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TEK-RMD user Rudy Berger and her husband David enjoy the view from their deck on the coast near Tillamook, Oregon. The TEK-RMD allows Rudy to enjoy the benefits of standing while remaining mobile and able to access places (and views) traditional standing wheelchairs simply cannot reach.
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SpeediCath catheters are available by prescription only. Patients performing self-catheterization should follow the advice of, and direct questions about use of the product to, their medical professional. Before using the device, carefully read the product labels and information accompanying the device including the instructions for use which contain additional safety information. The SpeediCath catheter is for single-use only; discard it after use. If you experience symptoms of a urinary tract infection, or are unable to pass the catheter into the bladder, contact your healthcare professional. The risk information provided here is not comprehensive. To learn more, talk to your healthcare provider.

For further question, call Coloplast Corp. at 1-866-226-6362 and/or consult the company website at www.coloplast.us
Many words can be used to describe happiness: contentment, satisfaction, well-being and pleasure are a few. TIM GILMER speaks with fellow wheelers Randy Alexander, Teal Sherer, Alice Wong and Jen Goodwin, plus shares his own story in this uplifting story that celebrates family, relationships and vocations.

Cover and Contents Photos by Mitchelldyer Photography
The hip-hop musical, *Hamilton* — based on the life of founding father Alexander Hamilton — is lighting up Broadway, not only because of its high-energy lyrics, but because so many of the founding fathers are played by actors of color. Thomas Jefferson, for instance, is played by Daveed Diggs, a black actor. Hamilton, played by Lin-Manuel Miranda, a playwright of Puerto Rican descent, is best known for being the founder of our financial system, the first secretary of the treasury, and the man who accepted Aaron Burr’s challenge to duel, was shot and died a day later.

But what most interests me is the little known historical fact, hypothetically speaking, that had Hamilton survived the duel, he would have been not only the most powerful economic figure in the history of the nation, but also an L1-2 paraplegic.

Imagine, history dreamers, where we might be today if fellow para Alexander Hamilton had lived. He would have been the first wheelchair user to 1. become a U.S. cabinet member, 2. lead the powerful Federalist Party, 3. lay the groundwork for the establishment of the United States Mint, 4. have his image appear on U.S. currency (the $10 bill). Do you think, if an economic genius/para like Hamilton had held the financial reins of this infant nation, that more than 25 percent of people with disabilities would be living in poverty in the United States in 2015?

But truthfully, Hamilton had little chance to live for no other reason than in the early 1800s, spinal cord injury was thought to be a death sentence. Like so many others before and after him, Hamilton did not expect nor want to live as a paralytic. The dogma that SCI is lethal goes back at least 5,000 years. The Edwin Smith Papyrus, considered to have been written in Egypt as early as 2,500-3,000 B.C., describes SCI as “an ailment not to be treated.”

At the time of Hamilton’s shooting, medicine was still in the dark ages, with bleeding being the most common “treatment.” A person’s health was thought to be somehow regulated by certain bodily fluids or “humours.” One year following Hamilton’s death, in the Battle of Trafalgar, Britain’s Lord Admiral Nelson, shot in the spinal cord, was told by his physician, “nothing can be done for you.” Another famous war hero, U.S. General George Patton, sustained a C3-4 SCI in 1945 from a vehicle accident, refused treatment, and died 13 days later.

Back to Alexander Hamilton in 1804. If medical progress could be transplanted from one century to another, going back in time, then all of the above-mentioned powerful figures would have lived and been celebrated as “courageous and inspirational.” Instead, today wheelchair users are still facing discriminatory policies that are rooted deep in the head-in-the-sand ignorance of ancient history. Case in point: The Centers for Medicare and Medicaid Services proposal to put limitations on complex rehab wheelchair accessories on Jan. 1, 2016. The 5,000 year-old dogma that SCI is lethal is still with us!

Tell your elected representatives that Alexander Hamilton is turning over in his grave [www.unitedspinal.org/essential-crt-components].

— Tim Gilmer
Patrice Priya Wagner was diagnosed with multiple sclerosis in 1988 and discovered yoga about 10 years later. She graduated from Integral Yoga’s Accessible Teacher Training in 2008. In 2009 she completed training on how to teach yoga to people with disabilities, injuries or chronic illness, and was certified as a Relax and Renew Restorative Yoga teacher. Wagner, who currently teaches Yoga for People with MS, was on the planning committee for the Accessible Yoga Conference 2015. The serenity that her daily yoga practice brings has been helpful in her healing journey.

Growing up in central North Dakota, Mark Boatman became interested in journalism and today loves chasing down an important story. After a three-year incarceration in a nursing home, Boatman moved to western Montana in 2006, where he pursued his dream of a degree in journalism, graduating from the University of Montana School of Journalism in 2012. Besides reporting and freelancing for New Mobility, Mark also has contributed to Quest magazine. He became a first time homeowner in 2014 and lives in Lolo, Mont., with his pug, Frank.

Tom Shankle and Walter Delson are the leaders of the Everyday Abilities Foundation, the San Francisco Bay Area Chapter of United Spinal Association. Shankle is the founder and CEO of Apple West Home Medical Supply. He founded Apple West so he could have a job where he was helping others and have a means to give back to the community. Delson has a master’s degree in rehabilitation counseling and works at a non-profit that serves parents with disabilities. He enjoys adaptive sports and exploring the outdoors with an adapted Segway.

Since sustaining a T12-L1 spinal cord injury in 1999, Minna Hong has acquired 15 years of experience working with others who have SCI. She is currently the SCI peer support manager at Shepherd Center in Atlanta, Ga., where she develops support groups as well as recruits participants for various SCI research studies. In addition, she is working on a “Tipping Point” group to create a space for people with SCI who are aging and have a need to share concerns and worries as well as positive solutions. She has also developed fun wheelchair cooking videos that can be viewed at Shepherd SCI Peers’ YouTube Channel.
I hope there will be many more park reviews to come from Ashley Lyn Olson’s pen.

More on National Parks!
I thoroughly enjoyed Ashley Lyn Olson’s cover story about accessible national parks [October 2015]. I hope there will be many more park reviews to come from her pen.

Way back in 1981 my husband and I took our kids on vacation to Carlsbad Caverns. I took the elevator to meet them in the Great Room. While I was waiting for their tour to show up, I wheeled down a slick narrow path toward the sign for an accessible bathroom. The path followed the abrupt bends of the cave wall. You couldn’t see who was coming around the next curve until you were face to face. The path was so narrow that it was even hard for walking people to pass each other. Before I could see them, I heard two ladies’ voices amplified by the cave’s natural acoustics. One voice said, “Can you believe that A wheelchair stall in that restroom. Why in the world would they put a wheelchair stall down in a cave?” Just as they emerged from the sharp bend, the other voice replied, “Stupid, isn’t it! What a waste of taxpayer mon …” The rest of her sentence was stilled by the horrified look on her face as she nearly fell into my lap.

Sharon Gardner
Leander, Texas

Antibiotic Prophylaxis
As a 53-year-old C6-7 post-SCI of 27 years, I found the September article on prophylactic antibiotic use most timely. Until recently, I had managed to avoid major foot or leg problems. Then came a succession of three hospitalizations for cellulitis within six months, each requiring a week and IV antibiotics. This occurred despite meticulous foot care, daily lymphedema pump therapy for 20 years to manage swelling, reduction of sitting time and monthly podiatrist visits.

Following the last hospitalization, the infectious disease physician prescribed prophylactic 250 mg of penicillin twice a day. Fearing adverse consequences of long-term use, I planned a one-year trial, then discontinuing to determine if I experience recurrence. However, your article led me to reconsider the risk-benefit of antibiotic prophylaxis.

Chronic edema increases risk for cellulitis. Not mentioned was the benefit offered by home lymphedema pump therapy. Full-length bilateral leg garments utilizing segmented, graduated and sequential compression replicate the muscle vascular pumping mechanism of ambulatory persons. Importantly, they decrease the excessive internal pressure within tissue compartments, reducing potential damage to fragile capillaries and tissues in the feet and lower legs.

Following vascular consultation and any necessary testing, such as a Doppler, private insurers and Medicare will, with rare exception, cover this durable medical equipment expense. Whether rent to own, or outright purchase, the equipment is a bargain if it helps prevent office visits and hospitalization.

Though I still had cellulitis, I have no doubt my lower extremities were, and are, healthier because of the lymphedema pump therapy.

Marc Schenck
Albertson, New York

Heels and Fashion
I enjoyed your article, “Fashion Enabled,” October 2015). I’ve always had a problem with getting the right footplate that will let me wear wedges and shoes with a heel. The young woman in the first photo of the NM article looks like she is using a longer footplate — her entire foot is on it. Mine is the standard Quickie footplate, and is only about 6 inches wide, which leaves my heels hanging off the back. This makes my toes always point up in an awkward manner.

Holly Bercik
Rancho Santa Margarita, California

Bravo, September Issue!
Issues like September 2015 make it hard for me to discard them. NM tries to push the content past the inspirational stuff. As a T12 para for 35 years with the typical baggage, here is what I found relevant in this issue:

1. “Battle of the Bugs.” I also always worry about drug-resistant infections. I did not know so many others had successful results with long-term antibiotics. I lost track, but I have been using nitrofurantoin for over 15 years, and it has made a huge difference.

2. “Letter to a Mother.” Laurita Tellado’s letter shows how she understands her own life and how she processed her mixed emotions while helping a mother who aborted her imperfect fetus. Tellado succeeded in seeing spina bifida through the eyes of this mother, and she had the courage to respond with kindness.

3. “A Day in the Life of Four Wheelers.” Sometimes I feel alone and I remind myself others are trying things. Reading about others making a go of work helps me reinvent myself as I age — and the world of work renews itself with or without me.

I always like Mike Ervin’s columns.

Holly Bercik
Rancho Santa Margarita, California

Correction: Horizon
The November Consumer Guide listed an incorrect phone number on page 33 for “Fitness and Sports Product: Horizon by Outrider USA.” The correct number is 828/654-7555.
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Seattle Sued Over Broken, Missing Curbcuts
Disability Rights Washington has filed a federal lawsuit against the city of Seattle over its long-term failure to fix thousands of broken or missing curb cuts. The Oct. 8 lawsuit claims the sidewalks are so dangerous that many city residents have no choice but to risk their lives travelling out into traffic until they can find a curb cut.
“Seattle has had 25 years to comply with the Americans with Disabilities Act and we want the city to come up with a plan that is reasonable and adequate to make sure people with mobility disabilities can safely visit, live and work in Seattle,” says Emily Cooper, an attorney with Disability Rights Washington. The ADA and Section 504 of the Rehabilitation Act both mandate that whenever a city newly constructs or alters a street, the city must install curb ramps at any intersection.
Seattle Mayor Ed Murray touted the city’s record on curb cuts in a statement. “The city currently invests significantly more per capita on curb ramps than other major cities such as Los Angeles and Chicago, in some cases by as many as three times over. In 2015 alone, we are scheduled to install over 1,300 curb ramps — more than the 1,200 that San Francisco is expected to install,” he said. Disability Rights Washington was in negotiations with the city for a year and a half until they broke off.
But it’s not the curb cuts that exist or may exist in the future that have residents upset — it’s the ones that aren’t where they’re supposed to be, or that can’t be used. Conrad Reynoldson, an attorney who uses a power chair, wants the city to act before somebody gets killed. “I would like some consideration from the city in realizing that people’s lives are being put at risk on a daily basis,” he says.

Reynoldson says he often risks serious injury by traveling on busy streets, sometimes up to a half-mile, to reach another available curb cut.

Economic Self-Sufficiency ‘the Bone in My Throat,’ says Harkin
Despite the tremendously increased accessibility the Americans with Disabilities Act has brought for millions, Iowa’s recently-retired Sen. Tom Harkin says it has also failed many. “Economic self-sufficiency, that’s the bone in my throat. That’s the thing that we just haven’t really accomplished,” said Harkin to over 500 disability inclusion leaders at the inaugural 2015 Ruderman Inclusion Summit, which ran Nov. 1-2 at Boston Seaport World Trade Center.
Harkin, best-known for shepherding the ADA into law 25 years ago and being its legislative guardian in the years since, was at the Summit to receive the Morton E. Ruderman Award for his lifelong dedication to disability rights. The award includes a $100,000 donation to the Harkin Institute of Public Policy at Citizen Engagement at Drake University in Des Moines, Iowa, to foster collaborative, high-quality, nonpartisan, multi-disciplin-
Carlos Moleda Wins Fifth Ironman Championship

On Saturday, Oct. 10, in Kona, Hawaii, Carlos Moleda cinched his fifth Ironman World Championship in the handcycle division, at age 53, with a finish time of 11:32:34. Second place finisher was Jason Gradyan with a time of 14:36:25.

— Josie Byzek

In a July 2010 New Mobility feature, Moleda, a T12 complete paraplegic and retired Navy SEAL, after winning his fourth Ironman World Championship in 2005, said he had retired to spend more time with his family and live a more balanced life. Last year, with his son out on his own, Moleda decided to give the competition — a 2.4 mile swim and 112-mile bike ride, followed by a marathon — another go.

On his Facebook page Moleda describes the conditions at this year’s race as the most difficult he has ever faced. “The whole thing started on the swim — choppy conditions made it even worse. People kept swimming on top of me, and I had to stop just about every other stroke after swallowing a mouthful of seawater.” On the bike section racers battled fierce headwinds and humid, 103-degree heat.

At the transition from the bike to his racing chair for the marathon, he was so dehydrated that he was dizzy and had to rest a few minutes to summon the willpower to get into his race chair, he says. Moleda says the marathon reminded him of going through Navy SEAL BUD/s Hell Week. “I went into 100 percent BUD/s Hell Week mode, just keep moving forward, mile after mile. At the end, I was able to keep myself at the front and earn one more World Championship title, probably the most rewarding one. My family was there to cheer me up the tough hills, and to catch me at the finish line. I am the happiest and most blessed man to have so many people in my life that are there for me.”

— Bob Vogel

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Inclusion because I am committed to making life more equitable for people with disabilities just as Morton was when he created the Ruderman Family Foundation,” said Harkin. “We must continue the fight for policies that promote equal opportunity, full participation, independent living, and economic self-sufficiency for people with disabilities and their families.”

— Josie Byzek
**BASE Jumping Full Circle**

Jumping from Perrine Bridge in Twin Falls, Idaho, a little over 10 years ago, a freak accident changed Lonnie Bissonnette’s life forever. Bissonnette, now 50, did a somersault, a trick to celebrate his 1,100th jump, but the parachute had a mind of its own. “The parachute became entangled around my foot, so it never had a chance to fully open. I hit the river below upside down on my neck doing between 70-80 mph.” He became a C3 incomplete quad, and today is able to walk short distances, but usually uses a manual wheelchair.

Thanks to his incomplete injury, as well as his insane bravery, he was back doing what he loved within a year of his injury. “From the very beginning I told the doctor and my family that I will jump again. For me, there was no way I was going to let this stop me from continuing with the sport I loved!” He decided his first post-injury jump would be somewhere near home — St. Catherine’s, Ontario — so he chose Niagara Falls, a 500-foot jump. Since then he has BASE-jumped several more times, including Sibu Tower in Malaysia and Kjerag in Norway.

As for any adaptations he needs to continue his hobby, there aren’t many. “I don’t really need any adaptations to BASE jump,” he says. “In fact, I’m still jumping with the exact same equipment that I jumped with when I had my accident. However, after a couple years of jumping, I wanted a new challenge, so I designed a strap system so I could jump and land with my wheelchair. The strap keeps the chair with me and has a single emergency release handle.”

**Stylish Handrims to the Rescue**

Ugly, pegged handrims for quadriplegics looking to push their own wheelchair may be a thing of the past, thanks to Marco Pilotto, a recent C6 quad from Montreal, Canada. Calling his creation BBraver, he has developed completely personalized ergonomic texturized handrims made of ethylene vinyl acetate that are nearly just as easy to push as handrims with pegs. You can choose what color, pattern and lettering you’d like added to your handrims as well.

Thanks to this special version of vinyl (nonstick and soft), as well as an offering of two different widths of handrims and a texturized surface, these handrims make the chore of pushing a whole lot more appealing to the low quads of the world, or to paras looking for more stylish and ergonomically-friendly handrims.

Note: The rims are most compatible with Spinergy wheels and include exclusive fasteners to help with placement on the wheel.

Learn more: [www.bbraver.com](http://www.bbraver.com)

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Winter is here and Mother Nature is covering colder climes in her annual blanket of snow. With the right adaptive equipment mounted on skis, her blanket of snow becomes a vast access ramp that enables thrills, high speeds and the freedom to venture deep into the wilderness. Here is a look at options to get your share of winter stoke.

**ADAPTIVE SKIING**

“Adaptive Alpine skiing offers a freedom and exhilaration that is hard to find in any other sport,” says Bill Bowness, 57, the technical director and staff trainer at Disabled Sports USA at Alpine Meadows ski resort near Truckee, Calif. He's been teaching adaptive skiing for 25 years, is the first disabled member of the Professional Ski Instruc-
tors of America’s Alpine demonstration team and is now in his 38th year as a T12 para. “Snow skis and adaptive ski rigs keep getting better, which makes skiing easier,” he says. “And more adaptive programs are offering a variety of high-end mono-skis in their teaching programs, partly for performance but also so students have the opportunity to try a ski before they decide to buy.”

Until recently there were two main types of adaptive skis: bi-ski and mono-ski. A bi-ski is a molded bucket seat mounted onto a frame attached to two articulating skis and is for people with limited movement. Just moving your head can help turn a bi-ski, and a stand-up skier holding tethers made of Climb-Spec webbing helps you turn and control your speed. However, bi-skis don’t have suspension and you’ll need a helper to load it onto the chairlift. Wheelers with more muscle control usually use a mono-ski — a molded bucket mounted on a suspension system that in turn is mounted onto a standard snow ski. Intermediate mono-skiers are able to ski and load onto lifts independently, and experts shred all aspects of the mountains at the same level as non-disabled skiers.

“Over the past three years a new ski called the HOC2 Glide has come on the market, and it bridges the gap between the mono-ski and bi-ski,” says Bowness. “It combines the easy balance of a bi-ski with the skiability of a mono-ski, has suspension and is self-loading for chairlifts. It’s a great option for a low quad or high-level para or a less athletic adaptive skier who wants to ski independently. If the skier’s ability improves, it converts to a mono-ski.”

When asked where potential adaptive skiers can go, Bowness says check out your local ski area. “Although it is important to call ahead and check about adaptive lessons and equipment, if a ski area has a ski school, by law they are supposed to offer adaptive instruction and adaptive equipment either through their ski school, or by contract with a nonprofit ski school like Disabled Sports USA Far West,” says Bowness. “If the ski area is on U.S. Forest Service land, it is under the Rehabilitation Act of 1973, Section 504, and if it is on private property, it is covered under the ADA. This also applies to access. If a three-story lodge has public facilities on the upper floors, they have to provide an elevator and/or ramp.”

Although skiing isn’t cheap, with some creativity adaptive skiing can be done on a budget. Two years ago Luke Ekenberg, 20, started traveling from his home in Michigan to California to take lessons at Disabled Sports USA Far West during school breaks. “I was hooked from day one,” says Ekenberg, who is in his fourth year as a T11-12 para. He’s so hooked that he recently moved to Truckee and is buying his own ski. He has applied for several grants to help offset the cost [see resources], has applied to be a volunteer at Disabled Sports USA Far West — a benefit of volunteering is earning lift tickets — and he has a goal of learning to become an instructor.

Jennifer Weast had a ski accident at age 16 in 1977 that resulted in C5-6 quadriplegia and her love of being on a mountain skiing taken away. Although

More than 30 years after a skiing accident paralyzed her, Jenny Weast rediscovered the thrill of skiing from the summit.
fear has been replaced with the trust I have in my instructor who holds my life in his hands with tethers. The ability to ski anywhere on the mountain has given me back a missing piece of my spirit that I had long ago buried.” Weast is fortunate that most of her skiing is covered by various forms of scholarships and she is able to ski a dozen times each year. “I live for the winter weekends and now can’t imagine my life without my mountain.”

Lesson prices at dedicated adaptive ski schools average $100 for a two and a half hour private lesson or $200 for all day, and include lift privilege and equipment. Most dedicated adaptive schools have some type of sliding scale or scholarship program for those who are on a tight budget.

**CROSS COUNTRY SKIING (XC)**

To experience the beauty and quiet of nature, get to areas that are inaccessible by chair and get some healthy exercise, adaptive cross-country-skiing (XC) is the ticket. An adaptive XC ski consists of a lightweight molded bucket-style seat mounted on two cross-country skis, is the exact width of a standard groomed XC ski trail, and is propelled by pushing with ski poles. Although it sounds difficult, XC skis are easy to propel on a groomed track, actually gliding much easier than a wheelchair. The poling action of XC skiing works neglected muscles in the back of the shoulders, which helps keep shoulders balanced and healthy.

“In the winter I cross-country ski every day. It feels great to be outside and I always feel better when I do it,” says Candace Cable, 61, from Truckee, Calif. Cable, who is in her 40th year as a T10 para, skis cross-country every day during the winter while she teaches and coaches backcountry with a little less effort, perhaps snowmobile touring is for you. “It is awesome. I’ve gone a dozen times,” says Matt Feeney, 52, the advancement director of Adaptive Adventures. Feeney explains that a snowmobile is perfect for a para because it is all hand controls, handlebar steering, thumb lever throttle and hand brakes like on a motorcycle, and there are stirrup-type foot rests with non-skid padding to place your feet. Feeney, who’s in his 27th year as a T9 para, puts a webbing strap under his legs to secure his feet in place. He snowmobiles at Grand Lake, Colo., an area that has many rental and guide companies. “You can go on a guided tour, or get a map and go straight rental. I can’t imagine a rental or guide company having a problem renting to a wheelchair user with decent arm and hand movement,” he says. “I rent and go with a couple buddies and we follow the trail maps.”

One of Feeney’s first times out he was having so much fun he went up a hill in deep powder without telling his friends and got bogged down in about three or four feet of powder snow. “I was about 100 yards from the trail and was stuck for 20 minutes — I got really lucky that a guy came by, heard me yelling and rescued me,” he recalls. “The moral of the story is to never go alone.”

Rick Dean, owner of T Lazy Snowmobile tours in Aspen, Colo., has been providing adaptive snowmobile tours for 26 years. “For a person with arm and hand movement, all that is required is straps to keep their feet in place,” says Dean. “Even if they have limited hand movement they can usually operate the controls.” Dean has one of his guides ride on the back of the snowmobile with people who have higher level injuries or problems balancing. The guide will put his arms around and drive the snowmobile of people with no hand movement. Rates are approximately $250 for a three-hour tour.

Ken Barrett, president and chief guide of Selkirk Powder at Schweitzer Mountain near Sandpoint, Idaho, has also worked with wheelchair users. “As a guide it is my job to adapt the experience for every person who goes with us. Adaptation and bringing the mountain experience to people is what makes my job worthwhile,” says Barrett. “When
somebody has an experience that is new and unique, that is what it is all about.” Rates are approximately $150 for a three-hour tour.

Arguably the ultimate in snowmobile touring is offered by Arctic Adventure, located an hour north of Montreal, Canada. The company has snowmobiles with custom seats to hold your hips, back and legs in place and offers a seven-day tour of the wilderness areas of Quebec. Your chair is transported on a guide’s snowmobile and each night you lodge in a fully accessible log chalet, complete with an outdoor hot tub overlooking forests and frozen lakes, and fully-catered meals. Additional activities include dog sledding, ice fishing, tubing, and a stop at a ski resort for adaptive skiing. The owner-operator, Nicolas Bourselier, has been guiding individual wheelers and adaptive groups since 2010. The price is $1,692 — I’m already saving and hoping there is some type of journalist discount.

For snow sports lovers, Mother Nature’s adaptive winter blanket never lasts long enough. Choose a sport, or two or three — and give them a try!

**RESOURCES**
- Adaptive Adventures, 877/679-2770; adaptiveadventures.org
- **Alpine Skiing:**
  - Disabled Sports USA Far West, 530/581-4161; www.dsusafw.org
- **Adaptive Ski Manufacturers:**
  - DynAccess, 484/767-0477; dynaccesstld.com
  - Enabling Technologies, 303/578-9345; enablingtech.com/pages/products
  - Freedom Factory, 262/898-4675; www.freedomfactory.org/index.html
- **Cross Country Skiing:**
  - Adaptive Cross Country Skiing Program Map, batchgeo.com/map/1ccf5b1464291f0f31f0e508c3d77883
  - Candace Cable Reeve Health Minute Cross Country Ski Videos, www.christopherreeve.org/site/c.ddJFKRNofG/b.5848659/k.5E06/Reeve_Foundation_Videos.htm Click on Reeve Health Minute and scroll down to Cross country sit skiing.
  - Enabling Technologies Nordic Skis, 303/578-9345; enablingtech.com/pages/cross-country-ski
  - Mount Shasta Nordic Ski Organization, mtshastanordic.org
  - Spokes in Motion Nordic Skis and Alpine Skis, 303/922-0605; www.spokesmiento.com/category/23
  - Tahoe Donner Cross Country, 530/587-9400; www.tahoedonner.com/cross-country
- **Grant Organizations:**
  - Challenged Athletes Foundation, 858/866-0959; www.challengedathletes.org
  - High Fives Foundation, 530/562-4270; highfivesfoundation.org
- **Snowmobile Tours:**
  - Selkirk Powder, 208/263-6959; selkirkpowder.com/snowmobiling-at-schweitzer/
  - T Lazy 7, 970/925-4614; www.tlazy7.com/dir/snow.html
iLevel has restored my mobility and freedom. Switching to iLevel was like going from an economy car to the deluxe model! When I am out in public, everyone asks me how I can drive so fast elevated. iLevel has taken away some of my disabilities and brought normalcy back into my life. I cannot imagine life without it.

Jay Smith
Founder of 90 Foundation and Livid Instruments
I learned how to teach yoga in a way that can be done from a chair. Does that surprise you? Twenty years after my 1988 multiple sclerosis diagnosis, I became certified as an instructor in Integral beginner level yoga and continued my training to learn how to teach people with disabilities. What I’m talking about excites me because it involves modifying poses for students with disabilities or physical challenges as well as doing breath work, guided relaxation, and meditation.

When I was first introduced to yoga, I benefitted from the serenity I would carry home with me after class. MS put me in a state of nervousness, in varying degrees, except when I slept, swam or practiced adaptive yoga. More and more doctors told me to avoid stress, so I did more adaptive yoga and reaped benefits I had never imagined. I learned breathing exercises to help me stay calm, stretches to facilitate better blood circulation, and poses to strengthen my abdominal muscles and correctly align my spine to avoid lower back pain.

In 2007 I enrolled in the first Accessible Yoga Teacher Training that was created by Jivana Heyman, director of Teacher Training at San Francisco Integral Yoga Institute, to accommodate the needs of people with a disability, chronic illness or injury. Trying to graduate from a mainstream teacher training was unrealistic since it squeezed 200 hours of required curriculum into 10 days or less, and severe fatigue was my toughest symptom. However, this program was stretched out over eight months with three-hour classes held twice per week — I could handle that!

STILLING THE SELF-DOUBTS

Having a disability shaped my experience from the first class I took as an awkward beginning student, through my basic training to become an instructor, and into my advanced studies. As a student I didn’t want to look different, so although the instructor gently placed a chair within my reach while I struggled to balance in a standing pose, it took me months to use the chair to stabilize and gracefully hold the pose. If my first instructor, JoAnn Lyons, hadn’t intuited how headstrong I’d be about accepting help, who knows if I’d have continued with yoga.

During teacher training, my voice of self doubt whispered in my head as it brushed over surface issues such as my appearance: You don’t look like a yoga teacher, especially when you’re sitting in a chair. You don’t even sound like a teacher. I explained there is no requirement that a yoga teacher look like a nondisabled person and how does anyone know what a teacher should sound like anyway? When I chanted Om, the nearby dogs howled along with me, so at least they thought I sounded yogic!

Failing to discourage me by questioning external appearances,
my self doubt dove deeper going into my muscles, tendons and bones where it yelled at full volume: *If you can't balance or bend as well as your students, how can you teach them?* I stated that if I know how to teach with words that safely lead students into and out of a pose, it doesn’t matter how well I can balance or bend. While I’m instructing, the focus is on my students’ abilities.

Still unable to stop my advancement, my self doubt tried to delve into my thoughts and emotions, only to find compassion there. Compassion has been woven into my mind and body from threads I’ve gathered along the pathway of 27 years living with increasing physical and cognitive challenges. It has shaped my journey by creating a motivation for me to observe, ask questions and find the right modification or prop to help a student experience comfort in a pose that previously eluded them.

After having quieted the voice that doubted my ability to teach yoga, I not only taught people with disabilities, but also joined the planning committee for the inaugural Accessible Yoga Conference, another cutting-edge creation by Heyman to expand the reach of adaptive yoga. “Yoga is at a tipping point in our society,” says Heyman. “My hope is that the Accessible Yoga Conference supports the transition from yoga for the few to yoga for everybody.” The conference took place on Sept. 12-13 in Santa Barbara, Calif., and was so successful we’re already planning next year’s.

Two of my former classmates from Teacher Training were also on the planning committee for the conference and, after conversations with them, I came to understand their differing perspectives on how disability shaped their experience of becoming a yoga teacher.

**SHARING THEIR PRACTICE**

Shakti Bell has been living with a mostly progressive form of MS since 1997. She told me, “I took my first yoga classes shortly after being diagnosed … I started attending classes offered at lunchtime at my work. I followed this Iyengar teacher to her studio — upstairs even! — and through her instruction, learned that I could stand in a healthy and strong way again,” says Bell. “I was the only person with a visible disability because her classes were not modified for accessibility, but she did her best to help me. I tried other classes, but didn’t feel like there was any point to it. I spent most of these classes in child’s pose since most of what was being taught felt too physically challenging.”

After Shakti graduated from the same basic teacher training as I did in 2008, both of us enrolled in Yoga for Healing. Shakti shared with me, “The fluctuating abilities of my body helped to inform ideas on how to adapt poses, and Yoga for Healing showed me how to adapt a practice to other disabilities.”

Shakti teaches yoga for people with disabilities or illness in Santa Cruz, Calif. When asked how yoga has affected her life, she replied, “First, learn-
ing that yoga could help me stand with strength and energy was very exciting. Later yoga taught me how to sit with a tall and supple spine and helped me maintain a healthy back — despite spending so much time in a wheelchair that lacks good back and seating support. Both yoga and Buddhism helped me loosen my attachment to the ups and downs of the physical body. Whatever the state of my physical body, my happiness and well-being can stay intact. This has been yoga’s greatest gift of all.”

Rudra Sam Swartz took beginner yoga classes as a fully able-bodied student in 2001 because his condition was relatively dormant. He explained to me, “It’s a strange form of arthritis — a rheumatologist once called it kind of rheumatoid arthritis and kind of ankylosing spondylitis,” says Swartz. “It’s really neither and kind of both.”

It wasn’t until Swartz started using a wheelchair in 2007 that he had to use the knowledge gained in yoga classes from prior

**SUN SALUTATION IN CHAIR, SHORT VERSION**

Sun salutations help students warm up and become centered before launching into more challenging poses. Here is a short sun salutation practiced from a seated position, as modeled by Patrice Priya Wagner.

**Position 1**
- Sit on your chair leaning slightly forward
- Press your sitting bones down into the chair
- Bring the palms together in front of the chest with fingertips pointing upwards
- Elbows can be facing down or to either side of you
- Take a deep inhalation through the nose, gently elongate the spine, and exhale slowly

**Position 2**
- Stretch the arms out in front, parallel to the floor, palms facing down, and lock the thumbs
- Inhale and stretch the arms up toward the ceiling until the arms are alongside the ears, or as far up as comfortable, then unlock thumbs
- Stretch up from the sitting bones through the spine, shoulders and arms

**Position 2 Variation**
- Sit up straight, place one hand on the thigh for balance
- Inhale and stretch the other hand out in front parallel to the floor with palm facing down, then raise the hand and arm up
- Exhale and release the outstretched hand down to the same side thigh
- Inhale and stretch the other hand out in front parallel to the floor with the palm facing down, then raise the hand and arm up
- Exhale and release the outstretched hand down to the same side thigh

**Position 3**
- On an exhalation, release the arms down alongside the outer thighs, lean forward from the hips, keeping the back straight, and lower the torso toward the knees
- Keep stretching out through the spine as you lower down
- Let the head and arms relax down toward the floor
- Inhale, lengthen the spine, raise the head back up and with a flat back raise up to seated

**Position 3 Variation**
- Same as above Position 3 except hands remain on thighs for support

**Position 4 (This can also be done with hands remaining alongside the body)**
- Inhale and take hold underneath the right thigh with both hands
- Lift the right thigh toward the chest, keeping the spine straight and chest facing forward
- Release the thigh back down, place the hands on top of thighs
- Repeat with the left thigh

Repeat Position 3 and Position 2
Repeat Position 1 starting with “Bring the palms together in front of the chest”
Release your arms down, close your eyes and take a deep, full inhalation through the nose and a slow, easy exhalation

*Talk with your doctor before starting any new exercise program*
times to adapt his practice to meet his needs. Now he teaches at the Integral Yoga Institute in New York City where he verbally instructs as though his body were able to do the poses, although it actually can’t.

Swartz states emphatically that he’s a student of Swami Sat-Chidananda/Integral Yoga and his philosophy has always been, “You don’t teach anything, you share your practice.” When Swartz teaches gentle yoga and the students’ bodies work similar to his, it’s straight sharing. He explains about other teaching circumstances: “Because my body is limited, I’m better able to see what adjustments I need to make based on what my students can or cannot do. I came into yoga with an ideal that by practicing yoga I would somehow be magically healed. I’ve since learned that there is no magic healing potion.”

“Yoga is designed to keep your mind calm no matter what your situation,” says Swartz. “Life is all about the condition of your mind. If your mind is peaceful, it doesn’t matter if you have a sickness or difficulty moving. It’s just a matter of what condition your mind is in and your body is just a tool to quiet your mind by having a Hatha yoga practice.”

Swartz summed it up nicely when he said, “Yoga has helped me quiet my mind, find peace with where I am and what I’m doing, or how my body is … be content that ‘the situation’ is ‘the situation’ and to not let my mind get disturbed about it.”

Patrice Priya Wagner teaches yoga for people with MS in Oakland, California, and is already starting work on the Accessible Yoga Conference 2016, tentatively scheduled for Sept. 16-18, 2016.

RESOURCES

• Accessible Yoga Conference, AccessibleYoga.org.
• Rudra Sam Swartz, Integral Yoga Institute, 212/929-0585; iyiny.org
• Mathew Sanford, Mind Body Solutions, 952/473-3700; mathewsanford.com
• JoAnn Lyons, Piedmont Yoga Community; piedmontyoga-community.org
• Yoga with Shakti, Shakti Bell, Shaktibell.com
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There are few things more terrifying and exciting to a person with a disability than being a first-time home buyer. Many options exist, from building new, buying an already-built home and renovating to your needs, or buying a new or used modular home. The trick is finding a home that works for you at a price you can afford and choosing renovations that won’t break the bank. Figuring out financing is another chore that can leave your head spinning, and it usually depends on the type of home and credit rating you have. There are loans and programs to help a person with a disability purchase a home or install accommodations, but I’ll discuss those later.

Most important in the hunt for a new house for our unique household was finding something with an open floor plan and enough extra space to meet our needs. I have Duchenne muscular dystrophy and use a trach and vent full-time, and I live with Dustin Hankinson who also has DMD and uses a non-invasive vent. Finding space for all of our medical supplies and equipment was another important consideration. We both live with his partner and our live-in caregiver, Theresa Martinosky, along with our gang of seven pugs. There are also several nurses we share our home with during the week, so we needed to figure them into the equation as well.

Our previous home was an older shotgun-style residence located in Missoula, Mont. At around 900 square feet, every inch of space was an extremely valuable commodity. As Hankinson puts it, “We had way too much crap and not nearly enough space.” The small bedrooms, single bathroom and tight floor plan were
“With the addition of the equipment necessary for two people with DMD, it was like living in a slide puzzle,” says Martinosky. Accessibility wasn’t necessarily a problem at our last house, but with limited space, it certainly wasn’t ideal.

The Quest Begins

In the spring of 2014, we decided it was time to begin looking for a new place. The main theme as we looked for a new home was adding storage space and keeping the access features we already had. Adding things like a double garage, laundry room, pantry and second bathroom may seem like extras, but they were essential in making the space more functional. Finding a home with a large deck for spending time outdoors and a fenced yard for our dogs was another goal. We figured that a workable budget for a ranch style home in our area would be around $210,000-225,000. However, finding a home with any disability access wouldn’t be easy.

“Finding an accessible house in Missoula has always been difficult,” says Hankinson. “No matter what you find, there will always be work that needs to be done.”

Our strategy for house hunting was simple and straightforward. We looked online at every house that had any possibility and narrowed them down by the list of features we wanted, but unfortunately it was difficult to get a feel for a house without testing out the wheelchair access.

“One frustration was the effort it took to transport and set up portable ramps for Mark and Dustin to look at potential houses, only to realize within the first 60 seconds inside the door that the place wouldn’t work at all!” says Martinosky.

The first home we looked at was a beautiful newer ranch, but it had several drawbacks that were deal breakers. There was a wide-open living and dining area but poor access to the kitchen and bedrooms, and the home would need extensive renovation to work.

House number two was a ranch built in the 1950s. It had a wide-open living room, dining room and kitchen area, but access to one of the bedrooms and bathroom would have been extremely difficult. The house had been recently updated, but just didn’t have enough usable space to be considered.

We looked at three other ranches in the Missoula area, and while they each had their definite plusses, the narrow hallways were the killer in all of them. The houses were all built in the past couple decades, but homebuilders didn’t seem to consider that potential residents might someday use a wheelchair. That was pretty frustrating, but soon we would find our gem.

The Search Pays Off

The next listing looked like it had possibilities, but we knew not to get our hopes up too high. As I rolled throughout the space, the potential quickly appeared. It featured a spacious living room, kitchen and dining area, but the hallway would be the big test. My chair sailed down the hall and my excitement rose as I actually could turn the corner into the master bedroom. Everything in the house looked like it could work with some remodeling.

We soon met with Jim Shafer from Straightedge Construction to discuss our plans. The front door wasn’t a good place for a wheelchair entrance because of a tight turn, so we decided to come in the back by way of the deck. Another issue was the deck’s narrow sliding door, but Shafer suggested a French door that was 60 inches wide on one side and 40 inches wide on the other. Lastly, Shafer suggested we put a railing around the deck so we wouldn’t accidently roll off.

The master bath proved to be the biggest problem. It had a wall separating the toilet and shower from the dual
sink area. We would have to remove the wall to put in a tiled roll-in shower and install a pocket door at the bathroom entrance. These ideas were vital to make the house livable but would cost a shade under $40,000. Since Hankinson and I both use personal assistance through our state’s Medicaid Home and Community-Based Services waiver, we approached the program about covering some or all of the remodeling costs. Lucky for us, the modifications were needed to make the house safe and livable, so the costs would be covered.

We now needed to move quickly on buying the house. The actual purchase was a fairly easy part of the process. It didn’t take much negotiating with the sellers, and at $225,000 we were able to stay within our budget.

**Hurry Up and Wait**

We applied for a traditional mortgage from the bank for the house. The process was a bit time consuming getting the paperwork all together and the inspection and appraisal completed, but before we knew it the closing on the house was scheduled for early August. It was a great feeling to take the keys, but the work was just starting.

Our contractor told us everything wouldn’t be completed until late September. It was hard to be patient, but soon progress started happening. The first completed part of the remodeling project was a sidewalk along the house with a gently sloping ramp that met up with the deck. Next was the French door — they worked with us to make sure the threshold was as gentle as it could be.

The bathroom was a huge undertaking. They installed a special water barrier from floor to ceiling before starting the tile work. We selected large ceramic tiles for the shower with subway style tiles for a border. A nice touch was the mosaic tiling we added in to break up all the white tiles. They tore out the open archway to do the framing for the pocket door, which was a nice alternative to a traditional door. “It gives us added space because we didn’t have to take into account the room needed for the swinging door,” says Martinosky. The last steps in the bathroom were sheet rocking, painting, installing the pocket door and laying down the Congoleum AirStep linoleum.

**Settling In Nicely**

It didn’t seem like the day would come when everything would be done, but in early October 2014 we were ready to plan our move. We couldn’t have arrived at this point without the help of our realtor, Brint Wahlberg. He didn’t have lots of experience with finding accessible housing, but he listened to our needs and worked tirelessly to find the right home for us.

“A lot of sellers think their houses are neatly put away, and that their big furniture doesn’t bother people,” says Wahlberg. “And they are mistaken because I remember in a lot of showings we were dragging a lot of couches, tables and chairs.” Now that he has experience, Wahlberg says he knows to preview
Homeownership Voucher Program: This program from the Department of Housing and Urban Development allows people with disabilities to become homeowners through a monthly voucher program. Once approved, vouchers can be used for the mortgage principal and interest, mortgage insurance, real estate taxes and homeowner insurance, and for allowed utilities, routine maintenance costs, and major repairs and replacements.

Participants must be first-time homeowners and not have owned a residence for three years. The home must pass an inspection by the housing authority and an independent home inspector. Individual public housing authorities may or may not offer the program, but they are required to if it’s a reasonable accommodation for somebody with a disability. The waiting list for this program varies, so expect a wait after you submit your application. Contact your local housing authority for complete eligibility guidelines and income requirements.

Section 203(k) Insurance Program: This program by the Federal Housing Administration allows homebuyers to finance long-term both the purchase of a home and the cost of its rehabilitation through a single mortgage, or to finance the rehabilitation of an existing home. Rehabilitation costs must be over $5,000, but the total value of the property must remain within the FHA mortgage limit for your area. For more information call 800/225-5342.

Fannie Mae’s Community HomeChoice Program: This nation-wide program helps low to moderate income people with disabilities afford homes. Qualified borrowers are offered low down payments, loans with lower debt-to-income requirements and more lenient credit evaluations. For more information visit www.fanniemae.com.

State agencies: Some states offer assistance programs for disabled first-time homebuyers that often feature low-interest loans or below-market interest loans. Searching the Web for your state name plus the term “home buyer assistance” will turn up useful links and contact info.
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It seems as if mainstream society has trouble understanding how wheelchair users could possibly live contented lives, let alone happy ones. But is it so surprising? After all, those of us who have lived a long time with our disabilities have been finding ways to adapt and prosper for years. Perhaps there’s a more important question: What specific factors in our lives are most likely to lead to happiness? To get some answers, I talked to four people, all wheelchair users, who represent a wide range of experience. Then I added in my own story.

By Tim Gilmer

Randy Alexander: Discovering the Tractor Dream

Tractors aren’t usually associated with fun, but they do have toy-like qualities, and they prepare the soil for growing much of what drives our lives: food, fiber, dreams.

Randy Alexander, 46, never considered farming until it just magically happened. “I’m a city boy, grew up in Phoenix, loved crowds and nightlife,” he says. Then in 1992 he had the distinction of being shot while stealing Bush/Quayle election signs from someone’s lawn. Sounds like a legendary story told by a gaggle of drunken liberals around a campfire, but it’s true.

As a C6 quad he got involved with ADAPT, wound up in Memphis and became active in the Memphis CIL. “As I
became more involved in advocacy and community organizing. I also examined myself, my place, my thoughts, life, community,” he says.

So how does that lead to farming?

“Through that work and learning, the issues of food, food security and modern industrial farming kept coming up in different ways. Farming is one way to work toward a more local, more equitable, more nutritious way of feeding people. Plus, I just flat love being outdoors and hard work.”

Now for the simplified version: He also met and fell in love with a dynamic, good-looking young woman from Maine who had interned on an organic farm and moved to Memphis and become involved in community gardening. Josephine, 33 — Jo from this point forward — mentioned to him that she wanted to raise chickens but didn’t have the space. Alexander offered his back yard, tore apart a used wooden ramp and set about transforming it into a chicken coop.

Fast forward: One day Jo, gathering eggs, discovered a shiny new engagement ring in a hen’s nest. Another legendary story, also true.

“It kind of evolved organically,” says Jo, who talks in puns naturally. “We started thinking, now that we have two incomes, let’s look at homes, then — why not farms! I doubted I could do it by myself, but when I pitched the idea to Randy, he got excited and that gave me confidence. We can do it together. We can share that dream.”

They cruised properties for months, then came upon Tubby Creek Farm in Ashland, Miss. “We pulled up here, and there was nothing,” says Alexander. “She took off, and when she came back, I could tell from the look on her face that this was it. The front third was old pastures and some fencing. We saw where we could put a mobile home, there was a place for a greenhouse, pastures, nice nearly level soil. And it was beautiful. Trees in the background, cedars all around. Really picturesque.”

The dream was becoming real before their eyes. And there is nothing more real, more solid, than dirt. “There is something natural about getting your hands dirty,” says Farmer Randy. “It’s creative, protective, taking care of little plants and animals, meeting all these people who become members of our CSA. And it’s all about enjoyment. It’s really quite a beautiful thing.” Patrons who join a CSA, or community sponsored agriculture, pay a yearly fee for a share of whatever the farm harvests each month.

Now that the Alexanders have transplanted themselves to the farm, how does all that work affect their relationship?

“Jo and I enjoy working together, we are around each other all day every day,” says Alexander. “We deliver produce boxes to two different drop-off locations, one at the University of Memphis and one at a farmers market. So far just a few people come here.”

Not counting Jo’s organic internship, neither one has prior experience with farming. “My grandparents and aunts and uncles were farmers,” says Alexander. “But until we got into community gardening, there was nothing. We got into it and took over our neighbors’ yard. When I saw I could do more than I thought with gardening, it opened up the idea of farming for me. It was the transitional experience I needed.”

They have an antique tractor fitted with hand controls, a 1949 Farmall Cub that pulls a 4-foot disc. A new larger tractor, an XR 4150 made by LS, has 50 horsepower, will have hand controls by the time you read this. It will pull a 6-foot disc, has a bucket, bush hog, box blade, and a bed shaper on the way. They will be able to plant more ground, get more efficient, boost production. They grow cover crops and disc them in, improving the soil and banking nutrients for future crops — the heart of organic farming.

What is most important to their happiness?

Randy: “Relationships. Money, not so much, as long as I can pay my bills. I’ve been a lot poorer than I am now, and I was happy then. I’ve always been someone who is content with circumstances, living on SSI, lived in a really rough neighborhood. Money is not an issue. We are pretty damn happy.”

Jo: “We appreciate the simple pleasures. Nothing better than eating food we grow ourselves and enjoying the outdoors. Those are the ways we are rich.”

D E C E M B E R  2 0 1 5  2 9
What attracted them to each other?

Randy: “Besides her being really attractive, she is really a hard working smart woman, conscious of community and culture, very self aware.”

Jo: “It was one of those mysteries of the heart. I was just instantly attracted to him. He’s assertive, principled, knows what he stands for, has strong convictions but is still very gentle. He’s good at letting other people take the lead and helping others be leaders while he’s kind of quiet in the background. And he’s compassionate.”

No wonder they are happy. They are embarking on a dream they both share, they love what they are doing, and they love each other.

Teal Sherer: Young Woman in Transition

You have seen her before. On the cover of this magazine, dressed in sleek black, her blonde hair thrown back beneath the retro klieg lights, posing in her TiLite as a 1950s glamour queen. Actress Teal Sherer, 35, a T12 para, has performed with Kenneth Branagh and Dustin Hoffman, has written and produced an acclaimed play and won awards for her Web series, My Gimpy Life. But her quest for success is not without frustration, if not rejection. Such is the life of any aspiring actor whose talent often goes unrecognized or misunderstood by agents, producers or casting directors who focus on wheels and spokes rather than the gifted artist who uses them.

In February 2013 Sherer moved from Southern California to Franklin, Tenn., a suburb of Nashville. It helped her see her life in a new light. “I was basing all my happiness on the entertainment industry — what roles I was getting or not getting. I love acting, but I kind of lost track of why I loved it so much, got stuck in thinking about the negatives, not getting a part, what did I not do or do wrong.” Self-doubt and second thinking is a byproduct of Hollywood, but Sherer casts no blame. “Los Angeles is definitely a high pressure place, but it’s not the city’s fault. It was my relationship with acting that got out of balance.”

So she and her husband, Ali Alsahleh, who were married in 2010, moved less than 200 miles from where Sherer had grown up (near Knoxville). “We wanted to move but be in a city that also felt like a small town. We had talked about having children, a good place to raise a kid, the cost of living. We looked at some homes for sale in LA and it was depressing seeing how much everything costs.” Franklin was not far from Sherer’s family, but later that year her mother suddenly died from an unexpected sepsis infection following rotator cuff surgery.

It was a shocking, sad and weird turn of events, but looking back, Sherer is grateful for one thing: “I’m so thankful we were here, instead of LA. My sister and I are now so close. Mom died in November. We had just wrapped filming the second season episodes of My Gimpy Life the first part of October. From there I went to Atlanta to dance for Full Radius Dance as a guest artist, and that’s when she got sick.”

Six months later came another life-changing event. “I got pregnant, and it was crazy going through all that without Mom. She was nervous about me getting pregnant because my body had been through so much. The accident happened in 1995, and my Harrington rods were taken out two years later because they were hurting me,” says Sherer. Then living in LA in 2007 her back kept popping, so she drove herself to emergency. Her spinal fusion had come unfused. “It took three surgeries to repair that, my bones were brittle. I had a lot of bleeding in one surgery and almost bled to death, and I also had augmentation surgery on my bladder. Mom was always there with me, so going through pregnancy without her was hard.”

But worth it. “River, my son, is my world right now, and of course, Ali. We meet with friends and cook dinner, drink wine. Franklin has a great historic area, it’s small, family town, a lot of activities going on, and there is wonderful music, being just south of Nashville,” says Sherer.

So different from her LA life. “It was go go go, I felt guilty just relaxing. It was always what project is next, what networking do I need to be doing, always hustling. Now it’s nice just not having an agenda, having friends. Now I’m in Mommy mode.”

Alsahleh is in IT at Horizon Health Care, which manages health care in prisons and jails. “He is very supportive of me,” says Sherer, “very much a handy man. He built a changing table for River
and me, built a desk, bed frames, a table for the back patio. He’s a jack of all trades. I needed help editing some videos and he even helped me with that. He is really good with teaching himself. And he’s great for helping with adaptive modifications. He ripped out stuff under the sink so I could roll under, built cabinets that can be pulled out.”

She’s immersed in Mommyhood. “River is the most important thing in my life. I will be very particular about what I spend my time on now. Whatever I get involved in will have to fit into my life with River and Ali.” Her priorities have changed.

“A part of me misses being in LA in the acting world,” she says, “but then I love my life right now and being a mother. I’m still acting, have an agent, did a one-day shoot for a Starz show — *Survivor’s Remorse* — went to Atlanta when River was just 9 weeks old.” LeBron James is the producer of the sitcom. It was a small role, just a day of work, but good for her, she says, because it brought her into Atlanta, paid for her travel, put her up in a hotel. “It was the first television part I booked, ever. It was cool, considering I’m now living in Nashville after living in LA for eight years.”

Sherer says she needs to find the balance of being a mom and continuing with acting. But she knows her baby and her family come first. “Now I’m finding happiness in being a wife and a friend and a mom,” she says. It’s about relationships.

“It’s odd that society does not acknowledge and celebrate caregivers,” says Sherer. “That is what I am doing now. Being a mom is the most important job there is. You are raising a child, building a foundation. It is a privilege.”

**Jen Goodwin: Leaving the Nightmare Behind**

Never mind how Jen Goodwin, 32, became a C5-6 incomplete quad seven years ago. As with many of us, it was frightening and traumatic, but to her
credit, she immediately focused on healing. Four days following emergency surgery she was in Baptist Rehab Institute in Little Rock, Ark. Then came a five-week gap before she continued rehabbing at Atlanta’s Shepherd Center. During that off-time, she returned home to chaos and complications.

“I moved back to live with my parents,” says Goodwin. “I had just bought a new home but couldn’t use it. Ramps didn’t work with my power chair, the bathroom was inaccessible, and once I got dumped out of a Hoyer lift. Luckily I landed in bed. Also, the guy who broke my neck lived across the street.”

She wasted no time qualifying for Shepherd’s rigorous, activity-based Beyond Therapy program, which she attended for an entire year. “I got stronger, learned cooking, bathing, all things in a home setting,” she says. “I was so focused on therapy that I treated it as my job. ... e-stim for hands and arms, Lokomat, crawling, e-stim with walkers. I got to the point where I could walk up and back on a basketball court, but it took one hour. I would work out until I passed out.”

When Goodwin came home from Shepherd, she knew that if more than a year’s worth of all-out therapy couldn’t get her walking in a practical way, it wasn’t going to happen. Change focus: “It released me mentally. I had been totally determined

Alice Wong: The Importance of Community

Alice Wong, 41, activist extraordinaire, is a dynamic, caring person with a passion for educating and informing those in power and advocating for the disability community. Born with spinal muscular atrophy, she grew up in Indianapolis, Ind. An interest in disability studies opened the door to her becoming part of the larger movement, and she felt drawn to Berkeley, Calif., and the Bay Area, where it all began. But she was also intimidated by the prospect of moving to a new place and connecting to new services.

“One of my professors gave me the phone number of Paul Longmore, the disability historian who taught at San Francisco State University,” says Wong. She knew he used personal assistance services like she did. “I called him completely out of the blue and told him about myself. He said, ‘Of course you can make it here — you must come to the Bay Area!’ At that time I didn’t know anyone like Paul and am so thankful for his encouragement. It was the one extra push that helped me make my decision and what would ultimately be one of the best decisions of my life.”

Her move was “a deliberate attempt on my part to find community.” She took up graduate studies at the University of California, San Francisco, and for the past 15 years she has been a constant source of information, direction and encouragement for those in our community, especially those whose need for in-home services is so critical. She uses every imaginable communication platform. “The Internet has changed my life profoundly, and also others with disabilities. Together online we can do a lot of amazing things,” she says. “It is different now, what it means to be an activist. It’s not just about chaining yourself to something on a march.”

The real power, she says, lies in information. “Sharing information is a radical act. There are so many avenues to express who we are. It’s all about choices, traditional or new, social media. These choices are more accessible, and the more the better.”

One of the newest choices allowed her to chat with President Obama via a telepresence robot in July. At the time she was serving on the National Council of Disability. The meeting made national newscasts and gave the nation a glimpse of some of what technology makes possible. It also gave Wong’s friends an opportunity to jokingly hang a new moniker on her: Robot Overlord.

What makes her happy is unique to her experience and her disability. “First is stability and security,” she says. “When you need assistance every day just to get out of bed, you must have a safety net. Programs like Medicaid and California’s In Home Support Services are always at risk for budget cuts. Sometimes you really feel a sense of tenuousness. Stuff can happen anytime, and it depends on where you are.”

Wong lives with her parents, who also are her caregivers, along with others. She uses a bi-pap breathing apparatus most of the time. “I can go without it for several hours if needed — when I’m eating or in meetings — but I use it during the day more often now because it saves a lot of energy and makes me feel more comfortable.”

As busy as she is (her résumé is a testimony to both her sheer energy and her effectiveness), she finds time to enjoy life and cultivate happiness. “I love going to my neighborhood cafes, to Golden Gate Park and the Embarcadero for walks. Other things that make me happy are watching cat videos, staying up late at night, live tweeting my favorite television shows like The Walking Dead or Game of Thrones, and having a hot cup of coffee with a doughnut, a cookie or a slice of pie.”

She also gets a lot of satisfaction in advocating for everyone as a community. “It’s not just about me. Privilege plays a role here. I now have an education, a job, a position. I know that this is not the case for others like myself. I appreciate what I have and it motivates me to try to help others.”
and committed, but walking was never functional, so I had to move on. I was now ready to learn to live in the chair.”

Her parents had an extra garage, so together they designed and built Goodwin’s accessible home by adding on to the garage. “We did tons of research,” she says. She bought a Honda Element and adapted it. It took about a year to get comfortable in her new home with her new life, living alone with no attendant. Her parents were always there for her when needed, “but it was hard doing everything on my own. It would take three hours just getting ready in the morning.”

Once settled, Goodwin set her sights on becoming a lawyer, tested high and landed a scholarship. “I decided that lawyers and preachers and salesmen were all pretty much the same, selling something, so since I had been in pharmaceutical sales and loved it, I decided to be a lawyer. There was an attorney in town I wanted to beat,” she says. It’s clear she thrives on challenges and competition. And her long term disability insurance from her pharmaceuticals job has helped greatly. “It’s probably more than what most make coming out of college.”

Goodwin naturally gives off vibes of happiness and credits her Christian faith and the joy that comes from it. “My church family has been hugely supportive every step of the way,” she says. But as happy as she was with her plan to go into law, another plan seemed more urgent. “I always wanted to be a mom, it was always a priority — I was going to have my four babies and become a doctor. My mom’s an OB nurse, I would hear tons of baby stories, and at 32, I was getting nervous about time running out.”

Everything fell into place. Her longtime gynecologist supported her desire to have a baby and care for it on her own. “I had planned to adopt, but I was ineligible for adopting from China,” she says. Instead she purchased sperm from an anonymous donor through the Fairfax Cryogenics Bank in Virginia and got pregnant on her second try. “Everything went perfect. No autonomic dysreflexia. Somehow, the way circumstances worked out, they put me back with Dr. Pinter, my longtime friend and OB gyn,” she says. In her second year of law school — June of this year — she brought Beckham Goodwin into her world six weeks early. After a week in neonatal ICU, Beckham came home and has been healthy and happy from the start. Her plans are to return to law school in January 2016.

As a new mom, you would expect her to be cooped up inside her house, but that is not her style. “We go out a lot,” she says. “My parents are next door and they help more now than even before. I have tons of
family and friends’ support. Several friends have newborns, so I plan lunch out at least two days a week. Beck and I go out, driving, just the two of us, in my Honda Element.”

What is most important to her happiness? Without hesitation, she says, “Family and friends’ support. And meeting other people with SCI along the way was helpful.” She ponders briefly. “Also, an inner drive — knowing that things are still possible.”

**Tim Gilmer: The Most Important Things**

If I have learned anything over the past 70 years, 50 of them as a wheelchair user, it is that what brings happiness changes with the seasons of your life.

At first, as a young man, it was all about the chase — the emotional rollercoaster of pursuing and being pursued by girls. That was the name of the game, and happiness rose and fell daily with the tide. Later, still young but nearing middle age, the lure of good times won me over. Smiling faces, thumping music, food and drink, drugs — if something felt good, it was instant proof that you were happy, at least until you woke up the next morning.

At some point I began to feel the need to leave a mark, to know that my life counted for something. Working and succeeding, doing something worthwhile was the path to happiness and fulfillment. Funny, how I look back now and think that all of it, no matter how memorable and valuable it may have been, is fading fast.

Change rules our lives, and time pushes us onward on our journey. What is really important? What is lasting? What do we leave behind?

For me the answer is right before my eyes. Those who are closest to me: Family and friends. People. Relationships. Memories. Love. Now I know, as time becomes more precious with each passing day, what really makes me happy.

My wife, Sam, and I met in 1973. From the beginning we loved taking drives together. Driving and talking is so liberating. We shared our life stories driving from Southern California to Oregon and sleeping in the back of her van for two weeks, waking in the woods, swimming in lakes, watching sunsets. And we still do it. We search for country roads that we have never driven before. Around each corner is a sight worth remembering, a beautiful mountain, a majestic tree, an animal in the wild.

When our daughter Lindsey came into our lives, we gained a willing passenger. One day, driving to the coast on a weekend, I suddenly slammed on the brakes, screeched to a halt at the side of the highway and screamed, “Fox!” I backed up quickly along the highway shoulder as Sam and Lindsey searched for what I had seen. I stopped, and we all stared in disbelief at a wooden fox stuck in the ground with a stake — a farmer’s wily version of a scarecrow.

Lindsey grew up too fast but always remembered my faux fox sighting. She never lets me forget it. Now when we go on drives, her children, Cooper, 6, and Peighton, almost 3, are often with us. On Sundays we drive to a promontory that overlooks Portland and drink our lattes and eat scones and doughnuts. We point out the landmarks. On clear days we can see Mount St. Helens. And we tell stories.

“My life would be complete,” says Cooper the child-man, spouting one of his best-known Cooperisms, “if only someone would explain to me how lava
gets into the bottom of a mountain and changes it into a volcano.”

Little Peighton does not talk much yet, but he loves to push me as fast as his little legs will churn, racing over the hardwood floors of our 1912 farmhouse, laughing and screaming with delight. I have to carefully guide the wheels with my handrims, or he will ram me straight into a wall and fall on the floor, laughing hysterically.

Cooper has discovered that he likes spiders. On our organic farm, we teach the boys that insects are a valued part of nature. Each one has a purpose, so if we see them in the house, we rescue them and take them outside to their natural habitat. Everything but flies and mosquitos, which we kill. And black widows, which I’ve never seen in Northwest Oregon. Cooper and I rescue bees, frogs and salamanders from the pool. We know which creatures are good and bad for the farm. Most are good.

Peighton is still learning. The other day, sitting at the breakfast table, Lindsey said he watched a sugar ant crawl across the table top, then picked it up on the tip of his finger and ate it. “Yum,” he said. That was the full extent of his breakfast conversation.

Sometimes we all go to Clackamette Park on Sundays, including Tom, Lindsey’s husband. The park is the confluence between the Clackamas and Willamette Rivers. We live in a land of rivers. A dozen bridges span the Willamette, connecting East Portland to West Portland. At the park Cooper and Peighton throw rocks into the river, we feed pigeons, ducks and geese, and sometimes go on walks. Cooper collects rocks and sticks and dumps them in my lap and litters my van with them. Sometimes we throw bread crumbs on the hood of the van and on the roof while we sit in the car and watch the pigeons go crazy in a feeding frenzy, beating out a staccato rhythm on the rooftop.

On Thanksgiving and Christmas we have friends over, three or four families usually, and I smoke a turkey or a ham outside on the deck that overlooks the creek area. The boys run around in the yard or play in the sand pile while the adults talk inside, where it’s warm. We usually have a wood fire burning. I open a few bottles of wine and we sit down together to eat. I always say a prayer when we sit down to eat together, no matter how few, no matter how many, no matter what day.

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For quality attendant care, first you have to assess how many hours a day you require personal assistance, and then you have to come up with a way to pay for it. Next you need to find people willing to work for you, and it helps if they’re not criminals. Once you’ve got all of that squared away, you still have to manage them. Does this sound impossible? It isn’t. Following are the experiences of people who use personal assistance, and use it well.

Issues surrounding personal assistance services are some of the most complicated and expensive results of being paralyzed. Without someone to assist with activities of daily life such as getting in and out of bed, using the bathroom, bathing, getting dressed, cooking, helping with eating, laundry and maintaining household cleanliness, many people with disabilities would be trapped in their beds and prone to even more medical complications than are already present.

People who hire care staff to visit their homes compete with home health agencies and institutions that use similarly qualified individuals, and often provide benefits to their employees. Therefore it is important for individuals to be innovative in seeking homecare support. Fortunately, unlike institutional employers, individuals can recruit non-medical personnel like family members, friends and neighbors to perform the duties they need to remain healthy and independent.

For many people with disabilities, their first experience with
personal assistance is Mom and Dad. Laurie Hoirup is an author who lives in Sacramento, Calif., and has been dealing with caregivers for over 50 years. “I was diagnosed with spinal muscular atrophy at 18 months,” she says, “and have required full personal care, other than feeding, for most of my life. My parents provided my care until I left for college when I was 17.”

For others, the switch to help from outside the family happens at a younger age. Barb Barrett was the primary caregiver for her son, Sean, who was born with juvenile arthritis. The single mom, now living in Arlington, Wash., had no outside assistance, and eventually had to reach out for more help. “There came a time when Sean became too heavy for me to lift safely, and he had also reached an age where it was no longer appropriate to have his mother giving him baths,” Barrett shared. “So I located a young man who was willing to take on the task as part of his college studies leading to a career in the field of medicine.”

Giving up the maternal caregiver role did not come easily, as Barrett revealed she stayed in her bedroom the first morning that student showed up for work. It all worked out, though. “I heard laughter, from both of them, coming from the bathroom as they were going through their routine,” she says, “and I knew at that moment that everything was going to be all right.”

Seeking out all available sources of funding for caregivers is important. Leaving an institution and returning home usually means responsibility for paying costs of nursing or personal care will shift to the individual and away from medical insurance companies. An exception would be in those states that have a Medicaid home and community-based services waiver to pay for homecare. Eligibility for waiver services is usually determined by whether the person needing the care would be eligible for placement in a nursing home or other type of institution, as well as having limited income. Unfortunately, there are still several states that have not applied for a Medicaid waiver to fund such home-based services.

Jesse Collens qualifies for Medicaid homecare. “As a young man in Alaska,” he remembers, “I was living the good life until the day that, just hanging out with a friend after work, I decided to attempt a front flip off a statue while riding my bicycle.” The crash and resulting C1 quadriplegia brought the stunt to a quick end. Now he requires assistance around the clock. During the six years since his accident, Collens, who uses a vent, has moved to Washington State and is receiving the assistance of a combination of private duty nurses and non-nursing caregivers. He continues to appeal to the state Medicaid agency for 24-hour coverage but is still a couple of hours short of reaching that goal.

Depending on the status of the person needing help, there may be other resources available for caregiver funding. State vocational rehabilitation agencies are funded by the Rehabilitation Act for the purpose of assisting qualified people with disabilities in obtaining an education and finding employment. Voc rehab

Setting — and Funding — a Schedule

A person being released from a hospital to return home, or a parent whose child has simply grown too large or too old for continued parental caregiving, will enter into a realm where there are multiple issues to be considered as decisions about homecare are made. The search for assistance can become a little easier with forethought and plenty of preparation.

In the early stages of being set up in the home, it is a good idea to consider whether hours of care might be reduced while still meeting the needs of the person requiring assistance. Hospitals, nursing homes and other types of institutional settings have qualified personnel on duty around the clock. If there is little or no care needed during nighttime hours, or even at certain times during the day, perhaps that can be figured into potential work schedules for attendant care providers once the person transitions into their own home.

A Sample Personal Care Assistant Schedule

By Mia Arends

- Start with range-of-motion exercises in bed
- Transfer to shower chair for bowel program
- Assist with shower
- Make beds and sweep
- Remove trash from bedroom and bathroom as needed
- Transfer back to bed and assist with dressing
- Finish dressing, including support stockings
- Move wheelchair to bed and transfer from bed to chair
- Prepare and setup breakfast
- Occasionally assist with bladder function
- Prepare meal for later consumption
- Drive van and assist with medical appointments, shopping and other errands
- Assist with swim therapy (PCA does not enter the water)
- Light housekeeping - cleaning and laundry

Weekday Hours — Note: some flexibility in afternoon hours

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Laurie Hoirup, here with husband, JR, has more than 50 years of experience managing her caregivers.
agencies covered some of the personal care attendant expenses during college for Laurie Hoirup, Sean Barrett and Dennis Rawlins, a C5 quad from Arlington Heights, Ill.

Local Centers for Independent Living are also a great resource. Operated by people with disabilities with funding and authority granted through the Rehabilitation Act, CILs offer information and referral, systems advocacy, individual advocacy, independent living skills training, peer support, and sometimes services related to homecare.

Securing Attendants
When it comes to recruiting personal assistants, Mia Arends, a C5 quad from Kirkland, Wash., has found that newspaper classified ads are not as effective as they once were. She posts her ads on Craigslist and other websites frequented by job seekers, like carelinks.com, care.com and mycnajobs.com. “I have also posted notices on local college bulletin boards, especially those that have nursing or nursing assistant education programs, with limited success,” she says. Most individuals interviewed for this article used similar strategies, but often the most effective approach was word-of-mouth.

Arends believes it is important to have a clear understanding of duties prior to a caregiver beginning work. She lists as many details about the position as possible, and requests experience, references and appropriate certification. Once a candidate shows up for an interview, she provides full information about the duties and probable hours of work for each day, and provides a separate list that explains in detail how she expects the range of motion exercises to be done.

Even if a caregiver candidate is located, problems can still occur. “I got a call this afternoon from a nurse I was hiring,” says Collens. “We were just waiting on his background check to come through so he could start, but he got another job offer and took it. This is the third time this has happened to me. My mom is working more than 48 hours a week. She is not getting paid and she is exhausted.”

Avoiding the above hassle by hiring a homecare agency has its own challenges. “I am in the throes of looking for a caregiver,” says Arends. “But it’s not going very well. I feel we offer fair wages plus paid holidays, vacation and sick days. As a backup, I met with the managers of an agency to set up a deal with them in case we don’t find someone, and I’m not finding anyone. I paid them a month’s fee and they provided me with a list of people to contact. However, I don’t seem to get anyone following through.” The agency referred Arends to care.com and carelink.org, paid services that also did not meet expectations.

As Arends has discovered, many businesses that describe themselves as caregiving, senior care or homecare agencies do not actually provide the employees to do the work. Instead, they recruit a variety of individuals seeking caregiving positions and add their names and phone numbers to a list which they then sell to those who are seeking care. They often take no responsibility for the many aspects of hiring, including background checks.

Some agencies that do hire caregivers charge customers about twice the rate than the employees are being paid. David N., a quad from a small rural community who requested to remain anonymous, has faced many challenges when seeking to hire someone capable of taking care of his needs on a regular basis. In desperation, he turned to local homecare agencies for assistance. “My previous and current caregivers are from agencies,” says David. “But the problem with this area is there are only two agencies that will service this small town and one agency only...
has limited service — one caregiver four days per week.”

All of his caregivers have been “private pay,” with no coverage by Medicaid or any insurance provider. “My first caregivers were paid $12.50 per hour cash, since I recruited them myself,” says David. “But the agency rate that I am forced to pay now is about $24 per hour and the caregiver is paid only half that.” To make matters worse, David pointed out that none of the agency caregivers have been capable of transferring him so he could be out of bed during the day.

Don’t Skip the Background Check

In the rush to find help, background checks are often skipped, but that can be risky. Dolores Carron, a quad from Connecticut, has had a succession of good assistants. According to Carron, “I have been fortunate that anyone who has left me has always made sure they find me a good replacement.” While that has worked well for Carron, it is important to learn as much as possible about individuals who will be spending hours at a time in your home.

There continue to be too many instances where caregivers, both strangers and family members, have abused, assaulted or stolen from those they were hired to assist. The federal Bureau of Justice Statistics found that, in 2009, there were 5 million vulnerable adults, 2 million elders and 1 million children reported as being abused. Background checks can minimize the risk of that happening, but they are no guarantee of safety.

Dennis Rawlins learned the hard way that those entrusted to care for us are not always worthy of our trust. “There was a time I needed help at home and contacted an agency for someone to help. It was only for a week or two and I had no choice in who the person was that they assigned,” says Rawlins. “The man they sent seemed all right until the day when he asked if I had some money that he could borrow for gas. I was in the process of telling him I didn’t think I had any money when he reached into my backpack and took $10 or $20 from my wallet. I was shocked, but he promised he would pay me back.”

The following week, when that caregiver wasn’t returning calls, Rawlins called the agency and explained the situation to the woman on the phone, who apologized, saying that caregiver had done the same thing to other people.

An Internet search for “background checks” will result in several pages listing information about how to accomplish them, and ads from many private companies offering to do it for a fee. Law enforcement agencies also perform background checks for a reasonable cost. “I have it done through local law enforcement, and that gets you information about misdemeanors and felonies,” says J.R. Harding, a C5 quad. “But it’s limited to the state of Florida. If you want a national search, that costs too much.”

Larry Littleton, who lives on the Hawaiian island of Kauai, had the responsibility of finding caregivers for his aging parents. Both of Littleton’s parents were living in the Los Angeles County area when he attempted to find a live-in caregiver for them because his mother had dementia. A friend of Littleton’s worked for a private investigator and ran background checks for him on 70 individuals who had applied to live with them. “All of those failed a very basic background check,” said Littleton. “So, as a result of my inability to locate a trustworthy individual to care for my parents, I moved them to Kauai to live out their days.”

Managing Caregivers — and Your Stress

Collens has learned that managing caregivers is not always easy. In a recent blog post, he wrote: “All of this staffing that I’m learning to manage is extremely stressful. I’ve definitely been learning to handle my stress a lot better in the past few months, but this is driving me crazy.”

That type of stress can also impact family members who serve as caregivers, says Littleton. “Hospice or respite services are a blessing, but we often do not ask for their services soon enough. It is important to find that balance between caring for your loved one and caring for yourself. Don’t hesitate when you begin to burn out.”

Managing caregivers takes as much time and skill as are needed to run a business. Even with clear expectations and a statement of duties, Hoirup advises that one of the big problems is that, over time, personal care attendants can lose sight of the fact that they are employees — they sometimes feel like the boss. “Too often, when they do so many things for you, they tend to become parent-like and want to do things their way,” she says. “And it is best to nip this in the bud. I think it’s important to always stay involved in whatever activity you are having the caregiver do. It’s also helpful to hold monthly meetings just to communicate and prevent problems from arising.”

What about when things do go wrong?
Hoirup shared that there have been various reasons for dismissing caregivers, such as showing up late, personality differences, etc. Other individuals also mentioned theft and abuse, even verbal abuse, as potential reasons for dismissal. “I have usually handled the situation tactfully to keep things peaceful and not ‘end ugly,’” says Hoirup. “Thankfully, I am married and my husband is my backup system.”

The advice from Harding is similar, as he stressed that orderly transition is critical, since each dismissal brings with it increased costs for training, changing locks and background checks, as well as heightened vulnerability.

Can the current system work better? Dan Thompson is a Certified Life Care Planner from Huntsville, Ontario. He is also a quad and feels there are lessons to be learned from how Canada’s provinces treat people with disabilities. As an example, the Ontario Disability Support Program provides living expenses, healthcare and other supports while still enabling people with disabilities to obtain employment. He noted the Medicaid homecare program appears to be very heavy on bureaucracy, especially at the state level. In contrast, most of Ontario’s programs strive to put more control in the hands of the consumer.

Another person involved in homecare at the professional level is Annette Jeske, who works for an Area Agency on Aging in Michigan. “The Medicaid waiver is for people who would be eligible for nursing homes,” she says. “But sometimes companies supplying the direct care workers have their own profit interests at heart versus meeting the needs of those they serve.” She cites the requirement for mandatory training for caregivers. No funding is available at the present time to offer the day-long program to care staff. “Additionally we often hear that the average wage here is $9.05 per hour for care staff, yet anecdotal evidence indicates many make only $8.15 per hour, even with a CNA license. Local fast food restaurants are offering $15 per hour.”

Jeske is passionate about this issue and hopeful it can be changed for the better. “The grassroots, especially young people, can change this in time,” she says. “But we need to develop a talent pipeline for caregiving as a great profession, starting young.” For the sake of everyone needing care, it would be nice if that pipeline was in existence today.

Resources:
• Centers for Independent Living — ilru.org
• Family Caregiver Alliance — caregiver.org/caregiving
• Medicaid Waivers — medicaid.gov
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Houston • Aug. 5-7, 2016
NRG Center

Boston • Sept. 16-18, 2016
Boston Convention/Exhibition Center

Bay Area • Nov. 18-20, 2016
San Jose McEnery Conv. Center
MY TAKE
Berkeley, Calif., is known as the birthplace of the disability rights movement. It was the first U.S. city to include curb cuts at intersections, which are now common in U.S. cities. University of California, Berkeley, affectionately known by locals as Cal, was the first public university in California.

The San Francisco Bay Area Chapter of United Spinal holds its meetings at the Ed Roberts Campus, which is named in honor of the first person with a significant physical disability to graduate from the University of California. Ed Roberts went on to open the first Center for Independent Living in the U.S., and was active in the disability rights movement throughout his life. Built according to principles of Universal Design, the Ed Roberts Campus houses diverse nonprofit organizations serving the disability community and is located above the Ashby BART station.

PLACES TO GO
Golden Gate Park is as beautiful as you think, and you should go there if you are in San Francisco or nearby. Redwood Regional Park in Oakland and Tilden Park in Berkeley have groves of magnificent coastal redwood trees. All parks feature accessible trails and sometimes paved paths.

The Berkeley Marina offers beautiful views of San Francisco, the Bay, and the Golden Gate Bridge. There is an accessible path along the water around the perimeter of Cesar Chavez Park, and out onto the nearby fishing pier.

The Bay Area offers a museum for everyone: the San Francisco Museum of Modern Art, the Asian Art Museum and the Walt Disney Family Museum; east of the Bay, Oakland Museum of California offers exciting exhibits with special focus on California artists and history; and Berkeley Art Museum and Pacific Film Archive is home to one of the largest film archives in the world!

GETTING AROUND
In the Bay Area, you can get around independently in a wheelchair, with or without a car. In the downtown and arts districts, driving and parking can be stressful and challenging. A car is helpful for accessing parks and natural spaces, or other areas in “the hills.”

The preferred way to get around is Bay Area Rapid Transit, more commonly referred to as “BART.” BART connects San Francisco, Oakland, Berkeley and various other cities around the Bay. Every BART car and doorway is accessible and barrier-free, and there are elevators at every station. Occasionally an elevator will go out of service, but there is system-wide communication when this happens.

AC Transit in Berkeley and surrounding cities, and MUNI in San Francisco, offer bus options on either side of the Bay.

EASY DOES IT
If catastrophe strikes while in Berkeley you can call Easy Does It, a unique local nonprofit that serves the elderly and people with disabilities. Easy Does It provides emergency attendant, transportation, and wheelchair repair services. So if your attendant gets sick or goes AWOL, you get stuck without a ride or your wheelchair breaks down, all you need to do is call the 24-hour hotline and someone will come out to help you. The service is funded entirely by Berkeley property taxes and costs $13 for the first hour or the call out.

SKINNY ON THE AREA
Since the 1960s, the San Francisco Bay Area has been famous for a tradition of cultural diversity and progressive politics, including the disability rights/independent living movement. In addition to the mix of intellectualism and free-spirited expressiveness, the Bay Area has a near-perfect climate year-round, and abundant natural beauty.

MUST SEE, MUST DO

OHLONE GREENWAY is Berkeley’s pedestrian superhighway, which is paved and includes painted lanes and scaled-down stop signs at intersections. The Greenway is level, and well-maintained. It’s a great place to practice handcycling or wheelchair mobility.

Conveniently located along the Greenway is Westbrae Biergarten. The chicken tortilla soup and the empanadas are delicious, there are accessible tables and a kids’ play area, and the restrooms are downright luxurious. All this in addition to an ever-changing selection of tasty local brews.
Tom Shankle had no aspirations to run a support group or manage a chapter of United Spinal Association when he started attending a monthly spinal cord injury support group in Berkeley, Calif., back in 2010. On the heels of a long career in the health care industry, Shankle had recently started Apple West Home Medical Supply. The monthly support group, then held in the basement of a local hospital, offered an opportunity for Shankle to connect with and learn about the community he wanted to serve.

“I started going every month,” he recalls. “I never said a word, I never recruited anybody. Over a four-year period I made a lot of friends, everyone knew me. When the leader stepped down, the group was going to dissolve. No one wanted to take it over, so I said, ‘Hey do you mind if I take it over?’”

And with that, Shankle took the helm in 2013. Soon after, he signed on to affiliate the group with United Spinal. Walter Delson, a para who lives and works in Berkeley, later signed on to help lead the chapter. Together the two friends are working to grow the chapter’s numbers and offerings.

The first thing Shankle did was find a new home for the group’s regular meetings. While the group had survived more than 10 years in the basement at Alta Bates hospital, Shankle thought the location might be hurting turnout and morale. “I didn’t like meeting at a hospital,” says Delson. “Life after SCI is about moving beyond the identity of injury associated with hospitals. I wanted to meet with my peers in the community, so I suggested the Ed Roberts Campus.” The group didn’t have any money, but Shankle’s company, Apple West, footed the bill to rent a space in the Ed Roberts Campus, a known hub of disability-related organizations and events, and to pay for some regular food and drinks for attendees. The group regularly draws 10-15 attendees and meetings often run into the wee hours of the night, as people share their stories and discuss what’s going on in their lives.

Aside from the support group, the chapter’s first big offering is a series of scholarships for advanced gait training at a local accessible exercise facility. Partnering with United Spinal, the chapter worked with SCI-FIT to give local people with spinal cord injuries a chance to use some of the most cutting edge rehab equipment and receive personalized instruction from SCI-FIT’s trained staff. That includes access to the Lokomat Namos and the Robomedica StepGain-GRF, two of the leading gait training machines.

“The scholarships are a great way to help expose people from our community to the latest and greatest when it comes to rehab technology. A lot of people are interested in this but can’t afford it,” says Delson. “Hopefully it can help some people make functional gains that will improve their quality of life.”

To that end, Shankle and Delson also hope to eventually open an accessible gym with exercise equipment tailored towards people with disabilities. They recently secured the first piece of accessible workout equipment, donated by Reggie Bennett, the head of Rebuilding All Goals Efficiently, the Las Vegas chapter of United Spinal. “We’re not looking to make money off of people with spinal cord injuries or disabilities. We’re hoping to get more grant funding so we don’t have to charge for admission or membership,” says Delson. Right now they envision using part of a property owned by Shankle’s company for the gym, but they both say the plans are fluid.

Meanwhile, the pair hopes to keep growing the turnout for the support group and plan more social events to bring the community together. To find out more about the chapter’s gait training scholarships, visit unitedspinal.org/pdf/scholarship.pdf or call 510/868-9175.
What happens in Las Vegas is usually supposed to stay in Las Vegas, but when United Spinal held its annual Chapter Leadership Meeting there Oct. 22-24, the goal was exactly the opposite. With 53 leaders and representatives from 33 different states and numerous chapters on hand, the goal for the three-day gathering was to share as much information as possible about what different chapters are doing, and take that knowledge back to the represented communities and use it to improve the way the chapters run and how they affect quality of life for people with spinal cord injuries and disorders.

United Spinal chapters are independent organizations that share the goals of United Spinal Association and support them within a specified geographical region. Chapters support the SCI/D community by promoting health and well-being, fostering inclusion and independence, organizing local events and projects, advocating for rights and accessibility, and offering information and resources to their chapter communities.

“The National Chapter Leadership Meeting offers United Spinal’s key staff and chapter representatives the opportunity to collaborate on future initiatives to enhance our organization’s mission,” said James Weisman, United Spinal’s president and CEO. “We are fortunate to have so many dedicated people who utilize each other’s skills and talents to support what we do.”

The meeting kicked off with an evening welcoming reception outdoors under the neon lights of the Rio Hotel and Casino. Attendees got a chance to mingle with staff and sponsors over drinks and heavy appetizers before the following day’s intense schedule of discussions and presentations. The meeting wrapped up Saturday morning with more discussion and planning for the future.

Topics highlighted at this year’s event included building community relations and membership and ways in which chapters can utilize a variety of resources provided.
by United Spinal to enhance their outreach efforts. United Spinal chapter representatives also had the opportunity to share their program success stories with one another to generate new ideas for the upcoming year.

“Networking with the other chapters and learning about their ideas and what they do is empowering for us as a chapter,” said Reggie Bennett, head of United Spinal’s Las Vegas chapter.

Joseph Pierce, from United Spinal’s Rio Grande chapter said, “Hearing how other chapters do things more formally and approach things like a business helps me to see the benefits of having more structure and organization.”

“Our chapters may have different programs, yet all share the same dedication to enhancing the lives of people with spinal cord injury/disease, their families, and those who provide their care,” said Nick LiBassi, United Spinal’s director of chapter relations.

This was the first year the event had been held in Las Vegas and the consensus was the new site was a success, as was the meeting. “I’m totally impressed with the amount of things going on,” said longtime board member Marty Ball. “It’s amazing all the things that are happening. There is no other organization like it – we’re the cream of the crop, we’ve just got to keep it that way.”

International Photographer Donates Work to United Spinal

Barbara Gracner, a documentary photographer from Slovenia, recently spent time with Ronnie Ellen Raymond, a United Spinal board member who has primary-progressive multiple sclerosis, to raise awareness of issues facing people living with disabilities. Gracner, a recent graduate from the photojournalism and documentary photography program at the International School of Photography in New York, captured an intimate portrait of Raymond, a New York resident and dedicated disability advocate, as part of her thesis and final long term project. The result is a highly personal, revealing, and beautiful look at Raymond’s life, which was shared with the public through an exhibition at the International Center of Photography, titled “Tipping Point”.

“Though the disease has drastically limited her mobility, Raymond still finds a way to remain independent and enjoy the art and culture of her city. I approached this project not looking at her but trying to understand the way she sees and functions in the world,” said Gracner.

Raymond, who was diagnosed with MS 26 years ago and uses a power wheelchair, met Gracner at a United Spinal meeting and became good friends with the aspiring photojournalist. “Barbara is an amazing photographer and an incredibly nice person. I was honored that she wanted to profile me for her project,” said Raymond. “For many of us living with disabilities, we often overlook how interesting our day-to-day lives may be to those unfamiliar with the challenges we face. Through her work, Barbara shares a personal perspective not often seen by the public. She was so unobtrusive during my time with her, I forgot she was a photographer,” Raymond added.

Gracner even got on the good side of one of Raymond’s pet cats that isn’t so friendly or affectionate. “She was the only person I have ever seen who was able to pick him up and pet him,” said Raymond.

The Tipping Point exhibition features work by advanced students in the 2015 one-year certificate program at ICP that provides these students an opportunity to strengthen personal vision, teach professional practices, and explore the many disciplines informing media and art today.

In mid-September, Gracner visited United Spinal’s headquarters in Kew Gardens, N.Y., with her parents to donate four framed archival pigment prints from her project so that they can be displayed in the main entrance for all to see.

Gracner’s work has also been exhibited in several collective showings worldwide, including the Floating Exhibition River in Ljubljana, Slovenia; International Center of Photography, New York; Fifth Annual Exposure Award at the Louvre, France and Pingyao, China. She is currently based in New York City.

You can check out her photos of Raymond and more of her work at www.barbaragracner.com.

Van Donation a Success

Donating an adapted van to someone who will be able to benefit from it seems like the kind of thing that should be easy to do. That’s what Don Brown, a retired NASA engineer, thought when he set out to help a widowed friend find a place for the van her husband, an amputee, had used. What Brown found was that all the charitable organizations that wanted the van had planned to sell it immediately, instead of giving it to someone in need. Frustrated, he started Googling relevant terms until he came across the page for United Spinal’s Resource Center. He called Bill Fertig, the director, and explained his desire to donate the van. Fertig connected him with Rafferty Laredo, the director of the Houston chapter of United Spinal, and Laredo knew just what to do. Only days earlier, Pedro Reyes, the father of a new quadriplegic, had been talking with him about how his family desperately needed a vehicle. His son Nick, 24, had been paralyzed the day before Valentine’s Day, and his older son had recently been in another accident and his car had been totaled, too. Laredo connected the two parties and after a month or so of paperwork and back and forth, the Reyes family picked up the van. “This van was a blessing,” explains Pedro. “We wouldn’t have had a car, or any means to get around.” He reports that Nick, a C3-6 quad, is progressing well and regaining function in his arms. Brown is happy with the outcome. “I’d never heard of United Spinal Association, but things sure seemed to work out well.”
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We are looking to break the mold and discover the best inclusive photos that will change the way the public, advertisers, magazine editors and business owners see disability. Your images can help eliminate social, structural and professional barriers!

Images should depict real people with disabilities of all ages in the following categories:

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2. Travel
3. Creative (unusual places, stylized, creative use of wheelchair parts, reflections, shadows, etc.)
4. Sports
5. Business/education
6. Portraits

The contest will run for 4 months, from September 1 to December 31, 2015. We'll announce monthly winners online and award the Grand Prize in the February 2016 issue of NEW MOBILITY.

- Monthly winners will each receive a $100 cash prize
- Finalists and winners will be published on Photoability.net (you’ll receive royalties for images sold)
- Finalists and winners will be featured in a special gallery on Photoability.net
- Winning images will be published in NEW MOBILITY
- Grand Prize winner will receive a $500 cash prize and a write-up in NEW MOBILITY that includes the Grand Prize image

Photos must be taken with a camera that is at least 8 megapixels and may include iPhones and other mobile. All people featured in the images must be willing participants in the competition and sign a model release. You may enter as many photos as you wish. See all terms and conditions and register for contest and upload images at photoability.net/disability-inclusive-photo-contest.html
I grin as the wind blows through my hair (OK, between the two of them). The smell of freshly-mown lawn permeates my nostrils, and the satisfying roar of the powerful V-twin engine rumbles. Cruising on a Harley? Nope, mowing the lawn. It all started when my wife tried our new mower.

“I think you can drive this thing,” says Teryll, as she pulls up smiling, not showing all the cards in her hand, methinks.

“Do you think so?” I’m a bit skeptical. History has taught (or at least presented several first-class opportunities to learn), that new endeavors do come with some risk and Murphy and his law is always available to lend a helping hand.

“It is really easy, and the controls are not touchy, I think you can handle it. Let’s get the lift and give it a whirl!” she says a little too enthusiastically, as if her love affair with lawn mowing is really over.

We live out in the country and have a lawn that is approximately five acres. The old lawnmower was slowing down, so Teryll had been spending a whole day mowing at least once a week. We finally broke down and got a new super-duper high-speed unit that has a zero turn radius — for her. But it dawned on her the first time she drove the mower that one only needs hands to operate it and that this might work perfectly for her darling husband.

Within minutes (seconds?) Teryll is back from the house with the “meat-hook,” our trusty battery-operated portable lift. We have installed a ring in the garage ceiling for just such an occasion, so I was soon hanging from the rafters! She pushes the lawnmower under me, lowers me down and presto! — pilot-installation complete. We tighten the seatbelts and add another large belt around my chest to hold me still. This seat feels every bit as comfortable as my wheelchair. I reach forward and put my paws on the controls, thinking maybe this will work.

“I think I’d like some way to shut the engine off if there’s an emergency,” I say, trying to anticipate some of what could possibly go wrong.

“OK, how about I fit a screwdriver through the key for now?” my wife replies, shoving it through the key.

I twist the key with the screwdriver and, sure enough, the lawnmower jumps to life! I then reach down, bump it back and the engine quits. “Perfect!” I feel safer now. Next we put a couple of zip ties on the yellow knob that controls the blades. I can now easily hook a finger in the loop and lift the knob up to engage the mower.

“I think I’ll move the van out of the garage,” Teryll says, jumping into the vehicle, thereby negating one of the more expensive potential calamities. In a few minutes I start the engine once more, and put my hands on the control levers. I gently push the levers forward and the mower starts moving forward out of the garage. I slowly pull back on the levers one at a time and find that it steers very responsively.

“Let’s go across to the big field and try to drive it around to get used to it,” Teryll says, wanting some room to play where nothing will get hurt.

I slowly creep across the lawn with the throttle near idle, my wife within reach of the key. Once in the open field I advance the throttle a little bit and try driving around. When it is moving straight ahead, it tracks pretty well with only small adjustments necessary. Pulling back on one of the levers while in forward motion causes a turn in that direction, and pushing it forward straightens out the turn. Simple. These things handle much like a wheelchair so it is quite natural to us folks who must use one.

“Let’s turn the mower on and play a little bit with that,” I say.

I pull the zip tie that is on the yellow knob, and the mower blades activate. Pushing forward on the levers, the mower starts to creep forward. Wow! After nearly 30 years, I am mowing a lawn!
Now it has been a few months since I first ran the mower, and I’m getting more and more comfortable with it. We just got a set of cuffs built because after a while my fingers kind of straighten out, making it hard to pull the levers backwards. I run the mower about half as fast as other people can, but that doesn’t matter at all as it is still a novelty and I love playing with anything that has an engine. It takes about four hours to do the whole yard, so I’m thinking I may have to slow down to prolong the fun. Hmmm … I wonder if irrigation and fertilizing equipment is in the works?

Frequently Asked Questions

What kind of mower do you have?
Ours is a John Deere 757 zero turn mower, controlled by pushing and pulling two levers that control hydraulic motors on the main wheels. The farther you push the faster you go.

Did you set out to adapt a mower?
No, it just happened that way.

Can a quadriplegic drive one?
Absolutely, I’m a C5-6 quad with no finger movement and have no trouble operating this machine with just a few adaptations.

What adaptations did you do?
The only thing we did was extend the key using splint-building material and tie a couple of zip ties on the knob that controls the mower blades so that I can turn them on and off.

How long can you mow?
It takes me about four hours to mow the lawn now, but I have ridden it for five hours or more with no signs of pressure sores, probably because the vibration and bouncing keeps the blood circulating.
Q. I’m in my 23rd year as a T9 para. I manage my bladder with intermittent catheterization, drink plenty of water and cath at least four or five times a day to make sure my bladder doesn’t get too full. I rarely had problems with bladder infections until recently. Over the past few years it seems like I’m fighting one after another. I try to flush them by drinking extra water, but more often than not, I end up on a course of antibiotics, which messes with my gut.

In a previous Para/Medic you wrote about an antibiotic called Neosporin G.U. that goes directly into the bladder and can be used on a daily basis. A friend’s urologist has him on a similar system, but it’s a mixture of saline and Gentamicin — he says it has kept UTIs at bay. Does one solution work better than another? And if you use them regularly, do they contribute to antibiotic resistance?

— Jeff

Good questions, Jeff. This is a topic that appears quite a bit on SCI-related sites, including CareCure Forum and Apparelyzed.com, which discuss a myriad of solutions that can be added via catheter to the bladder to help reduce UTIs. The solutions can be added during clean intermittent catheterization (CIC) by way of a 60cc syringe that fits into the end of the catheter, or in the case of a suprapubic catheter or indwelling Foley, adding the solution and clamping the catheter for 20 minutes.

To track down answers, I turned to Dr. Michael Kennelly, director of urology at Carolinas Rehab in Charlotte, N.C. Kennelly explained that although “irrigant” is the common term for solutions that go into the bladder, for the most part they are “instilled” — that is, added to the bladder for a period of time — usually until the next catheterization if you are cathing intermittently.

For the scope of this article, I will focus on some of the most common irrigant solutions — saline, acetic acid mixed with saline, Neosporin G.U. (neomycin/polymyxin B) mixed with saline, and gentamicin mixed with saline.

Saline is an irrigant that many wheelers, including myself, were introduced to in rehab. We were taught to add 30cc of saline after each cathing — a time-consuming practice that often faded when we went out the rehab door. Kennelly explains the theory with saline is that it addresses residual urine as well as sediment left in the bladder after a CIC. Residual urine has minerals that will start to crystalize and form stones, which can cause a UTI. Adding saline should help dilute residual urine and sediment and help prevent stones and stop bacteria from colonizing. This is a good reminder to try and empty as much urine as possible when cathing. Because the sphincter is at the bottom of the bladder, it’s best to cath in an upright position, and when urine stops coming out, pull the catheter out slowly. This moves drainage eyes (holes in the end of the catheter) lower in the bladder and lets more urine flow out. For SP and Foley users, your catheter should be flushed with saline to help keep it clear.

Another option that gets a lot of mention on SCI forums is adding distilled white vinegar mixed with saline to the bladder. This supposedly creates an acidic environment that is hostile for bacteria. Kennelly emphasizes that it is important to have a discussion with your doctor before trying any irrigant solutions, and the vinegar-saline solution is a good case in point. He says the solution can irritate the bladder and cause inflammation, which weakens the bladder wall’s defense mechanism and makes the bladder more susceptible to infections.

What Studies and Docs Say
The only FDA-approved solution for bladder irrigation is Neosporin G.U. irrigant, an antibiotic solution that is mixed with saline. I learned about the mixture five years ago from Paula Wagner, my urology nurse practitioner at U.C. Davis Medical Center in Sacramento, Calif. I had been getting frequent UTIs and wanted to get away from strong oral antibiotics that were wreaking havoc on my stomach. Wagner explained that although it is an antibiotic, Neosporin G.U. doesn’t get absorbed systemically, so I can use it as often as twice a day if my urine looks bad, or once every couple of days when things are good. It reduced my UTIs from one every couple of months to less than one a year. Wagner says at U.C. Davis they tried transitioning a couple of peo-
people from Neosporin G.U. to straight saline, but they came down with UTIs. Drugs.com says that Neosporin G.U. should only be used for 10 days. However, Wagner says it is OK for long term use if you are consulting your doctor.

Although there are anecdotal reports of success from irrigation with acetic acid, Neosporin G.U. irrigant, and saline, Kennelly points out that hard science is less enthusiastic — specifically a study on neurogenic bladder published in the 2006 Journal of Spinal Cord Medicine that followed 89 people. Some were using indwelling catheters; others used SP or indwelling Foleys. Participants were divided into groups of 30, 30 and 29, and each group instilled Neosporin G.U., acetic acid, and saline, respectively, twice a day for 20 minutes. Based on 52 people who finished the study, results showed no problems with side effects, but also no improvement in reduction of UTIs. Importantly, the paper said more studies should be done on these options, and the studies should consider incorporating increased or more volume of irrigant, more frequency of installation and/or duration of treatment. It will also be interesting to see a study that looks at these options in CIC users.

Kennelly says, “The study doesn’t mean ‘stop things like G.U. irrigant,’ because for some people it is effective. Some of my patients irrigate with Neosporin G.U. or gentamicin, but most just use saline for irrigation to keep the SP or Foley clear.”

A paper that reviewed a number of smaller studies, published in the December 2010 International Journal of Antimicrobial Agents, reported better results with Neosporin G.U. Of four controlled studies using neomycin (Neosporin G.U.) or Kanamycin, two demonstrated a significant reduction in bacteriuria (bacteria in urine) and two did not. And three case studies of gentamicin showed a significant reduction in UTIs and bacteriuria with no relevant side effects. Wagner says that gentamicin works well as an irrigant solution for people with UTIs that are resistant to other antibiotics. She says there is lots of literature on gentamicin, especially for use in augmented bladders.

Kennelly adds that irrigant solutions are really effective when someone has a UTI and the urine sample culture tests for something that is sensitive to Neosporin G.U. or gentamicin, or another antibiotic that can mix as an irrigant. “That is great because we can avoid an oral antibiotic and put the antibiotic directly into the bladder.”

“You can be doing everything right and still have problematic infections,” says Wagner. “When this happens, it is important to talk with your urologist and ask them if an irrigant solution like Neosporin G.U., or gentamicin, is an option you should try. The bottom line is you need to do something to control UTIs, and different things work for different people.”

For more info: www.newmobility.com/2011/04/neosporin-gu/
It was a bright, fresh, rejuvenating spring morning in 1993. I entered the dial-a-ride vehicle that was to take me to my destination. Little did I know what a historic day this would be.

About a dozen years earlier, this new Chicago public transit option called dial-a-ride was unveiled. There were zero accessible mainline buses so the cripples were ecstatic. Jane, my quad friend, was excited because she disliked relying on others to drive her in her cripple van to her appointments, such as her weekly session with her shrink.

But now, thanks to dial-a-ride, she could just make a phone call and an accessible cripple bus would arrive at her door and whisk her to her destination! Or so said the brochure.

It didn’t take long for the cripples to become unecstatic. The idea of dial-a-ride was way too good to be true. In reality, you had to call to reserve a ride a day in advance and call over and over until you broke through the busy signal. And by then all the ride slots might be filled, or available rides might not be at the time you needed. And then your ride might come an hour late, and even if your destination was 20 minutes away, it might take two hours to get there because a dozen other dial-a-ride cripples were picked up and dropped off along the way.

Jane only took two or three dial-a-ride trips to her shrink before she stopped using dial-a-ride altogether. Because she’d spend so much of her shrink session venting about what a degrading hassle it was just getting there on dial-a-ride that there wouldn’t be time to talk about much else.

The first batch of mainline Chicago city buses with wheelchair lifts hit the streets in 1992, after disenchanted dial-a-ride cripples filed a lawsuit and organized raucous protests — and after the signing of the Americans with Disabilities Act. But there were only enough buses to cover a fraction of the city. The only way to get most places was still to take dial-a-ride.

Those were the conditions that fateful morning in 1993.

The driver belted me in. We drove off. At a stop light, he asked me to pay my fare. Cripples like me, who rode mainline buses whenever possible, were well-stocked with half-fare bus tokens. It cost cripples half the regular fare to ride mainline but full fare on dial-a-ride. So I handed the driver two half-fare tokens.

“I'm not taking these,” he said. Why not?” I said. “It’s like two nickels or a dime. What’s the difference?”

“I'm not taking these,” he said again. I told him I only had half-fare tokens. So he reeled off a sharp U-turn and headed back to my home. En route, he cuss ed me out like I’ve never been cussed out.

And that’s saying something. “Everybody hates picking up your complainin’ ass!” he said. Back at my home, he unbel ted my wheelchair, pulled out the ramp and told me to get out. I told him to shove it. He cussed me out again. I restated my burning desire for him to shove it.

The driver radioed the dispatcher. The dispatcher said he was calling the police. I laughed as I pictured the cops springing into action. “Oh no! It’s a 10-82: cripple refusing to leave dial-a-ride van! I’ll need lots of backup for this one!”

After a few minutes, the dispatcher radioed back: “Take him where he’s going but tell him we won’t take him back until he calls us.” This meant I wouldn’t get home without receiving my punishment, which would probably consist of a stern lecture and a two-hour wait.

But I figured out that four blocks from my destination was an accessible bus line that connected to another accessible bus line that would take me home. So I took it.

And I haven’t taken dial-a-ride since. I want that one-way trip that spring morning to forever remain my final dial-a-ride excursion. I wonder if pinned to the bulletin board at the dial-a-ride center is a piece of paper, brittle and yellowed with age, reminding the dispatcher to lecture me when I call for my ride home.
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  • Can also help with incontinence thru Kegel Exercise.

(Not FDA approved for sale inside the USA for incontinence)
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USA Jeans makes pants designed for sitting. Call Darlene at 800-935-5170 or visit www.USAJeans.net

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Deerfield Beach Florida – Deer Creek Golf Course 17th hole condo. Two Bedroom, two bathroom with a roll in shower. Fully wheelchair accessible. Furnished or unfurnished. $140,000. Call 516-435-8231 or 516-698-2960

**WANTED**

NEW Bard Vinyl Reusable Urosheaths and straps in box – medium. Will pay top dollar – Call Gary 573-468-6549

**ADDRESS CHANGE**

Change your address? If so, please provide New Mobility with your updated information. Full Name, Street Address, City, State & Zip Code are needed for both the old & the new address. Please allow 6-8 weeks for this change to be processed. Please submit your request electronically to: mkurtz@unitedspinal.org or at www.newmobility.com. Or call: 800-404-2898 x7203

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**CLASSIFIEDS**

**United Spinal Business Member Updates**

**Gold**


Hollister Inc. is excited to launch the VaPro Plus Pocket hydrophilic intermittent catheter. No need to compromise protection for discretion. Request a sample: hollisterpeoplefirst.com/vapro

Permobil’s 2015 PowerTrip is bringing YOU THE BEST IN MOBILITY! http://permobilpowertrip.com/events/

Wellspect HealthCare believes a good start to CIC is crucial for a good life. For FREE samples of LoFric catheters, proven to improve short- and long-term urethral health: 855/456-3742 or www.wellspect.us

Abbbie, www.abbbie.com, 800/255-5162

**Silver**

Astellas Pharmaceuticals, www.astellas.us, 800/888-7704

**Bronze**

Numotion offers online and live CEU courses. Visit www.numotion.com/education-learning/

Asterias Biotherapeutics: SciStar Study recruitment for the second cohort is now open. www.scistar-study.com

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Synapse Biomedical

For more information on how you can support United Spinal and become a business member, please contact Megan Lee at mlee@unitedspinal.org or 718/803-3782, ext. 7253.

Acknowledgements on our website, in New Mobility, in United Spinal e-news or any other United Spinal publication should not be considered as endorsements of any product or service.
TEAM BOX HALLOWEEN COSTUME WINNERS
The top three winners of Team Box’ wheelchair Halloween costume contest are:

First Place: Calvin and his John Deere costume
Second Place: Dryden and his “arghh matey” costume
Third Place: Colin and his “trick or treat train”

Box Wheelchairs are known for strong frames, great shock absorbers, sponsoring WCMX riders who shred skateparks worldwide and getting kids customized wheelchairs that put the “oo” in cool.

View all the great costumes at www.facebook.com/boxwheelchairs/?fref=ts

DISABILITY INCLUSIVE PHOTO CONTEST STILL OPEN
It’s not too late to enter the “Disability Inclusive Photo Contest” sponsored by NM and PhotoAbility, but you do need to hurry — the contest ends on Dec. 31. The Grand Prize winning photo will be published in New Mobility and earn a $500 cash prize. To register, go to photoability.net/disability-inclusive-photo-contest.html.
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