at $27,000, but it is built to last in extreme conditions. Learn more about it in the New Mobility November issue [www.newmobility.com/2015/11/trackchair/] or visit www.trackchairextreme.com.

New Bedtime Friend

For those with limited hand function, Frog Leg Mobility is a bed mobility aid that could change your world. Made out of nylon, this sling goes on like a pair of shorts but stays around the thighs, and has two big loops to put your hands through to help you reposition in bed. Cost: $59.99.

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PHOTO CONTEST

Photo by Diane Edmonds

Photo by Robert Om

Photo by Terryll Wright

NEW MOBILITY + PHOTOABILITY
Our recent photo contest garnered a variety of interesting images. To see more of the finalists and find out the grand prize winner, please visit newmobility.com. Selected judges’ comments are in red.

1. Kary Wright flies a kite with the late, great Nakoda. “Stunning and surprising portrait.”


3. John and Richard Squires explore one of their local trails. “Seeing the shared experience is what makes it work.”

4. Terina Sprague catches a wave with the help of the adaptive surfing organization Life Rolls On. “Razor sharp and full of life.”


6. Alyse Einbender gazes out the window while her companion, Rocky, watches over her. “Beautifully composed shot. Unusual and interesting. I just want to keep looking at this picture.”

Thanks to our judges: Deborah Davis, Bill Forrester, Eric Stampfl, Loren Worthington, Scott Rains, Tiffany Gentry, Michael Hansel, Aron Tyler, Clara Davies and Jean Dobbs.
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In late 2015 Ali Stroker became the first Broadway actor to play a wheelchair user who actually uses a chair in real life. In 1947 Jackie Robinson became the first African-American to play major league baseball when he signed with the old Brooklyn Dodgers. After that historic season, baseball began integrating. Will Stroker’s breakthrough in the musical, Spring Awakening, do for wheelchair users in show business what Robinson did for African-Americans in baseball?

“I hope so,” she says. “I hope people with disabilities get opportunities on stage, on film and on screens. I hope that this is the beginning. We’re still putting nondisabled actors in wheelchairs, and we’re still having them play blind or play deaf characters,” she adds. “It’s a shame because when you live with a disability, you have all this information and this experience that will only heighten and make the role more authentic.”

By that standard, Spring Awakening could not have been more authentic. In addition to Stroker’s disability, about half the rest of the cast in the Deaf West Theater production was non-hearing. Stroker had to learn American Sign Language for her role. When she sang, she also signed the lyrics with her hands. Try doing that in a manual wheelchair. “Signing and singing is one of the hardest things in the world,” she says. “But it’s so expressive and so theatrical.”

No one should confuse Spring Awakening with happy musicals like Mary Poppins and The Sound of Music. This one is about teenagers figuring out their sexuality and boundaries. It is raw and dark. If it were a movie, they would give it an R, or maybe even an X rating.

Thanks to the ADA, Broadway’s theaters now
all have spaces for wheelchair-using customers and their companions. Backstage it’s a different story. None are wheelchair friendly. Before *Spring Awakening* opened at the Brooks Atkinson, its producers added a stage door ramp and an accessible dressing room for Stroker. She didn’t have to ask. They just did it. Those improvements remain in the theater. “It’s exciting to think,” she says, “that now there is an accessible dressing room backstage on Broadway.”

Her role wasn’t written for a wheelchair-using actor. In fact, her understudy was a walkie. Stroker didn’t want her to fake using a chair. “I don’t think she could have learned to do what I did with speed and precision,” she says.

There is nothing unplanned in a Broadway musical. The director and choreographer got this one running like a Swiss watch, a Swiss watch on steroids. They had the 28-year-old Stroker starting, stopping, turning, singing and signing. “The whole show was like a machine,” she recalls. “All the pieces had to work together.” She fit in so seamlessly that The New York Times reviewer almost overlooked her. “Incidentally,” he wrote, “the cast also includes an actor in a wheelchair — a detail I so easily assimilated that I almost forgot to mention it.”

Only a very athletic para could have handled the part the way Stroker, a C7-T2 incomplete, did. To stop her from rolling off of the stage as she raced around, they put a little lip across its front. The floor of the stage in the 1926 theater had its own problems. “It’s warped wood, which created little hills,” Stroker says. “I could feel them as I rolled over them. It was really funny when I realized that when I stopped to sign something, I was rolling away.”

Performing in a Broadway show can be a grind. The curtain goes up six nights a week, plus matinees on Wednesdays and Saturdays. “It is exhausting,” admits Stroker, “and definitely intense, but I found that if I got plenty of sleep, I can do anything. Sleep for me is the key. I made it a priority.”

**FINDING HER PASSION**

She began using a chair after being injured in an automobile accident. She was just 2 years old. “A life-altering experience when you’re young doesn’t feel life-altering,” she points out. She grew up with an older brother and a younger sister in Ridgewood, N.J., a pleasant New York City suburb. Her father is a teacher and coach there. He told her every day that she was a superstar. He encouraged her to compete. “I used to wheelchair race as a kid,” she recalls, “and I have this national record for my age, my injury, and a specific race. Yeah, I did really well. My dad always reminds me about it. It was fun, but I wasn’t motivated or driven to win.”

She was just 7 when she found her true calling, playing the title role in a backyard production of the musical, *Annie*. “We sang along with the tape, and we painted the sheet that was the backdrop,” she recalls. “It was really cute. It made me feel alive. That’s when I got the acting bug. After that summer my life opened up. I looked for opportunities to perform. I just wanted to be on the stage, to tell stories and play characters.” She started dreaming of being on Broadway.

Next she was Dorothy in a grade school production of *The Wiz*. Its musical director, Susan McBrayer, and her assistant, Catherine McCourt, still talk about Stroker’s audition: “She sang ‘Over the Rainbow,’” remembers McBrayer. “She was this tiny fourth grader with perfect pitch, rhythm and feeling. Our jaws dropped. I’m a voice teacher. I thought, ‘how does she do this?’ We looked at each other. Oh my God — she’s incredible. No way you can’t cast that child — she’s so gifted!” McBrayer started working with her. “I couldn’t let go of her! Such drive in her!”

That show changed the way people in her hometown viewed Stroker. “I was suddenly seen in this other light,” she says — “like, ‘Oh, she’s a talented little girl.’ It wasn’t just about, ‘Oh, this is a little girl who’s gone through a trauma. For me it was like, I’ve found my purpose! I have something to live for and something I love and am so passionate about and that makes me so happy.’

She wasn’t just talented. She was also popular enough to be elected class president in her senior year of high school.

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*Stroker played the part of Olive Ostrovsky in *The 25th Annual Putnam County Spelling Bee* at New Jersey’s Paper Mill Playhouse. Like all her earlier musical roles, it wasn’t written for an actor with a disability.*
the school’s production of *Les Misérables* she starred as Cosette, and then as Maria, the Puerto Rican heroine of *West Side Story*. “I know,” she laughs, “a blond, blue-eyed Maria.”

She went to college at New York University’s prestigious Tisch School of the Arts, becoming its first wheelchair-using student. “Everyone was a little nervous at first about how I was going to do the dance program. I became really good at translating movement for myself,” she says. “I learned that I had to be my own advocate, and that I had to really get good at having conversations with people that would ease their nerves about what would happen.”

She played Berthe in the school’s production of *Pippin* and the grandmother in *Into the Woods*. Both shows are musicals. By graduation everybody knew her. She was a Tisch spokesperson and shared a dais with Hillary Clinton.

After graduation, her career stalled before it began. “I remember it being very hard when I graduated from college, not even getting very many auditions,” she recalls. “I was like, gosh, they won’t even see me? They won’t even let me in the room!”

But she landed the part of Olive Ostrovsky in *The 25th Annual Putnam County Spelling Bee* at the Paper Mill Playhouse, a highly regarded regional theater in New Jersey. Like all her earlier musical roles, it wasn’t written for an actor with a disability.

The show was directed by Marc Bruni. He had known Stroker since she was 13 and took classes at the Paper Mill’s Summer Musical Theatre Conservatory. Patrick Parker, its associate artistic director, was one of her teachers and mentors. “She’s totally fearless,” he says. “She doesn’t see herself as someone with a disability. She happens to be someone who can sing and dance who is in a wheelchair.”

She broke into television on the reality series, *The Glee Project*. It was a talent contest. The winner got a part on *Glee*. Ali ended up in second place. The show’s creator, Ryan Murphy, said that it was “impossible to root against her.” She later did appear in the series, playing the mean-girl love interest of Artie Abrams, a wheelchair-using character who was played by nondisabled actor Kevin McHale.

**EARNING RESPECT**

Once you have been on television, fans aren’t inhibited about approaching you. Stroker recalls one who suddenly realized that she actually needs to use a wheelchair.

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to get around. “Wait, that’s permanent?” he asked, shocked. Or others who told her, “You’re too pretty to be in a wheelchair” or “You’re the hottest girl I’ve ever seen in a wheelchair.”

“If somebody thinks I’m too pretty to be in a wheelchair, well, maybe that changes their mind about what is possible,” she says. “There’s no reason why somebody can’t be beautiful and in a wheelchair, and why wheelchairs can’t be beautiful and cool! I don’t have to walk. I get to roll around. That’s cool! That’s different. Why not?”

At her first Spring Awakening audition, they just asked her to sing. They called her back again to see if she could dance. “I just went in and adapted it the way that I do,” she says. “I’ve gotten good at translating movement that somebody who’s standing does — to someone who’s sitting. When I’m in a dance call I usually do my own thing, and then if there’s a moment, I’ll say to the choreographer, ‘If you have any ideas, please let me know, but I’m going to translate it the way I do,’ and I actually enjoy that more because I understand my vocabulary better than somebody who’s not in a chair, because this is how I roll — literally.”

She wowed them. “Ali dove into the audition with such rigor,” recalls director Michael Arden. He had seen her work on TV and at the Paper Mill Playhouse. “I remember one moment when everyone had to jump up in the air, and Ali popped a wheelie. I was just so moved by her fearlessness — one of the show’s stars. “She picks up chairs and brings them off stage. When I saw that, I was like, ‘You’re my hero.’ It is incredibly inspiring.”

When she has the time, Stroker is a teaching artist with Arts InsideOut. She has traveled to South Africa for them twice, working with children and mothers affected by HIV/AIDS. That’s where she learned that she had achieved her childhood ambition: Spring Awakening was Broadway bound! “I saw the email and my jaw dropped, and my whole body went hot, and then I didn’t say anything. When we broke from the class, I went and found my friend, and we hugged and cried, and I was like, ‘I’m going to be on Broadway!’ It was so cool.”

McBrayer, who was Stroker’s voice coach in New Jersey, remembers that her daughter, Amy, told her the news. “She called me screaming, ‘Ali’s going to Broadway! Ali’s going to Broadway!’”

Spring Awakening closed in January after 859 performances. Stroker isn’t sure what she’ll do next. “I do miss performing every single night, and the people I got to meet and the people I got to perform with,” she says. “They’ll forever be like family to me because of what we have done together.”

At 28, projecting an authentic image of a woman wheelchair user in touch with her sexuality is important to Ali Stroker.
“To fully enjoy living elevated, you must know what it means when you are not. There are many things that most people take for granted, like being able to hang out independently or just take a walk with the person you love at the same height. With iLevel, the things I never dreamt were possible are now my reality.”

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I was working long, stressful days as an elementary principal while attending graduate school full time with the goal of completing my doctoral degree in educational leadership. My husband, a demanding man, was a prominent local pastor in our small community. We were raising two small children.

In the final stages of my doctoral dissertation, I began having terrible headaches in the middle of the night. I attributed them to stress — job, studies and marriage. While I considered myself successful in my job and studies, I felt like a failure in my marriage, which had become nothing more than a facade. Unable to continue living the lie, I began divorce proceedings.

For the headaches, my doctor ordered an MRI. I wasn’t overly concerned about the procedure. My life was mapped out, many of my goals already accomplished. It was a time for self-assurance and basking in my achievements.

I left the clinic feeling confident my MRI wouldn’t show anything unusual, went about my carefully scripted life and completed my degree. As I expected, my headaches disappeared. I forgot about the MRI. Apparently, so had my doctor — he never called to inform me of the results.

Within two years I was struggling with being constantly dizzy and found myself going back in for another MRI to try to find the cause. As the technician pushed me into the tube, she looked at the previous report and casually asked, “How are you dealing with your multiple sclerosis?”

I was speechless, confused, stunned. Finally, I uttered, “I want a copy of that report.” The banging began in the MRI tunnel, and I was unable to put my thoughts together.

Later I walked across the parking lot in a daze, sat in my car and read the two-year-old report for the first time, thinking it must not be about me. A flood of thoughts raced through my head. Denial gave way to tears as I realized the report was about me — a different me — a person with multiple sclerosis. Thus began a journey I never imagined, a plot twist I never saw coming.
Certainly I was upset by the diagnosis, but I was angrier with the doctor for not informing me of the diagnosis. It was now too late to sue him for non-disclosure. It was also too late to take back my divorce from a marriage that might have given me health care assurances. I probably would not have had the courage to leave the marriage had I known about the diagnosis two years prior.

Yet I do not regret choosing divorce. I certainly regret that my children had to go through it, but I’m happy that I no longer live in a constantly brewing kettle. The daily fear that many live with as part of this disease is mind numbing. Every day can bring the loss of some muscle or bodily function. What we do not know about the disease is when and how the progression will occur. That is why no two people with MS will exhibit the same symptoms or loss of function.

In the early days of my disease I wanted to know how many brain lesions I had. I wanted a definitive, scientific response to what functions in my body were affected by each lesion. I’m glad my doctor never responded to my inquiry. I’ve come to believe that how I meditate on each lesion in my brain influences their impact on my daily life.

Being an educator for almost 20 years, I set about doing what I’ve always done — educating myself. I knew of only two people who had MS in my circle of acquaintances. I didn’t know much about the disease but did know that I didn’t want to follow these women’s paths. All my learning has taught me how to live well with this disease. I’ve learned about various alternative medications, numerous clinical trials, countless adaptive exercises, modified home equipment and many food alternatives to strengthen my immune system. General attitude modifications and spiritual wellness activities have become a regular part of my daily activities.

I’ve come to learn that depression is a very common symptom of MS. The root cause of the depression might be the disease activity or having to live with an incurable progressively disabling disease. I’ve learned there are many things I can do to avoid the depression.

I determined that my will was stronger and more stubborn than any MS disease activity in my body. So I exercise regularly, eat well, participate in church activities, continue to meet with friends, sit by an amber light daily (it activates a natural melatonin response for better sleep), play brain games, pray, meditate, read and occasionally give myself permission to wallow.

Usually when I tell my father that I’m wallowing he asks me for how long. I take 24-72 hours to do some serious wallowing — a prolonged naval gazing and self-centered “woe is me” kind of thinking. Then my father calls me to ask if I’m done.

I find that by giving myself permission to wallow, I am actually giving myself a freeing gift. It allows me to go through the pain that I’m feeling and not avoid or dance around it. I embrace my sadness and get to the other side of the pain. I welcome my wallowing and try to live it fully — lying in bed most of the day in my pajamas, watching stupid TV, not answering texts or emails, eating unhealthy snacks and listening to really loud music.

I struggled in the early years with the stages of grief I encountered. I remember telling my lead office manager, “I don’t want to be the next poster child for MS!” Yet almost 10 years since my initial diagnosis, I can honestly say that I now love my multiple sclerosis. It has opened up a world for me that I never knew existed and given me endless opportunities to use my gifts and talents in the service of other people.

I have no idea if I will be bedridden some day, but I’ve already determined that I’m going to have a great bed, TV and a built-in pool boy to entertain me. Disney darling of the ’50s and ’60s, Annette Funicello, was diagnosed with one of the most debilitating forms of MS — primary progressive — at the height of her career. She lived her final years, no longer able to walk or talk, being cared for and adored by her husband. I could relate to her early years of being accused of being drunk because of the way I was walking and talking. My boss informed me that parents of my elementary school were saying the same thing about me. So I decided to retire early and set about taking care of my body rather than other people’s children.
I’ve attended countless doctor talks, pharmacological-sponsored talks, internet webinars, read countless books and connected with others in MS support groups. I knew, unlike with my cancer of 10 years prior, that I couldn’t beat it out of my system. I needed to figure out a way to let it live graciously within my system.

It has brought a renewal of my faith, in which God has given me countless Christian believers and seekers in a church home that feels more real than I’ve ever known. Learning about MS has given me a greater understanding of drugs, symptom management strategies and an understanding of ADA regulations. Most importantly, it has opened doors that I never knew existed. It has also forced me to do something I never did very well — slow down.

I have a blue parking pass that allows me to get a front row parking spot in most parking lots. I once hid the pass, but now I will bypass a store if there isn’t an open blue parking spot. I can no longer write with my right hand. So, I get to know strangers who fill out forms for me. I get to walk with two cool REI walking poles that only serious hikers use while climbing a trail. I get 10-plus hours of beauty rest every night. I get to work out at the gym with the wise seniors. I’m the youngest of the bunch, kind of like their mascot, cheering us all on in our swimming pool workouts.

I get to listen to others more than I talk. It amazes me that what Plato said — “Thinking is the talking of the soul with itself” — has actually given me more of an education than all my degrees combined! I get to focus on one item at a time, as I can no longer multi-task. I get to graciously accept help from others — strangers as well as friends.

Might I have learned all those things without having a progressively debilitating disease? I think not. Mainly, because I tend toward being stubborn, self-centered and egotistical. The wonder of my multiple sclerosis is that I’ve learned patience, grace, and tact. I would wish this disease on no one. Yet, the benefits I’ve learned about and received from this MS plot twist in my life — I’d wish on everyone.

Before I found JACO, I was not truly independent. If I dropped my phone on the floor, if I wanted to get a coffee from a café, if I wanted to reach a book on my shelf, or if I dropped my keys in my van I needed to find someone to help me (which could often take hours). This amazing piece of technology has given me my independence back, and the best part is that I’m finding new things that I’m able to do every day. Thanks to this robot arm, the impossible is now possible.”

Dan Harvey

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When planning your wedding, the most important part is finding ceremony and reception venues that fit your style and budget — and for wheelchair users, accessibility is another box to tick off. Trending venue options include getting married outdoors on farms or beaches, in warehouses or barns, or at poolsides. And as young wheelers make their way on their big day, some are opting for traditional wheels, while others use innovations that can include elevating chairs or standing frames, or in one couple’s case, a harness for jumping out of a helicopter.

All of the couples we spoke to planned exactly what they wanted for their wedding, from do-it-yourself country chic for $5,000, to no-holds-barred rustic elegance costing upwards of $50,000, to winning a chance to have their entire dream wedding donated. Here, they offer tips and ideas that can help you plan your special day.

Wish Upon a Wow

Tammy and Cameron Stay, both 39 with T5-6 injuries — Tammy incomplete, Cameron, complete — met at an Abilities Expo in Southern California in 2009. She was in a fashion show and invited Cameron to come watch her. In her wheelchair she looked like a bride in a white outfit with flowers in her hair.

“When I saw her, I knew I wanted to marry her,” Cameron says. They started dating October 2010 and became engaged April 2011. They were in California for another Abilities Expo. “It was at sunset and we were on the Hermosa Beach Pier. I got down on my knees and proposed and was able to get back up in my chair,” says Cameron.

“We knew we were going to get engaged,” says Tammy, “and I bought a joke ring, a $10 costume jewelry ring. Next thing I knew he was proposing with it. It turned my finger green!” They
were married one year later at Canyon Gate Country Club in Las Vegas, where they live.

While planning her wedding, Tammy was reading through a bridal magazine when an ad for Wish Upon A Wedding caught her attention. WUAW is a nonprofit that grants weddings for those “facing serious illness or life-altering circumstances.” Tammy filled out an application and the couple was chosen to receive their wedding wish.

“WUAW invited us to a bridal fair and took us around to meet potential vendors that would donate their services, materials and time to our wedding,” Cameron says. The couple was allowed 50 people, including the wedding party, and everything down to Tammy’s blinged-out shoes was donated.

“We were going to do something small and affordable,” Tammy says. “This was so much more than we ever expected. We were overwhelmed by everyone’s generosity.”

“The photographer who chose us even presented us with a CD of 700 photos and a hardcover book of our wedding,” Cameron adds.

For bridal attire, one concern of Tammy’s was shoes. “I wear Mary Jane-style Skechers a lot, because shoes tend to fall off my feet,” she says. “One vendor bought a pair and added Swarovski crystals!”

For their ceremony, Cameron had his best man push him to the altar where he waited for his bride. Tammy’s nephew pushed her down the aisle so she could hold her father’s hand.

“After our vows, we had our maid of honor and best man push us down the aisle so we could hold hands,” Tammy says. “We also improvised our first dance and had Cameron’s best friend pick me up and put me on Cameron’s lap.”

Tammy offers these tips for accessibility:
- Hold wedding and reception in the same location, eliminating vehicle transfers, especially for the bride.
- Designate seating on the end rows for wheelers’ visibility.
- Make sure you have enough accessible parking spaces.
- Have table service instead of buffet.

“Because Las Vegas is a ‘new’ city, the accessibility issues are minor,” says Cameron, a fourth-generation Las Vegan. “It’s pretty flat and most places are up to code. A lot of the hotels have Hoyer lifts and trained staff to help. Some security guards are even paramedics.”

How to Make a Viral Video

Indiana couple Joey and Michelle Johnson, both 28, met at a Miranda Lambert concert in June 2012 after he’d just returned from fighting in Afghanistan. They started dating in July. Then on August 12, Joey — who habitually rode his motorcycle for an adrenaline rush to relieve the stress of PTSD — crashed and sustained a T6 complete SCI. “He was in the hospital for 100 days,” Michelle says. “So we were able to really get to know each other. It brought us closer, I think, than a ‘normal’ dating relationship.

“The idea of breaking up came up,” she adds. “I don’t think there is anybody who wouldn’t think of that. But, at this point, we were in survival mode and our thoughts were about getting to the next step.” By April 2013, Joey proposed and they planned a June 2014 church ceremony.

Michelle, a wedding and event planner, was eyeing everything for wheelchair accommodation. “We looked at several venues,” she says. “But they all had hills or steps where Joey would have had to go all the way around the building to the back to get inside. We chose Milltop Conference Center in Noblesville, a renovated flour mill that’s fully accessible and features a man cave with a huge accessible bathroom.”

While searching venues, Michelle didn’t realize that Joey was focused on ceiling structures. When he saw Milltop’s huge ex
posed beams, he knew the plan he was keeping from his bride-to-be could materialize. Only Joey, his parents and two groomsmen knew his secret: The most important thing for him was to dance standing with his bride. At others’ weddings, they wheelchair-danced with Michelle on his lap, but on this day, he wanted to wrap his arms around her waist, hold her close and gaze into her eyes.

A once avid rock climber, Joey figured he could rig something up to those solid beams to hold him upright to dance. For weeks, he and his friends tried different harnesses in his garage. “We started with a rock climbing harness,” Joey says. “You basically sit in the harness and with no use of my abs, I couldn’t keep myself upright without holding onto the ropes.”

Scratch that. Next they tried a deer stand tree harness, but its elastic cord stretched too far and would not keep Joey upright.

Scratch that one, too.

“Then we thought about a harness we used in the Army,” Joey says. “It’s called Special Purpose Insertion/Extraction and worn when rappelling out of helicopters. It’s a full-body harness designed to hold a trooper wearing a heavy rucksack. It’d be perfect but we didn’t have time to try it out.

“We were just going to wing it at the reception, but my mom came in and said, ‘No, you will do a practice run,’” Joey laughs. “We practiced right before the ceremony while Michelle was getting ready and after my lawyer friend and Army buddy wrote up a liability waiver for the venue [at Milltop’s request.
when they learned of Joey’s plan]."

The 6-foot, 2-inch, 165-pound groom bought his own tuxedo, had the pants lengthened, the jacket shortened in the back and the pant pockets sewn shut so his hands wouldn’t catch while pushing his wheelchair.

While Michelle was distracted, Joey and his buddies installed the harness and hooked him in while guests looked on.

“When I came around the corner, I was in shock,” Michelle says. “Everything in the room stopped, and I only saw him. I walked up to him and started crying. It had been two years since we were eye to eye.”

A friend taped their first dance to the Glee television show version of “A Thousand Years.” ABC News picked up the video, aired it the following Veterans’ Day and a viral video was born.

Stand and Deliver

Kiley and Zach Nelson, both 24, had already booked the Milltop Center for their wedding ceremony and reception when a photo from Joey and Michelle’s wedding popped up on Instagram.

“I saw this groom in a wheelchair,” Kiley says. “I wanted to see if they made any modifications for their wedding, so I connected with Michelle on Facebook.” The four met for drinks and became friends. Joey explained his harness, but Zach, a T3-4 complete para, knew he couldn’t manage it.

Zach and Kiley met in high school and started dating just before Zach left for boot camp after graduation. In 2012, while on a convoy mission in Afghanistan, the vehicle Zach was riding in

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while strapped in on top as a gunner, hit a boulder. The vehicle rolled over on him.

“I was in my junior year of nursing school when he was injured,” Kiley says. “You knew there was a chance he wouldn’t come back, but it never even occurred to me that he could come back with a life-altering injury.”

While planning their November 2014 wedding, Zach, determined to stand next to Kiley, decided to use a manual standing chair. “Using the stander was our saving grace,” Kiley says. “Getting a tux that fits was a challenge, too — the jacket bunches up and the pants ride up. Plus, I wanted to showcase my dress, and we felt that we were very limited for photos when he was sitting in his everyday chair.”

Zach used his standing chair for vows, “first look” photos and the first dance. For bridal party photos, he was lifted onto a barstool and then used his wheelchair throughout the reception.

“I’m a very tall girl, and it was great to have him stand up with me during the ceremony,” Kiley explains.

“After my injury, I wasn’t expecting her to stick around, but we decided to give it a go,” Zach says. “That’s when we knew we could make things work, it’d just be a different way of life. It’s turned out pretty well so far!”

For the Love of Family

Maria Rabaino chose a fitted gown with an altered train and hem to help her look her best in the wedding.

Maria and Fel Ian Rabaino met one night at a bar in 2011. Maria was a stressed-out college student who’d had her heart broken so many times that when she met Fel Ian, he made no impression on her. Four months later, Maria, underaged, went out drinking with a co-worker and some of his friends.

“I didn’t know them too well,” she says. “They were all over 21 and I figured they knew their limits.” They didn’t, and on the way home, the driver crashed and was killed. Maria sustained an L1 incomplete injury.

“After my accident I realized I wasn’t happy doing what I was doing,” says the 22 year old. “So I decided to do what made me happy, and it all fell into place. One random night, I ran into Fel Ian again. He was fun and didn’t talk about my chair, just to me as a person.”

“My mom is in the medical field, and I’ve seen so many people in wheelchairs, it’s second nature for me to not see the chair,” says Fel Ian, 28. Within four months of dating, the two got engaged, then married July 2015.

The Rabainos (now living in Monterey, Calif.) rented their local Sacramento community center, saying their vows outside on the patio with a view of a pretty field. Inside, Maria decorated the gymnasium for the reception. There were no issues with accessibility for Maria and her 200 guests, including five wheeler girlfriends, whom she met dancing with the Walk and Roll dance team.

“After my injury, my dad found Chelsie Hill’s dad on Facebook and sent him a message about me,” Maria says. “They talked on the phone and her dad gave my number to Chelsie, who was set to be on the TV show, Push Girls.”

The girls became close friends, Chelsie encouraged Maria to join the dance team, and Chelsie became a bridesmaid for Maria.

Maria chose a fitted gown that the bridal shop altered so the train hooked up to avoid her chair wheels. They also hemmed up the dress more than usual as Maria had decided she would walk down the aisle wearing her leg braces and walker.

Maria mostly stood while trying on her dress, so she didn’t pay attention to the bodice corset. After sitting for hours at the wedding, the corset wires began to dig into her hips and became painful. She warns sitting brides to have the corset cut higher to prevent this from happening.

“I chose to walk down the aisle because I had a lot of friends and family who knew me before and wanted to see me walk,” she says. “I then used my chair after our vows, to show them what my life is going to be with Fel Ian, and that we are 100 percent OK with it.”

“I’ve been with her through a lot of physical therapy,” says Fel Ian. “So seeing her walk down the aisle was breathtaking.”

“I’m happy in love and that’s all that matters,” Maria says.
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In the four years since Reggie Edgerton, renowned SCI researcher from UCLA and chief research scientist of NeuroRecovery Technologies, announced the groundbreaking results of the epidural stimulator implant trial he designed, the media’s primary focus has been on the return of voluntary leg function and the ability to stand that the four initial subjects enjoyed. The fact that they also had improvements in sexual function has generally been mentioned as an afterthought, an unexpected and welcome surprise to the participants and researchers alike.

Indeed, improvement in sexual function may be, arguably, the most important functional gain for the four subjects in the trial. And it turns out another type of electrical stimulation can enable a similar result in some people with SCI. But the most dramatic return of sexual function following epidural stimulator implant has occurred with the first subject, Rob Summers, 29.

Injured in 2006, Summers was a C6-7 quad with no movement or sensation below his injury — except for some feeling in the anal region — at the time of his implant in December 2009. He had an active sex life prior to the stimulator, but intercourse was predicated on pharmaceuticals, with no genital sensation. “Before the stimulator I could only get a sustainable, functional erection with 100mg of Viagra, and even then it was a reflex erection [due to physical rather than mental stimulation], and I had zero sensation and wasn’t able to ejaculate, except for a few reflex retrograde [when semen mixes with urine in the bladder] ejaculations,” he says.

After the epi-stim implant, Summers’ sexual functions started slowly returning, much to his surprise. “My focus was on standing and walking,” he says. But his erections became stronger and were lasting too long, so he started scaling back on Viagra. “Within a few months I started noticing sensation. At first it was like, ‘Wow! When did this start?’ I had my first orgasm around the same time.”

Summers told his girlfriend that sexual muscles are like any other muscle, and to improve he had to train often. “The more sex I have, the more things have improved,” he says. “Within a year I was able to ejaculate most of the time, and I no longer needed Viagra for a functional erection. Now I get erections constantly, and they aren’t just reflex erections. If my girlfriend walks by in tight leather pants, I will get an erection.”

Epi-stim has also been a huge help with Summers’ autonomic dysreflexia. “Before the stimulator, I used to get dysreflexia so bad I would see stars and feel like I was going to pass out,” he says. “Since the stimulator, it has improved drastically. I rarely get AD, and if I do, it is minor and usually because of a UTI.”

Sexual sensation has continued to return for Summers. “It isn’t ‘normal’ sensation compared to before my injury, and it isn’t as heightened a sensation as before my injury, but it is pleasurable,” he says. “I can feel what feels good and what doesn’t feel good. I can feel when I am close to reaching ejaculation and I can feel ejaculation. If I’m in bed with my eyes closed, I can feel if my girlfriend touches the head of my penis, the shaft, my testicles, everything. We have been having a lot of sex. I can even tell if we need to add lube or if she is very wet.”

In an interesting twist, sex works better with the stimulator turned off. “It is more difficult to get and maintain an erection with the stimulator on because it targets and triggers so many muscles,” he says.

Three more subjects replicate results

In 2007 Drew Meas, 36, sustained a C6-7 SCI. At the time of his epidural stimulator implant in 2011, Meas had no movement below his injury but did have sensation. Meas’ sexual functions started improving within two weeks after the implant was activated. “I still have grip in my right hand, so that makes me the perfect candidate for self-exploration,” he says. “Before the stimulator my erections were hit and miss. It improved the quality of my erections, and although I had some sensation, it improved that as well. Now I can get aroused with the slightest touch.” Unlike Summers, Meas isn’t able to get an erection via sight or from erotic thoughts.
The most important sexual improvement for Meas is that the epi-stim has mellowed out his autonomic dysreflexia. “Before the stimulator, sex would cause dysreflexia so bad that I couldn’t reach ejaculation/orgasm. It felt like my head would explode. Now I can ejaculate without getting dysreflexia.” Meas says that, like Summers, his sexual function works better with the stimulator turned off because too many muscle groups are activated when it is on.

Kent Stephenson, 25, was injured in 2009, a T4 motor-complete para. He got his epi-stim implant in 2012. Before the implant he was not able to maintain an erection for intercourse without large doses of Viagra. In a CNN interview, he stated that a side benefit of epi-stim is the return of functional erections, saying, “I went from zero to hero.” He went on to explain that with today’s high-tech wheelchairs, walking isn’t a big deal to him, but being able to have sex is a big deal.

The fourth subject to get an epidural stimulator is Dustin Shillcox, 31, who became a T5 complete para in 2010 and underwent his stimulator implant in January 2013. Shillcox says prior to the stimulator he would get reflex erections, but they weren’t functional for sex. He says the quality of his erections are better since the stimulator, but haven’t improved as dramatically as the other guys. “I recently connected the dots. Erections are like standing — I need to work on them,” he says. “I just started working on them, and they have definitely gotten better.”

DIFFERENT STIMULATOR, SIMILAR RESULTS
Another form of electrical stimulation has improved the sex life of Eric Stampfl, 57, who is in his 40th year as a T11-12 complete para. Three years ago Stampfl’s urologist surgically implanted an InterStim (see resources) — a device designed to reduce bowel and bladder incontinence via an implanted electrode that stimulates the sacral nerve. InterStim is FDA-approved for the general public but is considered “off label” for use in people with SCI.

Following the implant, Stampfl wheeled into his urologist’s office, and she turned on the device’s remote control — about the size of a TV remote. “All of a sudden my penis started tingling, and I said ‘Wow! This is a sensation I haven’t felt in 40 years!’” Stampfl was given a controller to take home.
WHAT ABOUT WOMEN?
Susan Harkema, lead researcher in the Reeve Foundation’s ongoing epidural stimulator trials, explains that the reason the first four epidural stimulator subjects are male comes down to statistics and luck of the draw. Eighty percent of people with SCI in the U.S. are male, and during the first study, researchers went down a list of people that met the parameters for the study, and the first four volunteers that qualified were male.

Going forward, regardless of the study, Harkema says 25 percent of the subjects will be female. For example, if the first three volunteers are women, that will be fine. But if the first three volunteers are male, they will keep going down the list until they find a female for the fourth. A total of 36 subjects are in the process of being chosen for the latest epidural stimulator trial.

More specifically relevant to this story, what about female sexual pleasure? Will women with SCI experience the same improvements as men? Harkema says that although there are obvious differences between men and women, there will also be similarities; for instance, increased blood flow to the genital area. However, she says, pending trial results, “We have no idea what the response will be in women.” Hopefully, the results will turn out to be as positive and exciting as the results with men.

“Before InterStim I could imagine I’m feeling sex during intercourse, but it was all in my mind,” says Stampfli. “But if my girlfriend was playing with my penis and I didn’t see, I wouldn’t know it. Now, if she touches my penis, I know it instantly. I can feel sex now. The sensation goes from a dull tingly feeling, which still feels really good, and builds to feeling really-really good. The sensation is getting a lot stronger and better as I have more sex.”

Unlike with epi-stim, Stampfli must have the Interstim controller turned on and on the right setting. Turned to low, he doesn’t feel anything, but on high the tingling becomes too much — even painful — to enjoy intercourse. Moderation is the key.

Stampfli still needs to use Papavarine injections to get an erection and hasn’t been able to reach orgasm, yet. “I was 17 when I had my...
ABOUT OUR COVER MODELS

Steve Dalton and his wife, Sydney Sauber, posed for this month’s cover because they wanted to illustrate that intimacy is possible — and essential — after acquiring a disability. Steve, a systems analyst at UC Berkeley who became a T4 para from a motorcycle accident in 2002, says Sydney, an independent brain researcher, is his “dream partner.”

“I wanted someone in my life who would be an equal partner in our relationship,” he says. “Sydney is exactly that; she is open and compassionate in her communication, she works as hard as I do for our success, and I never tire of being with her.” The couple enjoys talking about ideas, making and listening to music, exploring the outdoors, spending time with family and watching documentary films. “And,” Steve says, “we’re constantly seeking ways to use our life experiences to help others move ahead in their own lives.” The photo shoot was a way to do that — and more. “I’m honored to have the relationship I do with Sydney — one in which just being around one another encourages us to be our best selves. She is an incredible person in her own right, and somehow this photo shoot seemed to me to be an opportunity to capture how much I love her.”

Edgerton explains that, hopefully, further research will give some insight into results like Stampfli’s. In Charlotte, N.C., says he has not heard any reports of return of sexual sensation in his patients with SCI that are using InterStim, and at least a few have reported similar sensations. “My urologist said, ‘Then, perhaps we should take it out.’ I told him that some of her other SCI patients have reported similar sensations, which results in more experimenting and information,” she says.

On Stampfli’s experience with InterStim sacral nerve stimulation, Harkema and Edgerton said it is probably a similar version of what is happening with their subjects, directly stimulating sensory fibers going back to the spinal cord and returning to the sexual organs, which is helping to reawaken that circuitry.

Edgerton and Harkema say they didn’t expect return of sexual function when they started the trial, so they didn’t look at any baselines. However, sexual baselines will be included for the next round of 36 subjects in The Big Idea [See resources].

Edgerton explains that initial observations with the stimulator have opened a whole new arena of possibilities. “We have just scratched the surface. With better technology — the next generation of stimulators we are working on — we can achieve more,” he says. “With all of this new information, there is very good reason for hope of improved function. I think it is going to happen. It is just a matter of how long it is going to take us to get there.”

RESO URC ES
- InterStim by Medtronic, www.medtronic.com/patients/overactive-bladder/about-therapy/
- Edgerton’s latest research, www.newmobility.com/2015/04/when-rehab-becomes-recovery/
The grassroots, no-holds-barred CareCure Community Relationship and Sexuality Forum is a thriving online resource for those with spinal cord injury. Rich with personal experience and trial-and-error anecdotes, the most active thread in the forum, with 347 replies and 22,730 views as I write this, is titled “Electro Nut Busting.” The conversation centers around “electro sex” — using electronic stimulators (relatively inexpensive, easy to find devices) — to evoke ejaculation in men with SCI.

Why such a strong interest in ejaculation? I call it the ejaculation affirmation, a term I coined while working on my research on pleasure and orgasm in people with spinal cord injuries. In that context, men in heterosexual relationships were telling me that their partners didn’t believe them when they said they were satisfied — because there was not the usual evidence. Their lovers needed to see the white with their own eyes. For most people who have sex with men, ejaculation provides the affirmation that they pleased their partner.

Ejaculation also affirms our manliness. After all, what’s more unique about male sexual pleasure? While ejaculation may be part of the female sexual experience, it’s usually the icing on the cake, not the defining moment of the typical orgasmic response. Ejaculation in men is associated with the feeling of completeness.

And ejaculation is primal; it is responsible for the survival of the species. Moreover, the loss of the ability to ejaculate strikes at the core of a man’s sexual identity. While the focus of my work with men is often shifting their emphasis off the goal of ejaculation and on to pleasure and learning to experience orgasm from stimulating other areas besides the genitals, the desire to want to restore this basic function after injury is certainly understandable — and something I support.

But the pseudo-scientific world of off-the-shelf stimulators, electrode pads and pulse amplitudes should not be approached lightly. Caution and due diligence are always wise.

So just how do we go about this?

START WITH VIBRATORY STIMULATION

As enticing as electro nut busting may be, for the great majority of men with both complete and incomplete SCI who no longer ejaculate through manual, oral, vaginal or anal stimulation, vibrators are the safest tools to use, especially in the beginning. We have relied on vibrators to provide the added stimulation necessary to evoke ejaculation at home for decades.

Vibratory stimulation has been shown to be a relatively safe and effective technique in men with certain types of SCI and other neurological impairments such as MS and transverse myelitis. It is most successful with men who have complete injuries at T10 or above, or incomplete injuries (both assuming a neurologically intact lumbosacral cord). People with SCI at or above T6 or who have experienced difficulties in regulating blood pressure need to take certain precautions to avoid autonomic dysreflexia, a spike in blood pressure that can lead to convulsions and/or stroke if not treated immediately.

Nancy Brackett, Ph.D., a research professor in male fertility with the Miami Project, recommends taking 20-40 mg of the calcium channel antagonist, nifedipine, by mouth 45-60 minutes prior to ejaculation, but only in those whose level of injury is T6 or above. Otherwise, it can be administered under the tongue, 15 minutes prior to ejaculation, but this route of administration requires some skill — make sure you fully understand your doctor’s instructions.

Regarding other ways to prevent dysreflexia, Brackett says, “We have not used nitropaste. We have used nitroglycerin tablets only in people with very labile blood pressures [may fluctuate abruptly] who require extra management in addition to nifedipine. Nitroglycerin tablets should not be administered routinely or casually, but only when indicated,” she cautions. “Ask your doctor before pursuing any kind of mechanical or electrical stimulation of your penis if you are prone to autonomic dysreflexia.”

— Nancy Brackett, Ph.D., Miami Project
ing away from your ejaculatory experience, it could leave you more disabled or dead.”

With that warning firmly in mind, it is safest to try your first vibrostimulation at a center or clinic where your blood pressure can be monitored. While this is ideal, it’s not practical for most. I encourage you to at least get a home blood pressure cuff to monitor yourself. AD is sometimes “silent” — as there are often no noticeable symptoms until it’s too late.

Over-the-counter vibrators are low-amplitude and work for maybe 30-40 percent of all men with SCI. The ideal vibrator is a high-amplitude medical model that works on 80-90 percent of men with injuries T10 or above and for about 70 percent of men with injuries at all levels. Until recently, the Ferticare by Multicept was your only option, priced at around $850. Now the Viberect X3 by Reflexonic is available and nearly as effective — for $299.

Try stimulating the shaft of the penis for about a minute, then focusing in on the frenulum on the underside of the penis next to the coronal ridge of the glans or head of the penis for another minute. Use the vibrator for only a couple of minutes at a time with at least a couple of minutes rest from the vibrator in between to avoid skin breakdown and excessive swelling. Some swelling is likely. It is very important not to stimulate yourself too long with the vibrator to maintain your skin integrity. When you are resting from the vibrator, you or your partner can continue to stimulate your penis manually or your partner can stimulate you orally. Massaging the perineum, the area between the base of your scrotum and your anus, while you are being stimulated with the vibrator may also help.

EROTIC ELECTROSTIMULATION: PROCEED WITH CAUTION

In the February 2015 edition of NM, I saw a reference to erotic electrostimulation at the end of “Second Chances,” the cover story about Brian Kinney and his wife, Tiffany. In the story, Brad Stubblefield told Brian about using a transcutaneous electrical nerve stimulation (TENS) unit to evoke ejaculation. Brian’s story inspired me to do some experimentation and research of my own. I had an e-stim unit that had been used for neuromuscular electrical stimulation (NMES) of my abs and glutes, but I didn’t know exactly where to place the electrodes and what settings to use for ejaculation.

I went to the scientific literature, but there was nothing on men with SCI using e-stim at home for this purpose. There is a body of research on the use of electro-ejaculation stimulation, or more descriptively, rectal probe ejaculation, but my sense is that most men don’t want to go there outside of the medical setting. There’s also an interesting 2005 study by Dr. Lance Goetz on the addition of NMES of the abdomen to the vibrostimulation protocols, which increases the success rate of vibrostimulation significantly [http://bit.ly/1JUlxIS].

Fortunately, I found the Electro Nut Busting thread at CareCure. Based on my rough analysis, there were about 31 guys and one brave woman who experimented with either vibrostimulation or e-stim contributing to this wealth of knowledge.

From what I could discern from those who mentioned type of injury and level, about two-thirds were complete and most were
cervical or upper thoracic. Of the group, 11 experimented with a vibrator and seven resulted in ejaculation. There was very little explicit discussion about pleasure and orgasm, with one person with a complete injury sharing they had both from vibrostimulation.

Of the 26 men in the discussion who tried e-stim, 22 reported ejaculation. That’s a remarkable 85 percent success rate. Five people specifically mentioned using this for fertility reasons. Ten explicitly noted that it was pleasurable, and two said it was not. Two, both with complete injuries, described the experience as orgasmic. The pioneer user who started the thread was one of them. He posted this raw response [edited lightly]: “The bottom line is: I did it! ... Holy fuck! It does resemble an orgasm ... it started to tighten, and it started to ‘spread.’ I was like, what the fu-aaaaahhhhhhhhhhh. The next moment, pump-pump-pump-pump ... I have shot a load like in good old times. I have turned the EMS off and savored the feeling, a good, relaxed state, for a long while.”

Success sometimes came with a price, with six people reporting significant AD. Here is one typical story: “Ahhhh. I finally got it with four pads! Bad thing was I had it turned up too much and the AD was unbearable, I thought I was gonna croak! Had a headache for three days. Had to ice my head every night just to get it away ... the AD was too much. Gonna try to go slower this time round.”

As you can see, for those prone to AD, there is ample reason to proceed with caution. This experience can be a blessing and a curse. Together this online community worked to share and refine protocol for unit selection, electrode choice and placement, settings, and timing.

WHAT ABOUT EQUIPMENT?

So what do you need to get started? A TENS, EMS, or NMES? What’s the difference? What brand? What size and type of electrodes?

Historically a TENS unit was prescribed for pain-related issues and a neuromuscular electrical stimulator (NEMS or EMS) for muscle strengthening. However, many units marketed today come pre-programmed with modes for both. Based on the various experiences shared, it doesn’t seem to matter what type of unit

**GLOSSARY**

**TENS** - Transcutaneous electrical nerve stimulation is the use of low-voltage electrical current for pain relief. Using a small, battery-powered machine, users connect electrodes from the machine to their skin at areas of pain or pressure points.

**NMES** - Neuromuscular electrical stimulation uses a device that sends electrical impulses to nerves. This input causes muscles to contract. The electrical stimulation can increase strength and range of motion, and offset the effects of disuse. It is often used to “re-train” or “re-educate” a muscle to function and to build strength after a surgery or period of disuse.

**EMS** – Electrical muscle stimulation is the use of electric impulses to cause muscle contractions. It is synonymous with neuromuscular electrical stimulation.
O NE WO MAN’S EXPERIENCE

The “brave woman” who joined all the guys in the electro nut busting CareCure thread posted this encouraging response:

“It worked for me! … I’m 50 and have trouble with my pudendal nerve and sciatica from my degenerative disc disease and L5-S1 herniated discs and have been two and a half years using a cane to walk for only a block, and I also have C6-7 nerve impinging. I have not been able to enjoy relations with my husband or have any desires by myself for over two years, and I used this first link with my Com-TENS unit with four pads and it did the trick, ladies!”

To try this at home, here’s the link she’s referencing: www.extremerestraints.com/male-e-stim-accessories_179/tens-pads-4-pack_30.html

you use as long as you can adjust the pulse rate, pulse width, pulse amplitude and have a continuous setting.

I purchased a basic two-channel TENS unit muscle stimulator — TENS 7000 — complete with one set of four electrodes, lead wires, 9-volt battery, instructions, and carrying case for under $30, delivered via Amazon.

This is everything you need to get started.

Some people reported better success using rings or bands rather than square electrodes. These come in single pole and bi-pole. For help in this area I turned to Gary, the owner of happystim-usa.com. I could not find much on Amazon, and there are a lot of con-

A TENS pad is considered a single pole electrode because you plug one wire into a single electrode. It takes two single pole electrodes to complete the circuit, one charged by the negative branch of the lead wire and the other by the positive (red) branch. A bi-polar electrode is technically an electrode that has two single pole electrodes fixed on one unit. The closer two electrodes are to each other, the more intense the stim.

Electro nut busting has the potential to be orgasmic, but most are doing this just because they can. There are the guys who experience physiological sexual pleasure, some not as good as before, some the same. Then there is the pleasure that the majority have in the fact that they can achieve ejaculation, even if they don’t have any sensation associated with it — and even when there is significant risk and pain.

RESOURCES

• Viberec X3, medicalvibrator.com/product/viberec-x3 or www.urologyhealthstore.com
• TENS 7000, www.medi-stim.com/stims/tens/tens7000.html
• E-stim supplies, www.happystim-usa.com
• Miami Project guide to male fertility following SCI, bit.ly/1JPZwq
[Editor’s note: To ensure proper placement of electrodes, it would be wise to contact someone with experience in erotic electrostimulation — such as an experienced CareCure Forum member, SCI nurse, or other person familiar with the process — before “flipping the switch.”]

When selecting between bi-polar and single pole electrodes, remember the bi-polar will be more intense. However, they are useful if you want to stimulate multiple sites on your anatomy. You can always start with your settings lower. I purchased the bi-polar Choker conductive loop to put around the head of the penis ($15.95) and Strangler to put around the base of the penis and scrotum ($24.95) — Oh, what I wouldn’t do for science! Note: It is recommended to use electrode gel with accessories other than TENS pads to avoid stinging or burning. I purchased the Spectra 360 Electrode Gel by Parker Labs (8 ounces for $7.50).

Once you have all your equipment, you are ready for placement. CareCure contributors often started with two sets of TENS pads (four electrodes). They placed the electrodes attached to the negative lead from each channel to the left and right of the base of the penis in the pubic area. It is recommended to trim closely or shave for best conductivity. They placed the electrodes from the positive lead of each to the left and right side of the shaft of the penis, each close to the head or overlapping. From there, individuals experimented with their own placement of the negative and positive leads.

I consulted with my colleague, Dr. Barry Komisaruk, a world-renowned sex researcher with expertise in neuroanatomy and physiology, to determine the theoretically best placement to facilitate ejaculation. Skipping the technicalities, he thinks you would definitely want to include stimulation of the scrotum in addition to the underside (ventral) of the penis, along the urethral sponge and on the top (dorsal) of the penis, to stimulate the nerves necessary for emission and propulsion, the two phases of ejaculation.

With regard to settings, the guys from CareCure were using a pulse rate between 2 and 150 Hz, a pulse width between 50 and 300 µs (microseconds), and a pulse amplitude between 0 and 100 mA (milliamps). Most would set the pulse width at 300 µs, warm up at lower levels of Hz, and ramp up the mAs during stim sessions.

Gary, owner of happystim-usa.com, always shares these three points of advice when coaching people on the art of electro sex:

- PPP — practice, patience, placement
- Retaining body water is a good thing, especially electrolytes.
- Mental state at time is important for sexual arousal

— MITCHELL TEPPER

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ELECTRODE PLACEMENT FOR EJACULATION

AN ADVOCATE WHO’S BEEN WHERE YOU ARE

When I broke my neck in a diving accident in 1980, I was a young kid going to college. I was confused and not sure what was going to happen. Even though it turned out that my accident was the result of a design defect, a law prevented me from filing a lawsuit.

My experience set me on a path that led me to Boston College Law School and the founding of my own practice that has recovered millions of dollars for injured persons. As I gained more independence, I was able to travel the world. Three years ago I joined the faculty of Boston College Law School as an adjunct professor.

Now I’m at a point in my career where I’m able to seek out and help others whose lives have been changed forever through catastrophic injury. I’ve represented people with spinal cord injuries, traumatic brain injuries, death cases and other serious injury cases throughout the US, including cases involving injuries sustained in other countries or against foreign defendants. I look forward to hearing your story - wherever you may be. My staff and I are equipped to travel throughout the country to meet with you and discuss your case.

What I’d like to convey to you during the dark days of your injury is that with the right amount of hope, support and financial security, there are no limits to what you can accomplish.

If you want to speak to someone who understands your situation, please contact me.

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MY TAKE
My favorite thing to do is roll around Philadelphia on a sunny day in the throes of the holiday season. I love watching different cultures of people go by, and on occasion see other wheelchair users cruising the sites as well. As someone who lives in the suburbs, visiting Philly provides me with many accessible sidewalks, stores and sites closer in proximity that make the city loads of fun.

The Reading Terminal Market (pictured at right) located at 12th and Arch Street has been in existence since 1893, and visiting it is an adventure all its own with its massive crowds, exciting smells and many indoor vendors with delectable eats you can sit down and enjoy right inside. Thomas the Train is there for the kids’ enjoyment: We have taken my niece there twice now and she loves it. The Market is wheelchair accessible but can get crowded, particularly during lunch and weekends.

PLACES TO GO
The Philadelphia Museum of Art, one of the most renowned museums in the country, is a great place to start. You can experience current exhibits such as the Art of American Still Life, Audubon to Warhol, as well as great pieces of art from around the world. The museum is wheelchair accessible with a parking lot and ramps entering through the front entrance. There are elevators to every floor and wheelchair accessible bathrooms. I love visiting here when I can — it is so easy to maneuver.

If you’re hungry you can visit many of the hotspot cheesesteak places. One of the greats is Geno’s Steaks on South 9th St. It is accessible, but be prepared for the long lines, as you will not be the only one hungry for a cheesesteak. If you visit in the summer, come to the Philadelphia Zoo, the country’s oldest, and see the many species of animals that live there. There is also a children’s zoo and so much to do that you can spend the entire day there.

GETTING AROUND
Philadelphia on the whole is mostly wheelchair friendly with access to public transportation, taxis, hotels, attractions and sidewalks. Wheelchair-accessible cabs can accommodate both manual and power wheelchairs, and their numbers are growing. They are available by phone, but wait time can be up to 30 minutes or so, plan accordingly.

If choosing to take the subway system, there are three separate lines that travel both above and below ground. The subway and its train cars are wheelchair accessible, but not all stations are. There are gaps between the platform and train, but bridge plates are available at all accessible stations.

The Philadelphia International Airport is very accessible and brand new. Bathrooms are large and ramps and elevators are plentiful for getting to different gates.

MUST SEE, MUST DO
If you want to take in a show, come to the Kimmel Center for the Performing Arts, where you will get to see our famous Philadelphia Orchestra, PhilaDANCO Dance Company, or the Philly Pops. I saw PhilaDANCO last December and they were absolutely amazing to watch, with a blend of ballet and modern style dance. The Kimmel Center has underground accessible parking. Park once and grab dinner at Bar Volver or the Dining Room of Volver and enjoy delicious food from the great José Garces.

Philadelphia is swimming in American history and offers attractions such as the Liberty Bell and Independence Hall. If learning about the Constitution is your passion, head to the Constitution Center, where you can increase your awareness and understanding with a bevy of interactive exhibits. Located at Independence Mall, the museum is wheelchair accessible and offers loaner wheelchairs.

If you’re in Philadelphia during March, don’t miss the Philadelphia Flower Show, located in the heart of Philadelphia at the highly accessible Convention Center.
After over two years in the works, the Greater Philadelphia Chapter of United Spinal is off and wheeling. The chapter introduced itself to the world on Sept. 12 with a handcycling and barbecue event held in conjunction with the Pennsylvania Center for Adapted Sports. Almost 60 people showed up for a fun afternoon of handcycling, food and learning about the chapter’s vision and plans. “I think everyone had a really nice time and there seemed to be a lot of interest in the chapter and what we’re trying to do,” says Alysse Einbender, the chapter’s vice president.

Einbender says recruiting new members and tapping into the local community has proved more difficult than the chapter’s board had anticipated, but they are optimistic they are on the right path. To improve its outreach efforts, the chapter partnered with Beautiful Social, a “digital media research collaborative” consisting of students and faculty at Saint Joseph’s University in Philadelphia. Based out of the university’s communications department, Beautiful Social works with nonprofits for no charge — a key for new groups like the Greater Philadelphia Chapter.

The chapter knew of Beautiful Social because of a project it had done for another local disability organization. It invited the team to the inaugural event with the goal of producing a video and material the chapter could use to market itself. The students took photos, video and conducted interviews at the kickoff event and then assembled a two-minute video which can now be viewed on YouTube or the chapter’s Facebook and web pages. “The video turned out really well,” says Einbender. “We’re hoping it will help us introduce us to the people we’re trying to connect with.”

To find out more about the Greater Philadelphia Chapter, visit the website at unitedspinalphiladelphia.com or find its Facebook page at facebook.com/unitedspinalphila. You can watch the video mentioned above at: https://www.youtube.com/watch?v=mszuSneP9vg
United Spinal Requests Safe And Lawful Ferry Access to the Statue of Liberty

On Dec. 21, United Spinal Association sent a letter to the superintendent of the Statue of Liberty National Monument requesting that the National Park Service provide safe and lawful ferry access for wheelchair users.

In the letter, James Weisman, United Spinal Association’s president and CEO, described significant and dangerous problems regarding wheelchair accessibility on the ferry that transports visitors to the national monument. “United Spinal Association has fought hard to insure that the built environment is accessible to and usable by wheelchair users,” said Weisman. “Access to the ferry should be standard, not ‘created’ with an operational solution every time wheelchair users attempt to board and disembark.”

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. United Spinal staff member David Heard, a quad who uses a power chair, demonstrated the haphazard boarding and on-ship conditions in a video posted alongside an accompanying article in the New York Daily News. There was no way to secure Heard’s chair on the ferry, and the bathrooms were not large enough for him to use in his chair. Heard required assistance getting on and off the ferry and had to do so at dangerous angles.

“I know that some people are not as outgoing as I am and would not utilize it,” Heard told the Daily News. “They should be able to. . . . Someone else is going to have a problem.”

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

(Watch the video of Heard riding the ferry here: http://launch.newsinc.com/share.html?trackingGroup=69016&siteSection=nydailynews-new-york&videoid=30147959)

Chapter’s Persistence Rewarded With Neilsen Grant

United Spinal sent a letter to the superintendent of the Statue of Liberty National Monument saying that Statue Cruises is not living up to its ADA responsibilities.

Managing your weight as a wheelchair user is notoriously tricky. Writing a successful grant and getting it funded is never easy. The Northeast Ohio Chapter of the National Spinal Cord Injury Association managed to find success by combining both difficult tasks — writing a grant to study how wheelchair users can best control their weight. Entitled “Expanding Quality of Life in a Wheelchair,” the grant was picked up by the Craig H. Neilsen Foundation last year and awarded $30,000 over the course of one year. The chapter’s success is a testament to the importance of persistence and savvy when trying to secure prestigious grants.

The chapter’s pursuit of the Neilsen grant began in 2013 when it submitted a proposal called “Weight Management in a Wheelchair.” The Neilsen Foundation, which is dedicated to funding endeavors that improve the lives of people with spinal cord injuries, selected the proposal as one of its annual Quality of Life award recipients but decided not to fund it. Undeterred, the chapter resubmitted the proposal in 2015 after adding a series of medical components they thought might sway the grant selectors.

“We added language that would get doctors, nurses, therapists and dietitians involved, monitoring blood and glucose levels and other medical results,” says chapter member Jeff Schiemann. “The premise of the new grant was that the doctors and the therapists would learn and benefit just as much as the participants were benefitting from it.”

It worked. “With that they picked up the grant,” says Schiemann. “They even said, ‘We realize this is basically the same grant, but we like the medical component.’”

With grant in hand, the chapter purchased ergometers, free weights, therapy bands and other miscellaneous equipment, selected 10 participants for the study and got to getting fit. Participants each received log books to track their activity and diet and signed up for an application called Lose It! that helps users keep track of calories and exercise. The program started off with a series of lectures relevant to weight loss, presented by experts in the fields. The lectures were open to anyone who was interested.

Schiemann says he is excited to see how the program goes over the next year. He also encouraged other grant seekers to keep pursuing their dreams, even if they have been rejected. “If you have an idea that you like and think will work, it’s just a question of getting it right in the eyes of the grantors,” he says.
### Mission

United Spinal Association’s mission is to improve the quality of life of all Americans living with spinal cord injuries and disorders (SCI/D). Membership in United Spinal is open to anyone with an interest in SCI/D. For more information on the benefits of joining, visit [www.unitedspinal.org](http://www.unitedspinal.org) or call 800/404-2898.

### Hospital and Organizational Members

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<td>Providence Alaska Medical Center</td>
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<td>Spaulding Rehabilitation Hospital</td>
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<td>MARYLAND</td>
<td>Adventist Rehabilitation Hospital of Maryland</td>
<td>Rockville</td>
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<td>International Center for Spinal Cord Injury at Kennedy Krieger Institute</td>
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<td>888/554-2080</td>
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<td>MICHIGAN</td>
<td>Mary Freebed Rehabilitation Hospital</td>
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Roger C. Peace Rehabilitation Center, Greenville, NC; 864/455-3779

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

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

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

NEBRASKA

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

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

NEW HAMPSHIRE

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

NEW JERSEY

Bacharach Institute for Rehabilitation, Pomon, NJ; 609/748-5480

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

NEW YORK

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

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

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

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

Strong Memorial Hospital of the University of Rochester, Rochester, NY; 585/275-2100

Sunnyside Rehabilitation Hospital, Schenectady, NY; 518/425-6560

The Burke Rehabilitation Hospital - Spinal Cord Injury Program, White Plains, NY; 914/597-2500

OHIO

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

SCI Program of the Rehabilitation Institute of Ohio at Miami Valley Hospital, Dayton, OH; 937/208-8000

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

OKLAHOMA

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

OREGON

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

PENNSYLVANIA

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

Healthsouth Rehabilitation Hospital of Altoona, Altoona, PA; 800/873-4220

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

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

UPMC Rehabilitation Institute at Mercy, Pittsburgh, PA; 800/533-8762

SOUTH CAROLINA

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

Roper Rehabilitation Hospital, Charleston, SC; 843/724-2800

TENNESSEE

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

Vanderbilt Stallworth Rehabilitation Hospital, Nashville, TN; 615/963-4051

TEXAS

HealthSouth RIOSA, San Antonio, TX; 210/691-0737

Texas Health Harris Methodist - Fort Worth, Fort Worth, TX; 817/250-2029

Texas Rehabilitation Hospital of Fort Worth, Fort Worth, TX; 817/820-3400

TIRR Memorial Hermann Hospital, Houston, TX; 713/799-5000

UT Southwestern Rehabilitation Unit, Dallas, TX, 214/493-0597

Warm Springs Rehabilitation Hospital of San Antonio Spinal Cord Injury Program, San Antonio, TX; 210/616-0100

UTAH

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

VIRGINIA

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

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

Virginia Commonwealth University Medical Center, Richmond, VA; 804/828-0861

VERMONT

Fletcher Allen Rehabilitation, Colchester, VT; 802/847-6900

WASHINGTON

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

Swedish Medical Center - Neuroscience Institute, Seattle, WA; 206/320-2000

WISCONSIN

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

Organizational Members

Center of Recovery & Exercise (CORE) Longwood, FL; 321/418-3050

Florida Spinal Cord Injury Resource Center Tampa, FL; 813/844-4711

Life Beyond Barriers Rehabilitation Group Rockford, MI; 616/866-6059

Miami Physical Therapy Assoc., Inc. Miami, FL; 305/444.0074

Neuro Fit 360 Pembroke Pines, FL; 954/252-8020

NeuroWorx South Jordan, UT; 801/390-0760

Neuroxcel North Palm Beach, FL; 866/391-6247

Project Walk - Atlanta Alpharetta, GA; 770/722-4239

Project Walk - Boston Stratham, NH, 603/583-5119

Project Walk - Houston Missouri City, TX; 281/410-8348

Project Walk - Kansas City Overland Park, KS; 913/451-1500

Project Walk - Mt. Laurel Mt. Laurel, NJ; 484/800-1563

Project Walk - Orlando Sanford, FL; 407/571-9974

Project Walk - San Francisco Freemont, CA; 510/623-1924

Project Walk - Spinal Cord Injury Recovery Center, Carlsbad, CA; 760/431-9789

Push to Walk Riverdale, NJ; 862/200-5848

Interested in becoming a hospital or organizational member? Please contact Nick LiBassi at 718-803-3782, ext. 7410 or nlibassi@unitedspinal.org
These days paralysis, or the inability to use feet or legs while driving, is not a hindrance to safe operation of virtually any type of motorized vehicle. This includes vehicles used for racing and other motorsports. Motorsports are enjoyed by millions of people around the world who watch on television or attend events each year, and some of those who are competing are using hand controls to do so.

Individuals who drive with hand controls have many avenues for participating in motorsports. Racing is one type of motorsports event, but there are also other events where drivers can test their skills on tracks by themselves and compete against the clock. For those, there is no risk to the driver involved or their vehicle.

Many drivers use their everyday vehicles while enjoying high performance lapping events without making expensive modifications to them. Jay Brickey, a T11 para from Redmond, Wash., recommends joining one of the local car club drivers’ skills days at a High Performance Driver Education event and then coming back for a lapping day when drivers with all levels of experience can take to the track.

Besides enjoying HPDE events in his modified BMW M3 coupe, Brickey is an instructor for such events, which he attends throughout the Northwest and Northern California eight to 10 times per year. Instructors introduce new drivers to the experience of riding along with a skilled driver in a high performance car to help them understand how important it is to develop their skills through practice. As their skills develop, drivers are approved for sharing the track with others. Brickey’s philosophy in regard to the value of skill development in high performance driving is simple. “Fast cars don’t make fast drivers,” he says, “drivers make cars fast.”

With years of high performance driving background in a variety of cars, Brickey has some advice for those who want to get involved and go faster. “Don’t scrimp on safety and positioning gear. Get a seat that fits and install the correct restraints. Build slowly, start with a stock, or mostly stock, car and go from the wheels up,” he advises, “and the motor should be the last thing you touch, not the first.”

**You Can Use Your Own Car**

Derek Mortland was an experienced motorcycle endurance racer from Columbus, Ohio, when he had a racing accident in 1997 that left him with paraplegia at the T9 level. He discovered, over a decade later, that it was possible to continue competing in motorsports while using the same car he used for daily transportation. He took his 2005 Ford Focus to a HPDE event put on by the National Auto Sports Association. The only modifications he has made to that car are a stiffer suspension and a racing harness for the driver. Since he now competes almost every weekend during the summer months, Derek has become an instructor in order to keep his costs down and to give back to others who want to try the sport.

The family sedan or van might be all that is needed to participate in some other types of motorsports as well. Sports Car Club of America autocross (asphalt) and rallycross (dirt) events are driving skill contests that emphasize the driver’s ability and the car’s handling characteristics. This is accomplished by driving a course that is designated by traffic cones in a low hazard location, such as a parking lot or inactive airstrip. Autocross course layouts are changed, and drivers often run them backwards, multiple times during the day.
Autocross is not a contact sport, as only one vehicle is on the course at a time. Pushing the cars to their limits while staying within the boundaries marked by the cones tests driver’s abilities and lessens the risk of high-speed crashes or injuries. Many drivers step up to higher-horsepower performance vehicles as their skills grow.

Some autocross competitors were racers in other sports prior to getting more involved with autocross. Lance Magin, a para from Holtville, Calif., raced the Baja 500 on a motorcycle in June, 1974, then was injured while racing in October of that year. He became the first paraplegic to compete and win his category while driving a “buggy” in several more Baja races. Magin later switched to off-road truck racing, winning his category in a truck he built, in the Best of the Desert Racing Series in 2006.

Magin partnered with the San Diego chapter of Paralyzed Veterans of America in 2008 to set up a racing venue at Qualcomm Stadium in San Diego. There are currently five individuals who use hand controls competing in that program open to all drivers, and Magin was the track champion for 2015.

Other Racing Options
Drivers who might not like to go around in circles have options, too. Patrick Cottini, a C7 quad from Chico, Calif., plans to build a car to race on the Bonneville salt flats, where he hopes to set a speed record for quadriplegic drivers.

Another inexpensive way to give motorsports a try is kart racing. Many of the best racing drivers in the world include kart racing as part of their résumés, as tracks dedicated to the sport have been established throughout the country. Some of those facilities are indoor, which allows drivers to compete year-round. Several tracks have also equipped rental karts with hand controls; the Unser Karting facility in Colorado has gone beyond that by installing transfer benches for use by those who need their wheelchairs to get to trackside.

There are several types of off-road racing, on closed courses and across open desert. Steve “Wheels” Bucaro, a para from Las Vegas, has raced on closed courses in the Lucas Oil Off Road Racing Series for several years, driving his Honda Pilot. “I chose the Honda because it is relatively inexpensive and is already equipped with a roll cage,” he says. “All I had to do was add hand controls, some safety items and a racing harness and I was good to go.” Bucaro is currently building a new off-road truck that will allow him to compete in the Pro Light category next year.

Rob Parsons, aka “Chairslayer,” is a professional driver who competes in drifting. Originally from Lethbridge, Alberta, Canada, Parsons was paralyzed due to a dirt bike accident in 2011. Drift races are held on a variety of courses where drivers in high performance automobiles push their cars to the limit while using the throttle, brakes, clutch, gear shift and steering to keep the car in a state of oversteer while cornering. Those races are marked by plenty of blue smoke from squealing tires. Parsons says that, while drifting originated in Japan, the United States has definitely beefed it up.

Like many of his peers, Parsons is a skilled mechanic who rebuilt his current ’89 Nissan with a Vortech Supercharged 600 hp engine, and in the process developed an electronic shifter and clutch to accompany a modified set of Monarch hand controls. “I am fortunate in one regard,” he says, “as I have Achilles Radial Tires as primary sponsor.” That can come in handy when a set of tires might only survive a couple of laps.

Parsons established the Chairslayer Foundation and has built a special drifting car that he will take to disability and veterans’ events around the continent to open the doors to what is possible for those who need to use hand controls. At those events he provides rides to individuals with disabilities and gives drivers the opportunity to learn firsthand by actually driving the car. Parsons enjoys spending
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paralyzed at the T5-6 level as a result of a racing crash at age 14. After recovering, he switched to karts and several classes of race cars. He was successful in all of them, with an even brighter future ahead.

Johnson’s successful racing career was interrupted when, in March 2015, his steering gave out during a practice lap and he crashed head-on into a wall in Saint Petersburg, Fla., at an estimated speed of 100 mph. Injuries included two broken bones, and the impact left him unconscious for two weeks. In 2016 he will be taking on a new kind of challenge when he resumes competition racing in the Mazda Sportscar series with a co-driver.

Obviously racing can be dangerous, which is why race cars are equipped with so many features to protect drivers and spectators. Combining motorsports with paralysis can be tricky, as there is always the possibility of getting a pressure sore from transferring or from sitting in a car or truck seat while traversing rough terrain for hours at a time. However, other sports have inherent risks as well, and the many drivers using hand controls in competition have proven that they are capable of handling risk successfully.

Resources
- Accessible Racing, 603/960-4402; www.accessibleracing.com
- Cal-Diego PVA, 858/450-1443; www.caldiegopva.org
- Chairslayer Foundation, chairslayer.com/robparsons/
- Conquer Paralysis Now, 609/737-1919; www.conquerparalysisnow.org
- Guidosimplex hand controls, 888/599-8267; www.guidosimplexusa.com
- MasterShift, 888/658-2727; www.supercarsllc.com/newmastershift/
- Monarch Hand Controls, 800/243-4051; mps-handcontrols.com
- National Auto Sport Association, 510/232-6272; www.nasaproracing.com
- Pacific Grand Prix Karting, 253/639-7223; www.pacificgp.com
- Pole Position Raceway, www.polepositionraceway.com
- Racing4Vets, www.racing4vets.org
- Schmidt Peterson Motorsports, 317/209-0099; www.spmindycar.com
- Sports Car Club of America, 800/770-2055; www.scca.org
- Unser Karting & Events, 720/282-5000; unserkarting.com/kart-racing/adaptive-kart-racing

Michael Johnson, T5-6, is the first paraplegic driver licensed to drive in the IndyCar racing series.

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Q. I'm 58 years old and in my 20th year as a T7 complete paraplegic. Over the past few years it seems I'm always tired, have difficulty focusing on tasks and have lost enthusiasm for going out and doing my usual sports of handcycling and swimming. It is a struggle to get out the door and do them.

I've read that people with SCI have a higher incidence of low testosterone and that testosterone replacement can help improve energy, muscle mass, and concentration. Have you heard of this? And if so, how do I find out about it?

— Scott

Scoott, you bring up a good question — a Web search of “chronic spinal cord injury and low testosterone” brings up page after page of articles and studies that conclude that low testosterone occurs in a higher percentage of men with SCI than the general public.

According to the Mayo Clinic (2015 online), in the general population testosterone levels peak in adolescence or early adulthood, then decline about 1 percent per year after 30 or 40. However, a study published in a 2014 issue of the Journal of Spinal Cord Medicine states: “Persons with SCI appear to have a higher prevalence of low T concentration for each decade of life than those in the general population and … the low T values tend to occur earlier in life in persons with SCI. The decline in serum total T concentration over time in the group with SCI was 50 percent greater than that for the nondisabled controls.” Also, an October 2011 study in Physical Medicine and Rehabilitation concluded that low testosterone levels were significantly associated with motor complete (ASIA A and B) injuries and much less with incomplete (ASIA C, D, and E) injuries and suggests that a testosterone level test should be included in standard screenings for people with complete SCI.

“We screen men for low testosterone if a man has low energy or low libido,” says Paula Wagner, a urology nurse practitioner at U.C. Davis Medical Center in Sacramento, Calif. Wagner explains that the range of what is normal is very wide, and if your results fall within the normal range, you do not need testosterone replacement. Testosterone levels are checked via blood test and should be done before 10 a.m., since levels tend to drop off in the afternoon. Lower testosterone production or metabolism can be caused by stress, excess exercise, and certain medications, including opiates.

Signs and symptoms of low testosterone include fatigue, low sex drive, depression, inability to concentrate, reduced muscle mass and strength, increase in central body fat, and decreased bone density. Stanley Ducharme, professor of rehabilitation medicine and assistant professor of urology at Boston University School of Medicine, discusses decreased bone density in his article “Testosterone and Spinal Cord Injury.” He says scientists are questioning whether osteoporosis in people with SCI may be related to lower testosterone levels, along with lack of weight bearing and other SCI factors.

Wagner says before taking testosterone replacement therapy, it is important to have a discussion with your physician and weigh the risks and benefits. Potential benefits of replacement therapy include enhanced energy and mood, increase in libido, increased muscle mass and strength, and decrease in body fat. Some of the risks include increased red blood cell counts (which also increases the risk of blood clots); causation or worsening of sleep apnea; and stimulating growth of prostate cancer. Men with an elevated prostate-specific-antigen test level should avoid replacement therapy — it may increase prostate size or worsen benign prostatic hypertrophy (enlarged prostate).

The key with replacement therapy is to take the correct amount of replacement to keep testosterone within the normal range, says Wagner. “It is important to have a doctor who can look at your lab values and say, ‘based on age, your levels should be X,’” she says. “If your levels are in the normal range and you add testosterone, you add a lot of health risk for no real benefit.” It is never OK to try testosterone replacement on your own. Personally deciding to try testosterone therapy or guessing at how much to use without consulting your doctor amounts to an extreme health
risk, and could even result in death.

If your testosterone level is low and you and your doctor decide replacement is the way to go, there are several options, including transdermal patches, gels, mouth patches, injections, or implanted pellets. Wagner says it is important to be monitored so your levels don’t get too high. This means having a blood test every three to six months.

Mike Trijillo, 68, from Huntington Beach, Calif., is in his 49th year as a T5 ASIA B, motor complete para. At 60, when he was a renowned wheelchair racer, Trijillo was in top physical shape but was becoming increasingly fatigued. He discussed this with his doctor, who ordered a blood test to get testosterone levels. The test showed his level was below normal. After discussing the pros and cons of replacement therapy, his doctor prescribed testosterone cream. “It was great, it raised my energy level and raised my sex drive, and it enabled me to do exercise workouts like a madman,” he says.

Replacement therapy worked great for about six years and then Trijillo started gaining weight around his middle, which testosterone replacement is supposed to reverse, so Trijillo stopped using testosterone cream a year and a half ago — the risks now outweighed the diminishing benefits. He is giving his body an extended break and may decide to talk with his doctor about resuming treatment at some point in the future. “I plan to get another 20 years on this planet, and with SCI it seems we are always adjusting or dealing with some health issue,” he says.

Recreational activity, exercise and proper body weight may play a role in testosterone levels. A study in the September 2014 issue of Andrology explains that there has not been an established cause for higher rates of testosterone deficiency in men with SCI. The study found a significant correlation in men with SCI who have low testosterone levels and who participated in fewer weekly leisure time activities and had an increase in body mass index. Which raises the question, which came first, low testosterone leading to inactivity and weight gain, or was it the other way around?

The study suggests a follow-up study involving life-style modification. The hypothesis is if you have symptoms of low testosterone and aren’t participating in leisure activities and are overweight, by modifying your lifestyle to lose weight and make time for leisure activities that involve exercise, you may naturally increase testosterone levels, improve energy levels and sex drive. If nothing else, trying this will help you feel better, an experiment that can be done on your own at low or no cost and put you one step ahead of researchers.

### Resources

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It seems that some stupid new proposed Medicare reimbursement rule changes regarding prosthetic devices have a lot of amputees up in arms (or at least those amputees who have arms).

One of the stupidest things the new rules would do is require amputees to prove that they can walk with a “natural gait” using an artificial limb before the limb would be covered by Medicare, according to the pissed-off amputees. They also say Medicare would no longer pay for prosthetics for amputees who sometimes use other mobility devices like a wheelchair, crutches or canes. The proposed changes were issued five days after the 25th anniversary of the signing of the Americans with Disabilities Act.

What a bunch of party poops those Medicare bigwigs are!

I can relate to the stress my limb-challenged cripple comrades feel about all this. Wheelchair cripples have often had to deal with this same Medicare crap. Why, even as we speak, some folks are raising a stink about a new Medicare policy they say will significantly reduce what Medicare pays for customized wheelchair stuff like cushions, recline/tilt systems and drive controls.

So I feel bad for the amputees, but still they’re pretty lucky. At least there’s light at the end of the political tunnel for them. I’m talking about 3-D printers. People make all kinds of crazy stuff with those things these days, including limbs. I see where a father in Massachusetts used a 3-D printer to make a functioning prosthetic for his 5-year-old son, who was born without fingers on his left hand. There’s an organization called e-NABLE, which uses a network of volunteers to make prosthetic hands using printers. The hands are then given free to people who need them.

And a lot of these homemade limbs are multicolored and really cool looking. They draw attention to the limb rather than playing that futile game of trying to make the limb look “realistic.” That never fooled anybody anyway. It’s like a comb-over.

All this makes me wonder what would have happened if Geppetto, the lonely woodcarver who whittled up Pinocchio, had a 3-D printer. No doubt he would have used it to create his perfect little boy instead of messing around with wood. And as soon as he saw the boy come to life, he would have rushed back to his studio and quickly drawn up plans to print up a buxom young woman. It also makes me wonder about this girl who was my fifth grade classmate at the segregated cripple school in the 1960s. They sent her to the segregated cripple school because she didn’t have a nose. There was nothing else crippled about her. She had a crude, homemade nose that looked like somebody made it for her out of clay. It was literally glued to her face and sometimes it fell off. These days, somebody could probably print her a new nose. And the nose could be hot pink or some cool color like that so she could flaunt it. “Check out my badass nose!”

But my point is, at least amputees can dare to dream of the dawn of a glorious day when they will no longer be caught in the evil tug of war between manufacturers of cripple products that charge a zillion bucks for their goods and the government that doesn’t want to pay for anything that costs more than a nickel. The amputees will soon be able to tell them all to go jump off a high bridge.

But what about wheelchair cripples? I see where some people used a 3-D printer to make a wheelchair for a crippled cat. That’s good news for crippled cats. Soon they too will no longer have to deal with Medicare. And some people have used 3-D printers to make ramps and parts for manual wheelchairs and motorized wheelchair stuff like joysticks. But as far as I can tell, nobody has ever printed up a big honkin’ loaded power chair like the one I ride.

Will that day ever come? Maybe soon. Maybe never. Who knows? If only I was a damn cat.
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New Mobility
55 FEBRUARY 2016
HE WON’T GET FAR ON FOOT

New Mobility Facebook fans decided to have a little bit of fun at the expense of Kevin Dennisson, the wheelchair user who robbed a bank in Queens, N.Y., on Jan. 4. Here are some of their comments on the article, “Man in a Wheelchair Robs TD Bank in Sunnyside.”

Bob Martinson: I’m taking ALL the money, on these two bottom shelves.

Stephen Harris: It’s tempting. Medicare and SSDI don’t cover much. Maybe it’s time to take matters into our own disabled hands?

Rey Gonzales: It wasn’t me, I was home! I swear!

Bill Jacobs: Give me all the money! Can someone open the door?

GOODBYE AND THANK YOU, JEWEL

The comics world is mourning the Jan. 7 passing of Jewel Kats, who was the inspiration for Archie’s love interest, Harper. Kats, who used crutches or a wheelchair since a car accident when she was 9, wrote the Fairy Ability books and was promoting her graphic novel DitzAbled Princess at Fan Expo in 2013 when she met Dan Parent, who penned the Archie comics.

“I wheeled up to him, looked at him square in the eye, and I said to him, ‘Why isn’t there a character with a disability in Riverdale? How is that possible?’ Dan didn’t have an answer prepared, obviously, but he gave me something that was way more important. He gave me his contact info.” That chance encounter led to shared messages, ideas from Kats, and eventually Parent creating Harper.

THE MIGHTY STUMBLING

In response to TheMighty.com’s love of “inspiration porn” and its sometimes clumsy attempts to reflect the experiences of people with disabilities, Disability Visibility Project’s Alice Wong created the #InspoPornResolution as a guide for greater authenticity.

#InspoPornResolution
On depiction of the disability experience

1. I will not co-opt the disability experience for the consumption of others.
2. I will not assume understanding of disabled experience. I will check my privilege and ask questions.
3. When in doubt about language, I will ask and respect the way disabled people self-identify and use resources such as the style guide from the National Center on Disability and Journalism for general guidelines.
4. I will ask my publication to hire and pay disabled writers, editors, collaborators, consultants.

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