



NEW MOBILITY

life beyond wheels



SCI Anniversaries: Why We Celebrate

TO
SUBSCRIBE,
CLICK HERE



**United Spinal
Association**

newmobility.com

AUG 2017 \$4



küschall[®]
designed for life

STAND OUT even when you're SITTING DOWN

küschall[®] Advance[™]

Visualize your own küschall[®] Advance[™] wheelchair at kuschallUSA.com/standout



küschall[®]
designed for life

©2017 Invacare Corporation. All rights reserved. Trademarks are identified by the symbols [™] and [®]. All trademarks are owned by or licensed to Invacare Corporation unless otherwise noted.
Form No. 17-006 170105

Onli

Ready to Use Hydrophilic Intermittent Catheter

Whether your day is ordinary or extraordinary, the Onli catheter is there for you.

Count on the Onli catheter to help you at the right time. The Onli catheter fits with your daily routine — an easy to open and easy to use hydrophilic catheter designed for smooth insertion with reduced spills and no staining.* The Onli catheter is designed for no mess, no fuss — ready to work with you, whatever the day may bring.

For more information or a sample, call 888.740.8999 or visit hollister.com/onli.

Ready. Simple.

*On denim, linen, or polyester. Data on file.
The Hollister logo and Onli are trademarks of Hollister Incorporated.
© 2017 Hollister Incorporated.



Continence Care
People First



**“THERE’S NOTHING LIKE
TAKING MY BEST FRIENDS
ALONG FOR THE RIDE.”**

- Gary

LIVE. FORWARD.

RAM PROMASTER®

Life can take you places. Whatever your destination or occasion, the 2016 Ram ProMaster® is always ready to go. With a best-in-class 55.8-inch interior width¹ and up to 460 cu. ft. of interior capacity¹, ProMaster can be modified with adaptive equipment. It's also perfect for transporting those who need assistance in and out of the vehicle. And with a best-in-class standard interior height of 65.4 inches¹, it's much easier for a caregiver to stand up and lend a helping hand. Now, get a reimbursement of up to \$1,000² when you purchase adaptive equipment for ProMaster. So get in, get out and get going.



 [FACEBOOK.COM/FCAUSAUTOMOBILITY](https://www.facebook.com/FCAUSAUTOMOBILITY)

 [#LIVEFORWARD](https://twitter.com/LIVEFORWARD)

[FCAUSAUTOMOBILITY.COM](https://www.fcausautomobility.com)



¹Interior volume and entryways vary depending on adaptive equipment purchased and installed by upfitter. ²Please visit [fcausautomobility.com](https://www.fcausautomobility.com) for full program guidelines and adaptive equipment reimbursement details. ©2017 FCA US LLC. All Rights Reserved. Ram is registered trademarks of FCA US LLC.



FEATURES

17 SHOULDER OF FORTUNE NED FIELDEN's shoulders were his gods. Then one forsook him. The road to redemption was longer and harder than he'd anticipated, but he made it. Here is his story.

30 RVS: LIFE ON THE ROAD The open road can be your friend, and your home, thanks to accessible RVs. NANCY GORE and WILL SIERRA share their experiences and advice.

37 MANAGING PCAS Between hiring, scheduling and payroll, managing personal care assistants amounts to running a small business. ALEX GHENIS and ROXANNE FURLONG offer tips to keep you afloat.



COVER STORY **SCI CELEBRATIONS** 22

Breaking your neck or your back might not seem like something to celebrate, but every day people all across the world with spinal cord injuries do just that. Some have parties and some reflect quietly, but "Break Your Neck Day" or a "Quadaversary" is a very real thing. TIM GILMER talks with 10 wheelers to try to understand the motivation and what people get out of this seemingly odd tradition.

Cover and Contents Photos by Matt Wong

DEPARTMENTS

- | | |
|------------------------|----------------------|
| 4 BULLY PULPIT | 12 EVERYDAY ADVOCACY |
| 5 CONTRIBUTORS | 14 HOW WE ROLL |
| 6 LETTERS | 42 OUTDOOR TRACKS |
| 8 NEWS | 44 RAISING A RUCKUS |
| 10 SCI LIFE | 47 CLASSIFIEDS |
| 11 EAT WELL, LIVE WELL | 48 CRIP BUZZ |



AUGUST 2017

NEW MOBILITY IS THE
MONTHLY MAGAZINE OF



PRESIDENT & CEO: JAMES WEISMAN
VICE PRESIDENT OF PUBLICATIONS:
JEAN DOBBS

EDITORIAL

PUBLISHER: JEAN DOBBS
EDITOR: TIM GILMER
MANAGING EDITOR: JOSIE BYZEK
SENIOR EDITOR: IAN RUDER
SENIOR CORRESPONDENT: BOB VOGEL
EDITORIAL SUBMISSIONS:
tgilmer@unitedspinal.org

CUSTOMER SERVICE

Toll-free 800/404-2898,
ext. 7203

ADVERTISING SALES

718/803-3782
NATIONAL SALES MANAGER:
MEGAN LEE, EXT. 7253
AD MATERIALS:
DEANNA FIKE, EXT. 7250

PRODUCTION

PRODUCTION MANAGER: DEANNA FIKE

CIRCULATION

CIRCULATION MANAGER:
BEVERLY SMITH
CIRCULATION COORDINATOR:
MARIA KURTZ

POSTMASTER: Send address changes to New Mobility, 120-34
Queens Blvd, #320, Kew Gardens NY 11415.

Subscription rates: \$27.95/year; \$35.95/year in Canada;
\$67.95/year international via airmail.

New Mobility (ISSN 1086-4741), Volume 28, Issue 287, is
published monthly by United Spinal Association, 120-34 Queens
Blvd, #320, Kew Gardens NY 11415.

Copyright 2017, all rights reserved. Reproduction without
permission of any material contained herein is strictly
prohibited. We welcome comments;
we reserve the right to edit submissions.

Periodicals postage paid at Flushing, NY
and additional mailing offices.

www.newmobility.com

(BULLY PULPIT)



Day of Rebirth

This month's cover story is about the out-of-the-box practice of commemorating the onset of paralysis — 10 stories of readers who celebrate the day that changed their lives forever. It has helped me appreciate, once again, the power that our individual stories hold.

But soon after I finished writing the stories, I realized my own date, July 11, was upon me, and I had no plan for celebrating the 52nd anniversary of my plane crash.

In my early post-injury days, I would party, even if alone, a kind of private rebirth day, feeling fortunate to be alive. Later I would invite friends, who were always happy to have an excuse to celebrate anything. In time, the celebrations became a symbolic ritual involving launching and crashing various flying objects — paper airplanes; rubber-band propelled models; larger, more aerodynamic hand-thrown replicas.

This year, due to a time crunch, it would have to be paper airplanes again. At the last moment I invited my daughter, son-in-law and two grandsons to join my wife and me on the deck for guacamole and chips, margaritas, and barbecued burgers. But first I had some deck repairs to do.

My faithful worker-friend, José — who comes each growing season from Mexico to our farm in Oregon to live and help — 28 years and counting — assisted me with the deck repair. When we were half done, I explained to José in my best Spanish that we needed to hurry to finish for the celebration. He looked up, puzzled. "Today's the day of my accident," I said. He looked blank. "I've told you, right? About the plane crash in Califor-

nia? My friend, the pilot, died?"

"Noooh," he said. "California? I thought you were in a war."

Twenty-eight years and I had never told him. Out of respect for employer-employee personal space, he had never asked. So for the first time I told the full story in a foreign language. José listened, rapt, his eyes large. When I reached the part where the pilot, my friend Jim, dies in the plane wreckage, I detached, looked away and stared at a rough spot in the deck.

We completed the repairs and the party began.

The grandboys played in the yard with their dad while I sat with my wife and daughter, now 30, on the deck. My daughter asked if there was an article about my plane crash. "Article?" I said. "Haven't I ... have I ever told you the full story of that day?"

"Not with any details, just that you crashed," she said.

I had told the full story countless times, but never to my own daughter. So I began the detailed, unadulterated version in English. This time, when I got to the part where I heard Jim take his last breath, I stopped, hearing it again, as if for the first time. Then came real tears. Fifty-two years and the emotion still surprises me.

Later, amid laughter, my wife broke out the rocket-copters she had secretly bought for the occasion. We took turns launching them, especially the boys, watching as they catapulted into the sky, then floated safely to the grass.

— TIM GILMER

(CONTRIBUTORS)



AUGUST 2017

CONTRIBUTING EDITORS

MICHAEL COLLINS
 MIKE ERVIN
 ROXANNE FURLONG
 RICHARD HOLICKY
 PRISCILLA MALTBIE
 ALLEN RUCKER
 ROBERT SAMUELS
 ERIC STAMPFLI
 ELLEN STOHL
 BOB VOGEL
 LOREN WORTHINGTON

COMMUNITY PARTNERS

KIM ANDERSON
 CHRISTIAAN "OTTER" BAILEY
 MARTY BALL
 TIFFINY CARLSON
 LAWRENCE CARTER-LONG
 RORY COOPER
 JASON DASILVA
 DEBORAH DAVIS
 TOBIAS FORREST
 JENNIFER FRENCH
 ALLISON CAMERON GRAY
 MINNA HONG
 MARK JOHNSON
 GARY KARP
 NANCY BECKER KENNEDY
 BRITTANY MARTIN
 LINDA MASTANDREA
 LYNN MURRAY
 ASHLEY LYN OLSON
 TEAL SHERER
 TARI HARTMAN SQUIRE
 MITCH TEPPER
 REVECA TORRES
 ANTHONY TUSLER
 KARY WRIGHT



Nancy Gore is a part-time, adjunct instructor of English at Gwinnett Technical College in Alpharetta, Georgia. She has a master's in teaching from Agnes Scott College and an undergraduate degree in journalism from Georgia State University. Prior to teaching, she worked for BellSouth (now AT&T) for nearly 30 years in various positions. In 1980, she was named Ms. Wheelchair America and in that capacity spoke to businesses, schools, and civic organizations nationally on issues facing the disabled community. She has been married for 21 years and enjoys traveling in her Airstream with her husband Mike and their Weimaraner, Beauregard.

Kary Wright has been a quadriplegic since 1986. Country life and living on a hobby farm suits him well, he says. As an animal lover, he spends time daily with his dog, cats and horses. His passions include flying gliders, drones, and radio-controlled aircraft, camping, fishing, hunting, photography, geocaching, raising large trout, and nearly anything that gets him outdoors. He also enjoys writing about his outdoor adventures for *NEW MOBILITY*. His favorite motto is "I'd rather do things than own things," and he believes a great sense of humor is paramount to a fun life.



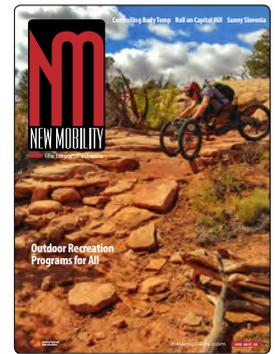
Joanne Smith went on to earn a psychology degree and become a certified nutritional practitioner after sustaining a spinal cord injury at 19. Since then, she has dedicated her career to raising awareness of disability issues. She now runs Fruitful Elements, her nutrition company, working with clients who have neurological injuries, and teaches nutrition classes at The Canadian Helen Keller Centre. In addition, she speaks publically and has hosted and produced two national award-winning television programs that focused on telling in-depth stories about Canadians with disabilities. She lives with her husband and loves to spend time handcycling.

As a restless small-town New England boy, Ned Fielden bicycled west as soon as his undergraduate thesis at Hampshire College was finished. Thirteen years later his bicycling days ended when a hit-and-run accident with a truck paralyzed him from the waist down. Now a tenured librarian at San Francisco State University, he has given academic papers internationally on library history. He is also father to four — two "grown and gone," one at university. He lives with his wife, "a wonderful and enduringly patient woman," in Berkeley, Calif., along with their teenager and three cats.



LETTERS

There is no excuse not to live an active lifestyle.



Anyone Can Benefit

Nice introduction to adaptive recreation ["Summer Outdoor Programs for All," June 2016]. There is no excuse not to live an active lifestyle, and organizations like Bay Area Outreach and Recreation in the San Francisco Bay area, as well as others across the country, can do wonders at modifying their equipment to get almost anyone on a bike, boat or sled. The only downside is figuring out how you're going to get that shit-eating grin off your face at the end of the day.

Eric Stampfli

Via newmobility.com

Re-Experiencing Adventure

Wilderness Inquiry is a fantastic organization that provides exhilarating outdoor opportunities for persons of all abilities ["Summer Outdoor Programs for All," June 2017]. Prior to my C5-6 injury, I backpacked through many mountains and paddled many rivers. When I learned of WI post-injury, I was excited but very doubtful that I was capable of participating in any wilderness activities. However, the many canoe trips I've taken with WI — in the Florida Everglades, Minnesota Boundary Waters, New York Adirondacks and on Maine rivers — have stimulated my pre-injury sense of adventure and allowed me to experience again the wonders of wilderness.

Ed Kopelson

Via newmobility.com

Hybrid Body Cooling System

I've used a battery-powered body cooling system that police/military use in bomb disposal suits ["Temperature Control," June 2017]. Paired with a cooling shirt used by race car drivers (not the type with the pressure prone tubing, but the ones with bladders on front and back instead) I have

been able to be out in open summer sun in 90 degrees-plus weather for hours. Not a cheap bundle, but definitely worth it.

Chase Treadway

Via newmobility.com

Choose the Right Boat

Our Grady White works great for me, even out on Lake Erie ["Accessible Power Boats for Fishing," Motorvation, June 2017]. If you look on YouTube, there are all kinds of boats that have been modified in some way that can give you an idea of where to start with your choice of boat type.

Burnard Barney III

Via newmobility.com

Flying Access Must Change

I have been a paraplegic for 31 years. I flew for business at least once a month for 10 years. I finally gave up flying because of the number of problems I encountered ["The Real Fear of Flying," Everyday Advocacy, June 2017]. I have been through everything from being removed from the airplane because I could not transfer over a non-movable armrest — after requesting a movable armrest seat — to being dropped while in the aisle chair no less than three times. The aisle chair itself is an issue for me because at 6 foot 4 inches and 300 pounds I'm not your average-sized person. Imagine sitting on an aisle chair being that size. It's laughable. Transferring is not the issue because I am very mobile, it is the size of the chair!

The laws and access to air flight are outdated and not acceptable and must change. There is technology out there that will allow wheelchair users to remain in their chairs, yet because the technology takes up two seats, the airlines are refusing to add them to their fleet.

Matt Peeling

Via newmobility.com

The True Alphas

There may or may not be such a thing as "alpha males." If there are, they are not the yapping curs that we misclassify as "alphas" ["The Alpha Male is Back," Raising a Ruckus, June 2017]. They are individuals whose strength of character and personality encourage other individuals to follow. Lieutenant General Harold Moore (Ret.) typifies in one way the true "alpha" presence. He was the commander of the first big engagement in Vietnam. He led his troops into a horrific battle — first one in and last one out. We attended an Independence Bowl a few years back where he received some kind of honorific at half time. In all of the din and halftime baffle gab, when it became his turn to speak, amazingly his command presence quieted the crowd. Somehow it was easy to understand, without even knowing who this guy was, that he was no yapping cur.

I had a similar experience working in a deep mine that was flooding. I was responsible for the pumps that, at the time, were not keeping up. One of our vice presidents, who had decades of experience in difficult and dangerous situations, sat down next to me on the main pump station and inquired as to my assessment of the situation — which I thought was dire. He assured me that he had seen worse and that my decisions would pull us through. He was right. This soft-spoken, kindly old man did not bark like a yapping dog. He led.

When the chips are down, the true alphas are at the front of the pack, taking care of business and the pack. That is hardly an apt description of today's self-serving alphas.

Don Harban

Via newmobility.com

ALLTRACK SERIES



Life is unpredictable...
your power wheelchair
shouldn't be



www.amysystems.com

Phone: 888-453-0311 / Fax : 877-501-8458 / info@amysystems.com



www



f

CMS Makes Complex Power Wheelchair Components Exemption Permanent

July 1 marked a significant victory for power wheelchair users, as the Centers for Medicare and Medicaid Services put into place a permanent policy that exempts complex power wheelchair components from Medicare’s competitive bidding process. The exemptions had been fought for by manufacturers, providers and disability advocates — including United Spinal Association — because they allow for better access to complex wheelchair components often necessary for those with neurological disabilities such as spinal cord injury, multiple sclerosis and cerebral palsy.

“It’s huge for 85 percent of people on Medicare who use power wheelchairs,” says Alexandra Bennewith, vice president of government relations for United Spinal Association. “On behalf of United Spinal, all of our members and everyone who attended the Roll on Capitol Hill this year and previous years, thank you all for doing a great job with keeping this issue alive with policymakers in Washington, D.C. You helped make a difference for your fellow

wheelchair users across the country!”

For those with neurologic disabilities, complex rehab components such as contoured backrests, tilt/recline systems, and specialty controls, in addition to many others, can mean the difference between hospitalization and living independently in one’s community. “Wheelchair bases are useless without the right features on them,” says Bennewith.

Higher payment amounts under Medicare for certain categories of power wheelchairs and related components, known as Group 3 and above were already in effect, under temporary exemptions granted in 2015 and 2016, but the second exemption was set to expire on June 30, 2017. Once expired, complex rehab power wheelchairs and components would only be reimbursed

How the Roll on Capitol Hill Puts a Face on Policy

With over 30 years of experience working on Capitol Hill, Kent Keyser understands the inner workings of policy making and how victories are won by advocates. Keyser, now working for the public policy division of United Spinal, highlighted an experience from this year’s Roll on Capitol Hill to show the indispensable role advocates play and how a simple connection can lead to change.

Keyser had congressional visits set up with Matthew Fritzie, a 24-year-old advocate with C7 quadriplegia who was attending ROCH for the first time. “We had five visits planned,” says Keyser. “The last one we were going to drop by his own House member, and we didn’t have a planned meeting set up with any particular staff member. But because of Matt’s age group, as a millennial, there’s this vast network there, that’s beyond my years, but they keep in touch, and Matt knew the staff assistant.”

Because of this casual connection, the staff member was willing to set up a face-to-face with the congressman’s legislative director, which then led to a meeting with Congressman Kevin Yoder. For his part, Fritzie was excited to be able to share his story — he was injured in a diving accident at 17, before going to college, earning a master’s degree, and finding work in business development for the rehab technology company Power Neuro Recovery — to be able to “put a face to the legislation,” as he says.

With Keyser and Fritzie introducing the congressman to the issues that those with disabilities have in obtaining complex rehab technology — individually configured wheelchairs, with customized seat cushions, tilt functions, headrests, operational controls and other components — under Medicare, Yoder agreed to become a cosponsor for legislation to permanently exempt CRT from CMS’ competitive bidding process. According to Keyser, it was “the quintessential meeting that you could only hope for, and it spoke very highly of Matt’s ability to know the people back home and use that to the maximum ability to push public policy forward.”

It was a perfect example of what the ROCH is all about — using personal connections and face to face meetings to put a human face on public policy and help advance the interests of the disability community.



ROCH advocates meeting with legislators such as Sen. Wyden helped make this permanent policy possible.

at the much lower rate used for standard wheelchairs and components, eliminating the financial incentive for durable medical equipment suppliers to offer complex components and service. The new exemptions permanently remove these power wheelchairs and related components from Medicare's competitive bidding process.

Still, Bennewith stresses that this policy is only a partial victory, as manual wheelchairs and components are still subject to the restrictive competitive bidding payments. "We got a win, but we got a win just for the power wheelchairs, not for the manual. So we need to continue to push for manual," she says. "It's as if CMS doesn't really understand they're discriminating based on conditions, which they shouldn't be doing. So if you have a certain condition that you need a manual chair, then you should be able to get that with the appropriate components."

United Spinal and other advocacy groups vow that they will continue to fight to make complex manual wheelchairs and components exempt from CMS' competitive bidding process.

— SETH MCBRIDE

Oregon State House First to Install Wheelchair Charging Stations

On May 29, Oregon became the first state in the nation to install wheelchair charging stations in its capitol building, granting power wheelchair users a much needed option if their batteries run low.

The stations are the innovation of Darrin Umbarger, a wheelchair user with multiple sclerosis who is a native of Pendleton, Oregon. Umbarger is CEO of Clearview Mediation and Disability Resource Center and a board member of Disability Rights of Oregon.

"The idea came to mind a couple years ago," says Umbarger. "One of my biggest fears as a wheelchair user is being out and about and having my batteries run dead. Not only does this affect me, but it affects my friends and family who are with me. If I need to leave a location to charge, then my friends and family have to leave also."

In 2015, Umbarger approached his local county transportation fund committee about putting eight to 10 charging units around the city of Pendleton to trial the equipment. The committee granted

his request and the charging stations were installed in the city's local parks.

"The stations are equipped with a standard power cord and a basic [24v] charging unit," says Umbarger. "Most individuals in wheelchairs that are high end and need special chargers carry those chargers with them. They would only need the power cord to connect their charger."

After initial success with the units, Umbarger received another disability inclusion grant through the Oregon Office on Disability and Health and the National Association of Chronic Disease Directors to expand the locations of the charging stations. Recently, a county in Ohio ordered and installed the units in its county buildings.

Umbarger hopes that Oregon's decision to install them in the Capitol building is just the start: "Parks, shopping malls, casinos, zoos, grocery stores, fairs, libraries, medical facilities, just to name a few," he says. "These wheelchair charging stations will provide individuals in wheelchairs confidence to be independent in their communities."

— MAUREEN GAZDA

With the Action Trackchair®
**Life's an adventure,
 sidewalks are optional**

- 18 custom colors and two track tread styles to choose from, all at no additional cost*
- Over 20 Customized Options*
- Sold and serviced throughout all 50 states*
- Delivery with personalized instruction on the proper operation*
- Action Trackchair® dealers are available to serve your needs beyond the sale*

**To find a dealer near you visit
www.actiontrackchair.com
 Or call 507-532-5940**

No sidewalks at your favorite destination?
 No problem, the Action Trackchair® loves the challenge of sand, rocks, snow, water and mud.
 With our expansive product line-up, Action Trackchair® gives you the utmost in selection and versatility.



By Tiffany Carlson

“It’s going to be very hard and dark at times, but when you get through it, the success becomes oh so sweeter.”



Moving On the Best Way He Knows How

Seven years ago, Devon Boyd was 19 years old and living in Detroit, Michigan, when his life changed. “I was in a carjacking and shot three times on December 22, 2010,” he says. After his injury, Boyd was sent to Shepherd Center in Atlanta, Georgia, for rehab, and he’s stayed in Georgia since. But it wasn’t easy for him in the early years of his injury as he learned how to live with T10-11 paraplegia.

“After my injury, I was very depressed and down and didn’t want to leave the house,” he says. “What helped me move forward was my whole family.” Boyd was able to stay in the Atlanta-area thanks to his aunt who purchased a new wheelchair accessible house. “For that I’m very thankful. My family still treats me the exact same.”

Since becoming paralyzed, there’s one thing he’s fiercely wanted to prove to society — being in a wheelchair isn’t what people think. “I want to show the world that I can do every-

thing that a person who’s not in a wheelchair can do, but just in a different way.” Boyd is currently in college studying business management. His classes have inspired him to become more active with spinal cord injury advocacy. His ultimate goal is to have a successful YouTube channel.

Earlier this year, Boyd launched this very YouTube channel, titled “DevonDoesEverything.” His channel includes “Wheelchair Wednesdays,” where he shows how he does everything in life. From how to make a bed from his wheelchair to shower chair transfers, he thrives on educating the public about life with an SCI. “It’s going to be very hard and dark at times,” he says about adjusting to life post-injury, “but when you get through it, the success becomes oh so sweeter.”

Watch his videos: [youtube.com/user/SASFreekieD0908/videos](https://www.youtube.com/user/SASFreekieD0908/videos)

OT Gets a Sci-Fi Upgrade

A video game with a purpose — that’s the MusicGlove. Created by Flint Rehabilitation, this one-of-a-kind glove embedded with wires can improve muscle movement by tapping into the neuroplasticity of the brain (the process of compensatory rewiring in the brain that happens after trauma). While this glove can’t restore movement in all quads (you must be able to move your thumb and touch it to another finger to use it), it’s a game-changer for anyone with a lower incomplete injury.

To use the MusicGlove, you must use coordinating software on a computer or tablet as well. It’ll ask

you to move your fingers in high-intensity movements to a melody, just like Guitar Hero, which is the key to how the glove works. Medicare

unfortunately doesn’t cover the MusicGlove

yet, but a home version is available for \$459, and it promises results in two weeks. If you aren’t satisfied, it has a 30-day return policy.

See more at www.flintrehab.com/musicglove



On-Demand Accessible Transport Comes to California

For wheelers in Southern California, a brand new on-demand taxi service (with hopes of spreading nationally) is now available. Called ButterFli, this innovative transportation service utilizes already-existing taxi providers to offer accessible rides on demand. While it was initially created to target seniors, the hope is that the disability population will take it to the next level. Visit gobutterfli.com

EAT WELL, LIVE WELL



By Joanne Smith and Kylie James, authors of *Eat Well Live Well with SCI and Other Neurological Conditions*, eatwelllivewellwithsci.com

Avocados to the Rescue

Did you know that “avocado” comes from the Aztec word meaning testicle? Different theories exist on whether this refers to the fruit’s gonad-like shape (and that they grow in pairs) or their alleged aphrodisiac qualities. Regardless of which reference is accurate, I highly recommend that people with SCI eat more of them.



People with SCI are at risk of dyslipidemia. Dyslipidemia means the fat (lipid) levels in your blood are either too high or too low. Studies demonstrate that people with SCI tend to have low levels of “good” HDL cholesterol; elevated levels of “bad” LDL cholesterol (which contributes to plaque formation in the arteries); and elevated levels of triglycerides (which also contribute to plaque formation in the arteries). These lipid imbalances increase the risk of developing cardiovascular disease and inflammation, the latter of which in turn can contribute to pain, digestive dysfunction and lowered immunity. Avocados contain healthy monounsaturated fats, which not only help lower LDL cholesterol and raise HDL cholesterol, but their good fats support the cardiovascular system and help reduce inflammation.

This love fruit’s high B-vitamin and potassium content also boosts energy levels and supports nerve and muscle function respectively. Amazingly, per ounce, avocados provide more fiber than other fruits — up to a whopping 12 grams per fruit — to help keep your bowel management programs moving smoothly.

Research shows when added to green salads avocados increase the absorption of two key carotenoid antioxidants — lycopene and beta-carotene — by 200-400 percent. So go

ahead and add some testicles to your smoothie, slice them in a salad, or mash them on toast!

Can Avocados Help You Lose Weight?

In one study described on authoritynutrition.com, people were split into groups: “One group was instructed to eat a meal that contained avocado, the other a similar meal without avocado. Then they were asked a series of questions related to hunger and satiety. The people eating the avocado felt 23 percent more satisfied and had a 28 percent lower desire to eat over the next five hours. If this holds true in the long-term, then including avocados in your diet could help you naturally eat fewer calories and have an easier time sticking to a healthy diet. Avocados are also high in fiber, and very low in carbs, two attributes that should also help promote weight loss, at least in the context of a healthy, real food-based diet.”

Avocados on Toast

- 1 small avocado
- 1/3 clove garlic, finely chopped
- 1 tsp. Truffle oil
- 1 slice whole grain toast

Toast whole grain bread.
Cut avocado in half and remove pit.
Squeeze avocado meat onto toast.
Sprinkle garlic onto avocado.
Drizzle with truffle oil (to taste).

EVERYDAY ADVOCACY



By Michael Collins

Paying for Home Access Modifications

Q. *At the moment I am probably like many other people who make a major purchase and then start second-guessing themselves, but I am hoping that some good advice will take away some of my trepidation. As background, I recently changed my status from a renter of apartments and small houses to that of a homeowner. That may not seem like a big deal, but some contributing factors make it big for me.*

I use a power wheelchair and had saved up sufficient money for the down payment on a mortgage, thanks to being steadily employed. I also protected my credit, even when times were tough, so no co-signer was needed. Not surprisingly, there will be several modifications needed to make this home accessible. Even though it is a single-level ranch-style home, it still requires some additional work for basic access, like a sturdy entry ramp, widened doorways and some relatively minor changes in the bathroom. Long term, I would like to remove the bathtub and convert it to a roll-in shower for convenience.

One of the first places I turned for assistance was a government agency — our state vocational rehabilitation agency — but was disappointed to learn that I have accumulated too much money and that my salary alone surpasses their limitation; I explained to them that I need to have enough money to live and sufficient income from my job to pay for things like mortgage payments, medical expenses and food. Even though an accessible place to live would help me remain productive and independent throughout my life, they could not factor that into their calculations. Are there other resources available to people like me so that we can make access improvements or repairs?

— Outside looking in at the moment

Congratulations on the home purchase. As you discovered, few funding options are available from the normal disability support programs. Many states have assistive technology loan programs that can fund access modifications, but they require good credit and the ability to pay back the loan. In your case, rather than taking on an additional monthly payment, it might be wise to seek help from organizations that use skilled volunteers to make these types of improvements on behalf of seniors and people with disabilities. Rebuilding Together is a nonprofit composed mainly of retirees who worked in the building construction trades during their careers. They schedule their work in advance, so contact a local chapter at your first opportunity to fill out an application.

Similar skilled help may be available from volunteers affiliated with local chapters of the Building Industry Association, the Master Builders Association or the National Association of Homebuilders. The Master Builders Association of King & Snohomish Counties, in Washington State, calls their program Rampathon. Their volunteers focus on constructing, repairing or replacing ramps. Don't overlook other organizations representing the building trades, like the Carpenters Union, as they may have similar voluntary programs.

Some of the needed work could go beyond actual construction. Repainting trim or even painting a new ramp can be accomplished by members of a retired senior volunteer program or volunteers from a local church or civic organization. There may be other improvements that involve structural changes, plumbing or electricity; in those cases, be sure that you

have licensed individuals doing the work to protect your investment and avoid problems related to your homeowner's insurance or a local building inspector. That is when some extra money comes in handy, and it may be time to seek financial assistance from people who understand your plight.

Crowdfunding websites like GoFundMe or HelpHOPELive host requests for all types of worthwhile causes. The latter program focuses on medically related needs, a category that includes accessibility, so there may be a tax deduction available to donors. If you have a large circle of friends and family, it might be worth giving it a try. Since there is great value in learning from our peers, I would also recommend checking with the local chapter of United Spinal Association to see what type of resources might be available in your area. Local Independent Living Centers may be able to provide you with some of that same information. If it worked for someone else, it may work for you as well. Good luck, and enjoy your new home.

Resources

- Rebuilding Together, rebuildingtogether.org
- Independent Living Centers, www.ilru.org
- United Spinal Chapters, www.spinalcord.org/chapters/directory
- GoFundMe, www.gofundme.com
- Help Hope Live, helpholive.org
- National Assn of Home Builders, www.nahb.org
- Master Builders Association, www.mba-ks.com/giving-back/rampathon

The Battery Matters



Photo © Scot Goodman



Demanding mobility applications like Power Soccer call for a robust breed of battery. MK Gel Batteries handle the rigors of Power Soccer just as they meet the demanding performance needs of everyday use.

For over 30 years, MK Battery has set the standard for batteries used in complex rehab power chairs. It is no wonder that leading wheelchair manufacturers and providers trust MK as the energy source for their equipment. For long life, high performance, superior reliability and less frequent battery replacements, **DEMAND MK GEL BATTERIES.**



MK is a proud sponsor and the official battery of the United States Power Soccer Assoc. and TEAM USA National Power Soccer Team. To find a team, start a team or get involved in your local area, visit www.powersoccerusa.org



(800) 372-9253 mkbattery.com © MK Battery 2017

Why MK Gel?



HOW WE ROLL

PUBLIC HEALTH SPECIALIST Erin Gildner



At 22, Erin Gildner's life was falling apart when, under the influence of alcohol, she wrecked her vehicle and found herself paralyzed. Her injury led her to public speaking, and that helped her find her passion for public health and the purpose she had been lacking.



Erin Gildner recently reignited her love for horse riding. She's shown with her family.

Passion and Purpose

Today Gildner is the section chief for administration with the Family Health Branch for the Arkansas Department of Health. Her title is a mouthful, and she laughs when she says it. "It sounds a lot fancier than it is," she says. That may be true, but as an administrator, grant writer and manager responsible for improving public health for the millions of people in her home state, her job is no joke, especially when considering how far Gildner has come since she was paralyzed.

In 2002, she had just moved to Arkansas to house-sit for her mom, who had been deployed by the Navy reserves post-9/11. She wasn't in school at the time she wrecked her car, resulting in her T11-12 SCI, and didn't know what was next for her.

Post-injury, she eventually started speaking to college and high school students about the dangers of drinking and driving and found herself hooked. "When I was younger, I never had anybody tell me that I could be injured or possibly kill somebody by drinking and driving," she says. "I just heard a lot of stories about

people getting arrested, and I thought I was invincible.

"I have a lot of people come up to me now and say, 'Wow you really made an impact on me.' They make pledges to never drink and drive. Who knows if that's really going to be the case, but I feel like it makes a big impact. I think it's important for me to give back and to be that voice that I didn't have. I get a lot out of it. I probably get more out of it than they do."

The more she spoke, the more she grew interested in public health and research. "I just fell in love with it," she says. She started working for the state and worked her way to her current position. "When you have an injury, everything about public health just becomes more [relevant] — you get more of an awareness of how the constructed environment affects your health, and the disparities between people who have spinal cord injuries and nondisabled individuals," she says.

Helping others with SCI and educating the public about life with SCI became a mission. "I became very interested in public



CAN'T LIVE WITHOUT:

My Spineray FLEXRIMS have made my life so much easier. They're really lightweight, and unlike standard wheels they have the rubber on the side, and I don't have to touch my tires to get good traction. I've invested quite a few bucks into several pairs.



BACK IN THE SADDLE:

I rode and owned horses up until I was injured, but I just recently got back on a horse for the first time since my injury. It was amazing.



ALTER EGO

Mom on Wheels

Erin is the proud mom of two boys, 11 and 13, and will tell anyone who will listen: "Being a mom and a wheelchair user is awesome." Still, that doesn't mean it is always easy.



“ The other day I was at a meeting for a summer program that my boys are attending and out of probably 1,000 people, I was the only person in a wheelchair. I think it's cool that I get to show people that you can be a participant in your child's life and do everything that they can, just differently.

Still, I do feel like sometimes the chair kind of separates me from other parents. I've become friends with quite a few parents over the years, but the chair makes it harder to develop those relationships. There are some days where I just don't want to fight the fight and I get frustrated, but I try to joke around with them and use humor and that usually diffuses the situation.

”

health and the lack of participation and employment for people who have disabilities, especially those who use wheelchairs," she says. "I was going out and working with all these people in state government, and it was such a novel concept to them that somebody with a disability was working. It started to really get under my skin, and I started to do a lot of research about what I could do."

To that end, she started a successful online community on Facebook for Arkansas women with SCI, and later, United Spinal Arkansas. Despite all the progress, she still sees plenty of room for improvement. "Arkansas is not great when it comes to accessibility," she says. "There are some good pockets, but overall it's kind of behind."

Gildner still finds time for public speaking engagements when she can, but must divide her time between her job, her nonprofit and her husband and two sons. She met her husband in a 12-step program and has been sober for almost 15 years. The life that was "falling apart" couldn't be more happily together, and in a way, it all came together because of her injury.



TRIP TIP:

We recently stayed in an accessible yurt. It wasn't 100 percent accessible and there were a few issues, but I could get around and the view was beautiful.

WHY I JOINED UNITED SPINAL: I helped found the Arkansas chapter because I wasn't happy with the resources that we had here. I wanted to build a broader network of individuals that have spinal cord injuries and disabilities. The guidance and innovative ideas I've received are helping me figure out what we want to do in our state.

SEE AND BE SEEN

with powerful LED fender lights



ALL POWER CHAIR USERS *NEED* FENDER LIGHTS!

LED FENDER LIGHTS ARE...

- Vital for crossing the street at dusk, night time, or during inclement weather
- Essential for visibility in parking lots, movie theaters, and concerts
- Necessary when heading to the bathroom in the middle of the night
- Crucial when transferring in a dimly lit or dark room
- Appropriate when walking the dog...and much more

Q6 Edge® 2.0 with iLevel® shown with standard LED fender lights; also available on select Quantum® bases at a low cost.



QUANTUM®



Dedicated to revolutionizing the power chair experience.

(US) 866-800-2002 • (CAN) 888-570-1113

Visit us on the web: quantumrehab.com



Shoulder of Fortune

Surviving Shoulder Surgery

BY NED FIELDEN

My shoulder had been trying to warn me for a while. While camping I discovered I couldn't get out of the tent and up into my chair unaided anymore. At home, increasingly embarrassed, I'd transfer into the car and fall short, finding myself stuck between my chair and the driver's seat. I'd have to claw my way in via the steering wheel or have some passing frantic AB shovel me into my seat.

I pretended not to notice. I told myself, "Hmm, getting older. Getting weaker. Don't have the old gymnastic timing anymore. Oh well."

I'm a 62-year-old T8 paraplegic — for almost 30 years now — using a fast, ultra-light manual chair. Shoulders are my Sherpas, my twin-turbo locomotives — my divine beings. I worshipped them and

refused to forsake them. But last March the pain had grown so severe that several times, mid-way on my morning commute, I wondered if I would be physically capable of pushing my way to my office. I finally had to face the music: Surgery.

The Diagnosis

At the orthopedic office, the shoulder doc asked me to raise my arms over my head. One went only halfway up. The standard medical poker face failed him. He frowned. Poked around. Examined me. Ultrasounds, MRIs, everything later revealed what he had already known: tear in the rotator cuff, pretty big one, four or five centimeters long.

It turned out the pain wasn't even from the damaged parts, it was all those other muscles back there, complaining about

the extracurricular work they were doing that they weren't designed for. That's the life of a paralytic: Half your body suffers because it is brain-dead, inert, unfeeling and unmoving, absorbing abuse, and the other half suffers because it is collecting time-and-a-half on the life-work time-clock. Try explaining THAT to the able-bodied. The all-too-obvious wheelchair and accompanying mobility issues are just the tip of the iceberg.

I got handed off from the diagnostician doc to the surgeon doc. These guys are like engineers surveying a buckled bridge. They have all the right ideas, the super-duper tools for the job, and couldn't care less if traffic is going to back up for six months if that's what it takes for a satisfying engineering solution. They want to fix it — now.

But what about my life in recovery? Work? The business of getting out of bed? How am I going to pee one-handed? Will I be able to make my own lunch?

He shrugged, "You can do the surgery now or not do it at all and just muddle along. Tears that big don't fix themselves on their own. Your call."

Thinking Ahead, Falling Behind

My wife, Lucy, and I knew from experience that ordering expensive medical equipment often took some time to wend its way through the system. We wanted to get an early jump on the process to minimize difficulties and ensure we'd have the equipment I needed to recover. We contacted the occupational therapist's office, explained the situation in some detail, and made an appointment.

At our appointment, the OT looked meaningfully at my manual wheelchair, knowing that I had pushed my way down the hall and into her office. "We can't order you a Hoyer lift and a commode because you don't need them," she said. I explained

that my shoulder surgery was scheduled for six weeks ahead and that I needed the equipment for then. "But we'd have to train you, and that won't be necessary until you need the equipment. We won't authorize equipment until you have been trained. Things happen if you don't have training," she suggested ominously, looking at my wife as if the first thing Lucy would do, armed with a newly authorized hoist, would be to dump me on my head.

Lucy and I looked at each other open-mouthed. What universe had we just been plopped into? Of course! The Medical Insurance World — a wild disorienting galaxy where up is down and right is left. A place where the use of a commode requires training.

"Besides, you need to talk to the Wheelchair Person, not me," she explained. "I'm in Geriatrics. Why did you schedule with me?" The office had made the appointment with her, not us. She pursed her lips and said, once again, we needed "the Wheelchair Person." We were clearly wasting her time.

We had thought, silly us, that contacting occupational therapy with lots of time

in advance might help with the inevitable delays and Murphy's Law situations that inevitably result. Boy, were we wrong.

We made another appointment, two weeks later, with the Wheelchair Person. But she was sick that day, and the next open slot wasn't for another two weeks. By then, the Day of the Long Knife was imminent and panic was rising.

The Adventures Begin

Surgery went OK. It hurt plenty when the pain medication wore off, but I only needed one dose of pain meds in the days following. I suspect most of us living with SCI have pretty high pain tolerances anyway, so perhaps surgery is not as terrible for us as it is for others.

I had more use of my hand than I had imagined, but for weeks you have to watch your arm like a hawk — no raising it. Anyone who ever does this should get one of those portable, powered "shoulder ice pack" things. You strap it to your arm and run it for a couple hours at a time, cycling ice-cold water around your injury off and on for a few days. It keeps the pain way, way down.

The Safe, Practical and Convenient way to travel wherever and whenever you want.

No more waiting for accessible facilities.

- Different models to meet specific needs!
- Simple to assemble; no tools required.
- Safe and easy to use.
- Seat and footrest heights are adjustable.
- Casters have "total-lock" brakes.
- Lightweight and durable, high-quality aircraft-grade aluminum.
- Compact, convenient, and PORTABLE!
- Won't Rust or corrode; easy to clean.
- Virtually maintenance-free.
- Cushions are available in (3) colors and remove easily for cleaning.
- Optional accessories include: wheeled custom travel bag, positioning belts, slide-out commode tray, 2-way adjustable headrest, and upgraded cushions!



Mobility Solutions

"GO-ANYWHERE" Chairs



30-Day Risk-Free Trial

For Home AND On-The-Road;
When Ya Gotta Go, We Go With Ya!

www.GoesAnywhere.com | Sales@GoesAnywhere.com | 800-359-4021

“All you quads out there — I have gathered complete respect for the moral, cognitive and emotional fortitude you embody every day to deal with an extremely hostile environment.”

But the real adventures began as I recovered. My loaner power wheelchair had only arrived the day before the surgery — after frantic calls between us and OT and the supplier — so I had a way to get home from the operating room at least, but the lift to hoist me in and out of bed (no transfers) didn't arrive until a couple days later. I slept in the chair for two nights. I do not recommend this.

To be fair to the original OT, the hoist did take some getting used to. Simple enough in operation, it took a little while for us to adjust placement and timing so that everything worked smoothly.

Prior to the surgery my general practitioner had warned me, “You will be at high risk for skin breakdown.” I wish she hadn't been right. Within ten days, with all that sitting in the chair with no way to do pres-

sure releases, I had managed to get a really good pressure sore going on my bum. It was off to complete bed rest and a two-front war, both shoulder and seat.

Quad Life

So what is worse than a one-armed paraplegic? A one-armed paraplegic who can't sit. This started a progression that would go on for six months and would ruin what might have been a decent, if prolonged recovery. My life after surgery, for someone who has been close to complete independence since my original injury, was devastating. After the pressure sore developed, I felt like a complete invalid. And not a happy one.

As a para, not much has stopped me. Stairs. Steep grades. Gravel. Pickle jars on the top shelf at the grocery store. But this

was a whole new world.

All you quads out there, anyone who uses a power wheelchair, depends on attendants or other nondisabled folks, you have complete permission to snicker, long and loud, right now. I have gathered an entire and complete respect for the moral, cognitive and emotional fortitude you embody every day to deal with an extremely hostile environment. It was a humbling experience to go from para to quad. People treat you way different when you are in a power chair. Especially if one arm is in a sling. And you look cranky.

My frustration level was intense. Formerly easy tasks, like slicing cheese, buttoning my shirt and typing were impossible or difficult. I missed my regular portfolio of home cooked foods — bread, pizza, lasagna, chilaquiles. Lucy, thank goodness, took over the house-made pesto production, so the family didn't do without that staple during the summer. For some reason, I developed a craving for cilantro.

All the normal things that anyone with a good imagination could think of applied to the shoulder surgery recovery phase — do-

ENABLING PEOPLE WITH DISABILITIES - AND THOSE WHO CARE FOR THEM - TO ACHIEVE THEIR GOALS AND LIVE LIFE TO THE FULLEST FOR 140 YEARS.

HELPING PEOPLE LIVE THE LIVES THEY WANT.

Since 1877, we've created a space in which people with complex physical disabilities articulate their desires, make their own decisions, maximize their abilities, share their talents and achieve their goals.

UNDERSTANDING TODAY.

Inglis is the largest provider of affordable, accessible housing for people with disabilities — with more than 300 units to date, and another 100 in the pipeline.

A MAGNET FOR TRAINING.

Inglis is working with every college and university health program in the area providing internships and hands-on training for the next generation of doctors, nurses, social workers, therapists and more.

SEEING THE FUTURE.

Inglis is emerging as a national leader using technology from eye tracking and voice recognition software to smart home automation to help people with disabilities connect, contribute and learn.

Please visit us at Inglis.org.



**Ability &
Independence.
Redefined.**

**Inglis welcomes
DYANN M. ROTH
as our new President & CEO**

“I am incredibly excited to have the opportunity to join the Inglis community. To learn from and work with the people Inglis supports each day to live as independently and fully as possible.”



ing stuff one-handed, no daily chores like dishes, sweeping, making dinner, inability to move around in a manual chair, etc.

The idea of a decent, even semi-adequate, night's sleep was ruined. Only one position, on my side on top of my "good" shoulder, would work. I would wake at 2, then 4 a.m., my mind racing through unpleasant thoughts. My blood pressure went way up. My appetite went way down. I found I could not do much in the way of carbohydrates. I couldn't eat a whole baked potato. Inactivity took a toll on my muscles and outlook.

Helping Hands

I never threw anything but I cussed a lot. I never broke any crockery or assassinated any medical practitioners (at least outside of my fantasies), but the six months after the surgery, compounded mainly by the skin breakdown, was about the most miserable stretch of time I have had since my initial spinal cord injury.

The first piece of advice I would give to anyone contemplating shoulder surgery is to be sure you have a sound network of

faithful, patient, even saintly helpers in place. In my case it was Lucy who extended the concept of amazing. She solved problems of every description, large and small, put up with my black moods, indulged me and my multiple needs with mercy and tact. I never would have made it through without her. I am astonished, thrilled and grateful that she still talks to me.

On the days when she was gone, I relied on Easy Does It, a nonprofit that provides emergency attendants in Berkeley, California [see NM, November 2016]. They were astonishingly prompt and reliable, getting me in and out of bed, etc. I felt fortunate that my city had gone ahead and set up this program.

Lessons learned: If you are going to do this, you will need a lift to get in and out of bed. It took us two weeks to realize the OT folks had ordered a sub-optimal sling, diagnose its limitations and buy a cross-leg sling at our own expense. You'll also need a loaner power chair to get around. Most importantly, you need to prepare for the drastic, inconceivable loss of independence, which will last a minimum of three months if your damage is

moderate. Make sure you have a good set of activities you can do one-handed for amusement. I read a lot of books, watched the Tour de France on TV from beginning to end, and fumed. I had hoped to be doing some writing, but for the first stretch you can't type with both hands, and have to be careful later. And of course for me, with the pressure sore, it was almost impossible to type when in bed on my side. When would this ever end? Would "normality" ever return?

Looking Ahead

Eleven months later, it almost has. There were some milestones. The biggest one was finally being given medical clearance to transfer, so I could get out of bed and into my manual chair again. That was nearly four months after surgery.

My skin has healed well enough to be back at work, although I have to take frequent breaks off my seat. Transfers are almost back to normal (cars are still hard.) Shoulder flexibility and strength are back to 90 percent (the doc had said he would be thrilled to get me back to 80 percent.) My cardiovascular endurance took forever to return. And I am still improving, although more slowly.

Would I do surgery again? If I could manage my skin condition better, yes. But I would go in a whole lot more prepared. I would expect to be one unhappy camper for six months.

I asked the doctor about the root causes of my injury: was it more the long-term use, all those miles of pushing around? Or was it the shorter, high-stress, intense loads, like transfers? I was trying to figure out how to manage the future, establish the best ways to preserve my arms. I didn't get a good answer. He mostly said "both" and indicated that it would be a good idea to be conservative with my arm usage.

I am still doing daily shoulder stretches and an hour of physical therapy strength exercises three times a week. One day each week I resolve to give my shoulders a complete sabbatical and not do anything more strenuous than a roll to the grocery store a few blocks away. My sense of humor has nearly returned.

But I still have another shoulder. **MI**

Want to learn more? Search for "shoulder surgery" on newmobility.com.

Register! Educate! Vote!

Use your Power!

REV UP!

MAKE THE **DISABILITY VOTE** COUNT

The REV UP Campaign aims to increase the political power of the disability community while also engaging candidates and the media on disability issues.

www.aapd.com/REVUP



SCI ANNIVERSARIES

Why Do We Celebrate Them?

BY TIM GILMER

WHY would anyone want to celebrate the anniversary of their becoming paralyzed? There may be as many reasons as there are causes of spinal cord injury, but surprisingly, a large percentage of people with SCI do find ways to celebrate, or at least observe, remember and reflect. A recent brief NM newsletter survey yielded some interesting results. Out of 94 readers who responded, 65 percent said that marking their SCI anniversary has become a regular event. Ages of survey participants ranged from 23 to 80, and number of years since onset of paralysis ranged from one to 66. Most importantly, a majority of those who said they marked their SCI anniversary regularly also said it has been helpful to them.

But why? What accounts for such a significant number of SCI survivors' positive attitudes about a life-changing event that began as a catastrophe? A team of researchers from the psychology department at the University of North Carolina, Chapel Hill, has put forth a theory known as Posttraumatic Growth, which explains such counterintuitive behavior. The simplified version is that facing trauma and surviving personal catastrophe can provide us with opportunities to appreciate life and be grateful for what we have, even if it takes years of struggle, frustration, and periods of depression. In fact, the greater the struggle, the more fulfilling the ultimate reward can be.

Our survey disclosed a number of ways of observing SCI anniversaries, from all-out parties to recounting memories with close friends and family, or simply by remembering and reflecting when alone. One thing links all of the stories: The SCI experience cannot be separated from the date it happened. No one ever forgets that day.

Here are 10 stories of SCI survivors, each with a unique perspective, that provide real-life glimpses into just how people recover and grow following a spinal cord injury.



BROOK MCCALL, 37

Fell from a balcony
15 years ago:

**"I get my own holiday,
it's awesome."**

Anniversary date:
September 25

ARIES:



September
25

“THE DAY before my senior year at college I was climbing on an apartment balcony, lost my grip, fell backwards, and landed on my head.” After rehab at Craig Hospital in Denver, she moved to a small group home in Los Angeles. “As a C4-7 quad, I wanted to be independent but was only there for 45 days. I was not good at having caregivers tell me what to do, and there were weird dietary rules. This was not independence.”

So she moved back to her childhood home in San Luis Obispo, California, but ran up against the cultural roadblock that often awaits newbies with SCI: “Others couldn’t see I was the same person. My mom wanted me to stay home so she could take care of me, but I wanted to go back to school. I wanted to do

more. Prior to my injury I had lived in Chicago and worked at Bloomingdale’s. I didn’t want to get stuck in a small town. I wanted to prove to myself and others that I could do this, I could handle my future as a quad.” She went back to college and eventually earned her master’s degree in public health at the University of North Carolina, Chapel Hill.

“I’m really glad that in that first year I had the drive to move forward,” she says, “because you can get stuck being too comfortable. It’s part of being an adult, someone who goes and takes chances.”

Currently she is in between jobs, living in Portland, networking, volunteering, writing a newsletter and running

a Facebook page for Oregon Public Health Association. She also enjoys the time she spends with friends, especially on her special day: “On my anniversary I’ve always gone out with friends, celebrating being alive, feeling grateful and appreciative. Life is short, and it’s my day. I’ve worn a tiara or two on that night. On the first one I wore a feathered boa. The main thing is to enjoy life.”

But what about when life throws you a curve?

“Even when things aren’t exactly what I want, I use the anniversary to look back and take stock and go forward.” It’s the day she gets to feel proud of herself, she says. “I’m stronger now, my confidence better, my friendships deeper.”

TYSON GENTRY was injured on Good Friday in 2006 when a teammate tackled him during an Ohio State University spring football practice, becoming an instant C4-5 quad at 20. Besides having to give up his NFL dream, he worried about his ability to be a husband and father. "I had always looked forward to getting married and starting a family, but if I was going to be in a chair the rest of my life, what kind of woman would want me?"

TYSON GENTRY, 31

Football injury 11 years ago:

"At the time of my injury, it had always been a dream of mine to play in the NFL. Now I try to look on the bright side."

Anniversary date: April 14

In his senior year, 2009, he ended up sitting next to a girl who was late the first day and had to sit in the back at the wheelchair accessible desk. "We hit it off right away. Megan was so comfortable around me, I was amazed at how easy it was to be around her and not be worried about everything that came with being in a wheelchair. We started dating, were engaged a couple years later and married two years after that."

Next came the dream of having a family. "I was really worried if my sperm would be healthy enough to conceive. On top of that, if we would have to do in vitro, it would be really expensive and complicated." Fortunately, his sperm passed muster and Megan got pregnant after insemination.

Gentry is quick to credit their good fortune to a higher power: "The fact that Adam was born on Easter Sunday says it all. I feel like he was a gift from God." Out of gratefulness, in 2014 Tyson and Megan created the New Perspective Foundation to provide financial support for travel expenses for families and friends of newly injured SCI survivors.

Today Gentry sees his own injury in a positive light. "I wouldn't have met Megan if I hadn't been injured. I consider her and my son the biggest blessings in my life." Now they are trying for number two.

It's easy to see why his SCI anniversary has always been an important day for him, and he has a favorite: "Megan, her friend Cassie, my mom, father-in-law and mother-in-law surprised me with a ninth anniversary cake," he says, "complete with wheelchair symbols. Good things can come out of bad situations."

ASHLEY MUNROE, 28

Gunshot wound 5 years ago:

"The day he shot me turned out to be the day I was saved from him."

Anniversary date: July 3

"ABOUT FOUR YEARS

into our relationship my boyfriend started using meth and things got really violent. There were many breakups and finally I said I'm done." He started stalking her and one day saw her driving. "He clipped the rear end of my car, pulled over, and came up to my window. I stomped on the gas and he shot me. I was instantly paralyzed, so my car coasted downhill, I lost consciousness and drove through a house."

He followed her, pulled her out of the car, and tried to make her stand up. "He said he was sorry, why did I make him do this? When the cops came, he lied and said he was with me in the car and someone came up and tried to rob me."

When she was intubated, with her lungs collapsed, he showed up at the hospital again, where the cops arrested him on outstanding warrants for knocking her teeth out the year before. Unable to talk, she was able to write the first letter of his name when questioned, and the cops made the connection instantly.

"It was so bizarre. The moment I woke up in the hospital, I knew I was free of him, and I was OK with it" [what happened]. "Don't get me wrong, I do get down and I'm in a wheelchair and all [C7-8 SCI], but I have grown so much. My relationships with friends and family have gotten better now that he's not around, and I have come to know that I'm a strong person. And if this can't hold me back, nothing will."

In the hospital the chaplain had read her the last rites. "Now I call the anniversary of my injury my re-birth day. I got a second chance. The day he shot me turned out to be the day I was saved from him."

She's now a full-time community college student working on her associate's degree,





hoping to help others who find themselves trapped in abusive relationships.

ON THE VERY

first anniversary of the motorcycle accident where he sustained his SCI, John Casey threw a party to remember: “We invited the entire family and friends, about 100 people, and celebrated “The First Year Survival Anniversary Party.”

Most SCIs result from traumatic vehicle crashes. What was so momentous about his?

“I was home, on my motorcycle, going to ride to a car show, just a short trip. My 3-year-old daughter came out to see me and gave me a hug and a kiss. The last

thing I remember is seeing her in that new, pretty dress.”

On the ride to the car show an oncoming car turned in front of him and ran right over him, paralyzing him at the T11 level. He lay unconscious in the hospital with 20 broken ribs, both lungs punctured and a traumatic brain injury. On his 11th comatose day he went into cardiac arrest. In a last ditch effort, doctors induced hypothermia in what is known as the arctic sun treatment. They redirected his blood flow in an effort to save his brain function, organs, and his life — and they told his wife that even if he made it, his brain function was in doubt.

“When I woke up 40 days after being run over, my daughter’s photo was on the wall. She was wearing the same dress she wore that day. I knew I had so much to live for, for my beautiful wife, Christina, and our wonderful twins, Marlena and Johnny. Now I celebrate life every July 11. I am a very fortunate person.”

Casey’s gratefulness can be seen in what he has accomplished in just four years. He joined a small local support group, became chairman of the board and spearheaded a fundraising campaign that raised over \$100,000 last year. It is now the Rochester Spinal Association, a United Spinal chapter. He retired from his position as a successful construction executive and devotes his time and resources to the chapter.

“I was a workaholic in my previous life. I would still probably be a workaholic. But my injury has forced me to enjoy my life. And I am loving it.”

JOHN CASEY, 61

Run over by a car when on his motorcycle four years ago:

“They told my wife I might not make it, to prepare herself for the worst.”

Anniversary date: July 11



ALEX AITKEN, 62

Surgery went bad just one year ago:

“It’s always in the back of my head that this is too difficult. But I do see signs of improvement.”

Anniversary date: June 13



ALEX AITKEN

was looking forward to retiring last year when she underwent spinal fusion surgery to relieve pain from scoliosis. All seemed much improved when she was discharged. But two weeks later her osteoporotic T2 vertebra instantly fractured and her legs went out from under her.

Back to the hospital for repairs. But her spinal cord had been damaged and she was going downhill. She developed a UTI, then things went from bad to worse. “I got paranoid, lost my mind, started hallucinating and had no idea what was going on,” she says. Her insurance would only cover uninterrupted circumstances, so they cut her rehab short and she ended up in a nursing home for six weeks.

Once home, she ran into a common problem that often faces people with new SCIs — difficulty getting around. “I couldn’t even get out of the house on my own,” she says. She has to hire personal care attendants out of her own pocket. What bothers her most is the tremendous letdown she has experienced from looking forward to a leisurely retirement to dealing with paralysis every day.

But something inside her is beginning to fight back and good things are starting to happen. She went online, became a member of United Spinal and also found useful information on the Reeve Foundation website. She says her strength is coming back and she wants to find a way to access private rehab to make up for what her insurance wouldn’t provide. She thinks a power assist chair might help. A volunteer group came and built a ramp and deck onto her house. “I was astonished,” she says.

Now she is just one year

post-injury. Did she celebrate her first anniversary?

"I invited a friend over to watch the same movie we were watching on the day my legs went out from under me. You'll laugh when I tell you what it was," she says ... "an old Vincent Price horror movie called *The Tingler*. About a creature that lives in your spine and kills you."

Now she is making a list of things that are getting better, and it's growing, day by day.



ELIZABETH SHANKS, 43

Car accident 23 years ago:

"I make cupcakes on my anniversary and celebrate it as a new birthdate."

Anniversary date: March 3

AT 20, ELIZABETH Shanks, from Niles, Ohio, was riding with a friend when the car in front of them braked suddenly. They skidded on black ice, her friend lost control and hit a telephone pole. Following emergency surgery for a T12 SCI and rehab, she was discharged to her home, where she lived with her mother and stepdad.

Always an outdoorsy girl, she found that wearing a back brace and sitting inside all day did not suit her. "It took a while to get a ramp built and I didn't have a car or know how to drive with hand controls. The ambulance driver who drove me to outpatient rehab had to come inside and help me out."

Over the next two years she took college classes and a secretarial program. Then she met Jack. "He came walking up wearing a cowboy hat, boots and a duster." Not being shy (she rode a hot pink wheelchair), she asked him out. Twenty years later, they are still together, 16 years married.

At 30, she went off the pill, thinking it was time to start a family, but nothing happened. "I was starting to think I might not be able to have a baby." Then — surprise! — she conceived when she was

37. All went well until her eighth month, when she got a UTI. Docs treated it but it returned and spread to her kidney. Then she became septic. "If I had known how much danger I was in, I would have been very worried."

Doctors did a C-section and baby Justin entered the world after seven years of trying. On her next SCI anniversary following his birthday, she decided to go beyond her usual celebration routine of making cupcakes at home. "We went out to eat and I had my favorite seafood dinner," she says.

Today, not only is she a wife, a mom, and an 18-year employee of Hillside Rehabilitation Hospital, she is still that country girl. "I drive an Arctic Cat four-wheeler, hunt deer, pheasant, turkey and

duck, and ride horses for therapy." She also likes to go handcycling with Justin. When March 3 rolls around, she'll be busy in the kitchen making cupcakes. And maybe have a shot or two of Wild Turkey. "I'm lucky to be alive," she says.

WES HIXON, 32

Roadside bomb in Iraq War nine years ago:

"Ever since I made my peace with the Lord, all is OK."

Anniversary date: February 8

HE DOESN'T TALK about it much, but Wes Hixon lost four of his Army buddies when the bomb went off that day and his spinal cord was injured at T2.

"Oh my gosh, I was brokenhearted, I tried to be positive, but inside I was dying," he says. Like many others who experience trauma and near-death, he had to battle PTSD. "The problem was not so much drinking, I was just really depressed and sad, thinking about the future, wondering am I going to be like this when I'm 60."

Then something happened four years after his discharge. "I couldn't take the weight of the situation any more and was lying in bed. I started reading the Bible and it came alive in me. This feeling came over me and my heart started beating real fast. It was the first time I cried like that, and ever since that moment I've been brand new."

That was five years ago, and although he still has complications from his SCI, he no longer worries about the future.

In late June, when we talked, he was in the hospital with an open wound on his sacrum. Doctors told him an MRI confirmed the wound had involved his bone. They would have to operate. "It isn't flap surgery. There're going to go in and clean the area and the bone. I'm getting fluids now. They'll put me to sleep, but I'm not worried about it."

His plans after he's discharged from the hospital? "I'm going to get my permit and drive my truck around and hang out with my older brother."

And when his anniversary day comes



around next February 8, what will he do? “I’m not sure. A couple of years ago we released some balloons just outside my house” — in memory of his fallen brothers. “I’ll be keeping everyone in my prayers, paying my respects. Giving thanks for my life and praying for the guys that I love.”

MATT BARKLEY is looking forward to the 20th anniversary of his becoming a C6-7 quad. This year, October 18 will be a milestone, the halfway point, the day his nondisabled life and his life as a quad will be equal in length. It is an important milestone for SCI survivors.

“The big halfway point,” he says. “From that day forward, I will have spent more time in a wheelchair, a date I can’t ignore. At first the anniversary was depressing, a period of adjustment, accepting my disability and the thought that I would never be like I was before the injury.”

When he was injured at the age of 20 he didn’t want to have a career in anything having to do with disability (marketing was his dream), but he never got

MATT BARKLEY, 40

Fell out of a window 20 years ago:

“A mentor of mine introduced me to the concept of ‘Break Your Neck Day,’ a re-birthing day.”

Anniversary date: October 18



to do an internship. He eventually got involved in peer counseling and found that it wasn’t so bad. From there it seemed like a natural evolution to the independent living movement, where he began to enjoy the connections. He worked for the National Council on Independent Living in Washington, D.C. and as an ADA coordinator in Fairfax County, Virginia. But his journey to becoming a truly committed advocate wasn’t complete until he became involved with ADAPT.

As the anniversaries rolled by, sometimes he ignored them, other times he was just too busy to notice. Then one day John

Hudson, a mentor of his, introduced him to the concept of calling his anniversary “Break Your Neck Day” — a day of acknowledging how his injury had laid bare a meaningful path for him, a kind of re-birthing. “John was a transportation advocate who took great pictures. The *Washington Post* did a story on him and ran a photo he had taken that illustrated the stupidity of the term ‘wheelchair bound.’ — he was tied up and bound to his chair.”

This month he and his wife will be celebrating a different milestone, five years of marriage, as well as exploring a new frontier: having children.

WheelAble

Collapsible, wheel-able, for the spontaneous traveler

Rolling commode and shower chair that folds compactly and packs into a carry bag. Fits over most standard toilets, or rolls into shower stalls.



1-888-347-4537 | www.clarkehealthcare.com

BEACH MOBILITY Solutions



DIY with WheelEEZ[®]
Beach Conversion Kits for Walkers and Wheelchairs



www.wheeleez.com



**SHELLY LOOSE, 56, and
KEN LOOSE, 59**

Separate vehicle accidents:

**“Our anniversaries – they’re the days
that made us who we are today.”**

Anniversary dates: May 14 (hers)
and May 27 (his).



THEIR EMAIL ADDRESS

says volumes: quadsinluv@aol.com. They were married on “Live with Regis and Kathie Lee” 23 years ago.

They met at Mary Free Bed Rehabilitation Hospital in Grand Rapids, Michigan, when she was 30 and he was 28. “I was back in rehab for a ‘tune-up’ and he was new to SCI. I was able to help him learn a few things.” After rehab, they went their separate ways, but their respective spouses, both of them, left them. Ken contacted a physical therapist and got a message to Shelly that he wanted her number. From

then on they have been inseparable, but their path as married quads, while rewarding, has not been easy.

Ken had two children from his previous marriage, but they didn’t want to stop there. “We conceived Katherine (named after Kathie Lee) in 1997, but we got lots

of flack,” says Shelly. “We even had family move out of state because they disapproved and thought they would have to take care of the baby. We got turned into Child Protective Services before we even got home from the hospital.” But the C5-6 quads, with help from a parenting class at Mary Free and an array of adaptive equipment, did all the parenting themselves. However, when Ken had dual shoulder surgery five years ago, they had to bring in part-time help.

Since 2007, Shelly has loved her role as president of the Ms. Wheelchair America pageant in 31 states. “It has given me purpose and fulfillment.” Both of them also do mentoring at Mary Free Bed.

Every year they celebrate their combined “Happy Quadaversary,” but this year was special. “It was my 30th,” says Shelly. “We got out my halo and showed it to the [now grownup] kids and went through old photos and really remembered what it was like, how we felt back then. These are things we thought our kids would know about, but they didn’t. To them, we’ve always been just mom and dad.”

OPEN SESAME

REMOTE CONTROL DOOR SYSTEM
Automatically opens and closes a door ...from your wheelchair!

- Releases a locked door
- Allows remote and manual use of door
- Simple to install
- Adaptable to almost any door
- Portable, take it with you when you move
- Keypad for attendant entry

Built-in battery back-up!

Invest in your own mobility!

CALL FOR OUR FREE BROCHURE
1-888-973-7263
www.opensamedoor.com

24 Years of Excellence
OPEN SESAME DOOR SYSTEMS

BRAND NEW You Must See!

WHEELCHAIR ACCESSIBLE MOTORHOME

NEWMAR

Call Us for Special Introductory Pricing!

800-635-7008
email: **Ricky Dee**
RickyD@dickgoesrvworld.com

14590 Duval Place West, Jacksonville, Florida 32218

DICK GORE'S RV WORLD.com

Dick Gore's RV World



JOSE HERNANDEZ, 37

Diving accident:

"I like being part of something that is greater than myself."

Anniversary date: June 19

I TALKED WITH JOSE

Hernandez just days after his latest anniversary, when he had posted this on Facebook along with a photo of the beach where he sustained his SCI: "22 years ago today I broke my neck at the beach — it's been a long hard road but I have to keep pushing forward and make everyday better."

Publicly declaring his SCI anniversary like that was a first for Hernandez.

He was just 15 and full of adrenaline when he ran into the surf at Orchard Beach in the Bronx and dived in, instantly becoming a C5-6 quad in 1995. Following rehab at Mount Sinai Hospital, he returned home to live with his mother, brother and sister in a first-floor apartment with limited access.

By 18 he had gotten his high school diploma through a home study program. After moving into his own apartment and getting his associate's degree from Bronx Community College in 2003, he went on to get a bachelor's in computer science from St. John's University.

About three years ago he became involved with the Balance Initiative Program through the New York State Department of Public Health. "It was supposed to be a one-year grant," he says, "but it only lasted for six months. I was disseminating information to people in nursing homes and helping them get into community-based living. Luckily, the company I was working for saw my value as an employee, so they hired me when the grant ran out."

This April he took a job with United Spinal Association, but it wasn't his first contact with United Spinal. He participated in the first Roll on Capitol Hill six years ago. That event turned out to be a

huge influence in his life, a milestone that marked his journey of personal growth.

"Up until that time, I didn't really celebrate my anniversary. It was more like a mourning experience. But after passing the 'halfway point' [15 years disabled/15 years nondisabled], I embraced my identity in the disability community."

Embracing his identity at ROCH turned out to be a profound emotional experience. "I teared up, feeling the value I had both as a person and as a representative for others." The lesson he took away from that day seemed all the more important because of what he had to go through to learn it: "I like being part of something that is greater than myself." **MI**

NOT EVERYONE 'CELEBRATES' THE DAY

A sampling from our anonymous survey shows there is no one way people mark the day:

"I think about it, but I don't say anything to anyone."

"It's neither good or bad, it's just the day I started a new way of life."

"The biggest help was the year I missed it — like year 17 or 18. It made me realize it's just another day. Not that it's not a special day. Just not one to ponder the what-ifs."

"I keep on going, as it does no good to just stay in bed ..."

"I find it therapeutic to do some reflection. It's an important day. It's a day that changed the course of everyone's lives. Not just my life, but my family's lives, and my friend's lives."





Enjoy driving with both hands on the wheel



kempf-usa.com
1-888-453-6738



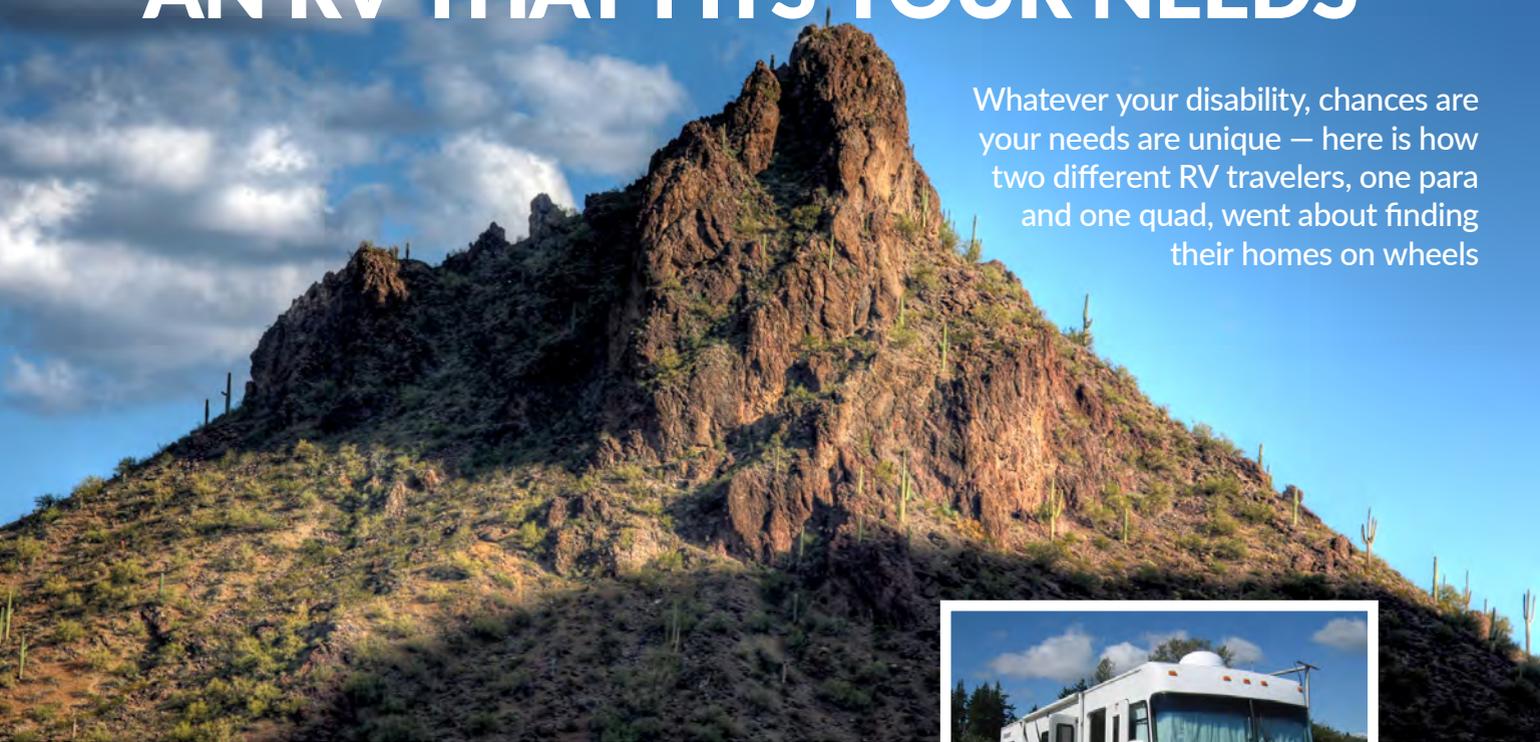
DARIOS digital accelerator ring and main hand brake

- Lifetime warranty
- Free at home pick-up and delivery and free at home service
- DARIOS is VA accepted.

WANTED:

AN RV THAT FITS YOUR NEEDS

Whatever your disability, chances are your needs are unique — here is how two different RV travelers, one para and one quad, went about finding their homes on wheels



FINDING ATHENA

BY WILL SIERRA



Framed by the bright blue Sonora Desert sky, Picacho Peak gazes down upon my wife and me as we walk and roll along the expansive desert landscape around Tucson, Arizona. We look downslope from the road toward the campground and see our motorhome with her sun, rain, and wind-weathered exterior sitting among the saguaro cacti. After a three-month journey in which she has taken us more than 2,000 miles from our Pacific Northwest home through countless scenic places, we agree that this is the motorhome for us.

The purchase and the decision to go on the road was the result of considerable thought and research, mostly online. We wondered if it was practical to invest in a motorhome and travel for several months, given the additional considerations of my having a spinal cord injury and using a wheelchair. Eventually, after

talking with other motorhome owners and learning about their travel experiences, we got a sense of the features that might make our travels easier and decided to go through with purchasing.

The Setup

We searched for an RV with capabilities that met our specialized requirements for the daily tasks that needed to be accomplished. To maximize resources and limit the number of modifications required, we focused on finding a used RV that already included most of the accessibility features we wanted. Our short list included one level floor with wheelchair access from the front of the motorhome to the back, roll-in shower, bed with a height that worked well for transfers, secure upfront passenger seating for a power wheelchair, and a wheelchair lift. In addition, there were

features of interest that most RVs include, such as a kitchen with a sink and refrigerator, heater, air conditioning, electrical outlets, etc. When visiting new places, we wanted to enjoy the campgrounds and the local area, so the motorhome needed to be able to tow our Honda Element.

After months of searching online, we found a 36-foot long, 22,000-pound motorhome in Georgia. We eventually named her Athena. Built by Thor Industries in 2002, she is a V10 powered Windsport [see sidebar, page 34]. She was already accessible, met most of our requirements, was sufficiently large and powerful to tow a vehicle, and had enough room inside for a wheelchair to maneuver fairly easily. Based on the online photos, the motorhome's condition appeared to be good. We called the owner, who seemed nice, asked many

Continued on page 32

CONSIDER AIRSTREAM RV TRAVEL

BY NANCY P. GORE

I travel with my hotel room behind my SUV. Actually, it's not a hotel room; it's an Airstream, and I camp with it. Well, that is if you consider traveling with everything, including a microwave and a flat-screen TV, actually camping.

I was born in 1958 with spina bifida. My parents pushed me to always do my best and live life to the fullest. While I worshipped my father in almost every way, the one trait we did not share is that he wanted nothing to do with the great outdoors. My mom grew up spending summers in the Adirondacks, but she was never able to inspire my father into leaving the comfort of central air and heat. Despite the fact I had never been camping, I must have inherited my mother's passion for it, so decades ago I got it in my head that my bucket list included traveling in an Airstream.

For years I pored over Craigslist and eBay searching for the perfect Airstream. It was all part of the grand plan: After working for nearly 30 years for BellSouth (now AT&T), I would start a second career in public education with summers off to travel. At first the idea was

to keep costs low by refurbishing a used Airstream. That all fell apart the day my husband, Mike, and I went "just to look" at a new one. After climbing around several different models, next thing you know I'm signing on the dotted line, committing myself to payments for the next 15 years.

"Let me get this straight," said my banker father. "You've never been in a trailer before. You don't even know anyone who owns one. You've only been camping twice in 50 years, in a tent, and didn't like it. Your salary has been slashed in half. You've just paid off your house and now you go out and buy this? What are you thinking!"

But I knew what I was doing. I had spent too many nights in wheelchair accessible motel rooms that were hardly wheelchair accessible. Since 9/11, I have not enjoyed invasive TSA body searches required to board the airplane, and I was done with schlepping luggage across hectic airports. You know the drill: You spend sleepless nights at the airport waiting on delayed flights; you arrive in Los Angeles and your wheelchair lands in Poughkeepsie;

you stress the entire flight wondering whether or not your wheelchair will be in one piece after a flight — even if it did land at the same airport you did.

But I loved the adventure of travel: new cities, new terrain, new restaurants, new shops. I also craved the great outdoors with bonfires, babbling brooks and the occasional deer sighting. Having an RV

Continued on page 33



Gore pulls herself up into the sleeping area, unless her rotator cuff is bugging her. Then, she'll use her Para Ladder.



Gore's wheelchair stays outside as she scoots and lifts herself when inside the Airstream.

FINDING ATHENA

Continued from page 30

questions, and made an offer conditioned upon its passing a pre-purchase inspection. The offer was accepted. After the purchase, since both of us were working at the time and neither had driven a motorhome, we hired a motorhome professional to drive Athena the 2,800-plus miles from Georgia to her new home in the Pacific Northwest.

The scale of Athena impressed me from the moment she arrived. Rolling from the back to the front of the motorhome, I began to believe we actually could live in this 250-square-foot rolling home for several months, or more.

As nice as we thought Athena was at the time of purchase, we wanted to make a few changes to improve her usefulness for our planned trips. We added a wheelchair docking system and a more durable tile floor. We removed the wardrobe and moved the bed slightly. Thus, rolling next to the bed, in the transfer zone, I am about five feet from the back window, where the nearly 270-degree scenic view from three glass windows can be appre-

ciated. We also installed an inverter, increased the number of batteries from two to four, and added a propane heater.

Before we camped hundreds of miles from home, we wanted to feel comfortable living in the RV, and managing the plumbing system, and confirm that the bathroom setup worked well. We used the local campgrounds as a testing ground. We realized managing the plumbing was less difficult than expected. The key was figuring out a process, then practicing and refining it.

The RV bathroom has a roll-in shower with a hand-held showerhead. The shower floor is slightly sloped toward the drain, and there is a slight bump on the floor to keep water from flowing out of the shower that 5-inch shower chair casters can roll over. We found both the temperature and water pressure to be good. The bathroom sink and toilet are a few feet from the shower, right across the hallway. This setup works well, allowing us to avoid campground bathroom facilities.



The RV's bathroom setup works well enough to completely avoid using campsite facilities.

Living the Life

After several weeks on the road, we really appreciated the conveniences of extended travel in accessible comfort. In the past, we had alternated between the cramped quarters of a van for shorter camping trips and the more comfortable but costly alternative of traveling via car and staying in motels. With car and motel travel, at each stop there is the unloading

Continued on page 34

Lift & Care® Systems as versatile as a pair of hands

SUREHANDS® transferring solutions are designed to enable users and caregivers to maximize abilities and function.



SUREHANDS® launches new and innovative versions of their Ceiling Motor, Body Support and Handi-Slings. See how these advanced solutions can assist you...

SUREHANDS LIFT & CARE SYSTEMS

1-800-724-5305

website: www.surehands.com

Call today for your free catalog or to request a free home demo.

- activities for daily living
- bathing • hygiene care
- repositioning • transferring
- accessing pools & spas
- exercising, ambulating and standing
- a back-saver for caregivers

CONSIDER AIRSTREAM RV TRAVEL

Continued from page 31

allows me to have the adventure without the inconvenience. Plus, the best part is that no matter where we go, I never again have to worry about bathroom access as long as my RV is with us. That alone is worth its weight in gold.

Choosing the Right Airstream

Airstreams come in a variety of sizes and configurations. We chose the 23-foot Safari because it was small enough to park in someone's driveway, but large enough to sleep four, which enables us to travel with our 90-pound Weimaraner and our grandchild. Our model has an L-shaped couch and no dinette, which gives me the floor space I need to scoot around. I don't usually take my wheelchair into the Airstream because it takes up too much room and would make moving around more difficult for my nondisabled husband. And I'm used to scooting and lifting myself — I've done it since childhood.

The stairs to enter the trailer fold up, making the transfer from wheelchair to the floor of the trailer virtually even. Once I'm in the trailer, I generally have the strength to pull myself up on the couch or bed, but if my rotator cuff is giving me problems, then my Para Ladder (paraladder.com) allows me to climb up on the couch or the bed with ease. I can also use it to reach the sink and the stove, but we generally tend to cook outside the trailer. What I also really like is that the toilet and the shower are both literally next to the bed. Mike built a platform that he made from a discarded desk, so I can easily transfer from bed to toilet to shower. He also threw in several grab bars around the bedroom/bathroom area, making the process of moving about even easier.

Although Mike does all the work of setting up the trailer, such as connecting the water, sewer and electricity, there isn't any reason why I couldn't do it — other than sheer laziness on my part. Everything is within reach. Technically, I could even tow it myself, but he prefers to do all the driving. Most state and federal campgrounds have wheelchair accessible sites that tend to be more level, a bit wider, and sometimes easier to traverse because the sites are concrete instead of gravel. Almost always there



The best part of traveling is the people Gore meets.

is a wheelchair accessible bathroom and shower, if for some reason I want to use it instead of the one in the trailer.

We've had our trailer since 2008 and have put over 50,000 miles on it. We are on our third Weimaraner since we started this adventure, and I am now working as an adjunct instructor at a technical college, teaching only two days a week to give us more time for travel. We've been up and down the East Coast, covered virtually every inch of Florida and have driven as far west as Yellowstone and the Grand Canyon. We've spent as much as 36 days at a time in the trailer so far without any issues, often spending precious little time actually in the RV during the day because we're off adventuring.

More Than Just Travel

The best part of traveling is the people we meet. I love rolling around a campground and stopping to talk with people, finding out where they've been and what they recommend. It's great to think that the friends we have made will be people we will travel with for years to come. What I love about our friends is that I am one of the crew and am included in whatever the group wants to do. My disability is never an issue. Kayak? OK, I'm in. Shop? Got my wallet, let's go. Visit the brewery? Absolutely! When I visit other people's trail-

ers, I will typically sit on the floor. Oftentimes, they will sit on the floor with me.

While Mike and I have made several trips on our own, we are also members of a great Airstream club with over 160 different members with whom we travel (not all at once!). Recently our club went to Savannah, Georgia, and the person who coordinated the event found a History of Savannah Bike tour and made sure before he booked it that it could accommodate someone who uses a chair.

Traveling with an RV is a great way to travel, especially for people like me who encounter too many obstacles with traveling through airports and hotels. As a disabled person, I can stay at a national park for half the cost, so some of our trips cost as little as \$15 a night. Walmart and Cracker Barrel also allow people traveling with RVs to spend the night in their parking lot for free.

The bottom line is it feeds my soul to spend the night sitting by the fire with friends and star gazing. I love the camaraderie of our club and am thrilled that I will be president of it in October 2017. As president, I will be traveling to the International Airstream convention in Salem, Oregon. Since we live in Roswell, Georgia, this means we will be driving completely across the country. That will be the adventure of a lifetime. **MM**

FINDING ATHENA

Continued from page 32

process of moving luggage, supplies, any food, etc., to the room, and the reverse process when leaving. Although many motels are very accessible these days, sometimes accessibility is lacking, which can add time and effort, and be problematic.

When traveling via a motorhome, we are always at home, taking along the personal space we've created — a homey comfortable interior — with our clothing, food and supplies. We're assured of a dependable accessible shower and bathroom. Having a kitchen with refrigerator and cabinet storage allows you to stock food focused on your tastes and any dietary considerations, and being able to stock two weeks or more of food allows you to shop at your convenience. With storage cabinets, managing medical supplies is simplified when compared to suitcase storage. If a need arises to order medical supplies

while on the road, medical supplies can be shipped to USPS general delivery at a nearby location.

We noticed the efficiencies and conveniences added up, allowing us to focus more on enjoying the travel locations, which markedly improved the travel experience. When in a reflective mood, my positive view of motorhoming always seems interesting to me, as there was a time when I thought I would be one of the least likely people to own a motorhome. Now I know that embracing RV travel has widened our world.

Tonight, outside Athena, the desert temperatures could be in the 40s, with some wind, but we will be sleeping several paces from a large saguaro cactus in windless comfort as we look up through Athena's glass at stars lighting the desert sky. Perhaps we will dream of where she will take us next, as we head east toward Texas. **MI**

Manufacturers of Accessible RVs

As far as I can determine, our particular RV model is not currently being manufactured. However, I have seen accessible Windsports occasionally on the used market on RVTrader.com, and they may be available elsewhere. Other companies that may be currently manufacturing wheelchair accessible RVs are Newmar and Winnebago. For Newmar, it seems that three models with wheelchair floorplans and lifts are available: Canyon Star, Ventana and the Dutch Star. Winnebago's Vista and Adventurer models may also be available with accessible floorplans. There may be a few other manufacturers, so conducting your own search is advisable.

Manufacturers:

- Newmar, www.newmarcorp.com
- Winnebago, winnebagoind.com

Other RV Resources:

- Dick Gore's RV World, www.dickgoresrvworld.com
- RV Trader, www.rvtrader.com
- HTC Travel Club, www.handicappedtravelclub.com/about-us/

MULTICHAIR Slider Systems

ALL NEW! MULTICHAIR 6000RS



DON'T REMODEL YOUR BATHROOM, "NUPRODX IT!"

Is the threshold of your stall shower preventing you from rolling in? Is access limited by a narrow shower door? With the new MULTICHAIR 6000RS, you'll be able to get into your existing stall shower without spending \$1,000s on bathroom remodeling costs. Nuprodx' exclusive compact modular design allows the system to fit showers of nearly any size. Log on to www.nuprodx.com to see the entire range of shower and commode systems that will improve the quality of life for users and caregivers alike. Nuprodx, the one system that can last a lifetime. Proudly made in the USA!

Features Include:

- Eliminates bathroom transfers and is an effective alternative when installing a roll-in shower isn't possible or affordable
- Under 22" wide with a rotating base, it easily gets into small, hard-to-access bathrooms and showers
- Available with Tilt-in-Space seating
- Fold-back padded locking arm rests and adjustable swing-away/removeable footrests ease transfers and improve comfort
- 5" casters with Total-Lock brakes prevent swiveling and rolling
- High-quality soft and comfortable padded seat and back cushions
- Seat height adjusts over the highest toilets required by the ADA
- Removable locking bridge section available in optional lengths
- Won't rust or corrode: Aluminum, brass, stainless steel and plastic construction—it's going to last!

nuprodx inc

www.nuprodx.com (855) 220-5171

Tub, Toilet and Shower Access Systems

Visit our web site for complete information about our products.
"light, strong, and portable"

DO YOU HAVE A RELIABLE SOLUTION TO YOUR BOWEL PROGRAM?

CEO-TWO®

Laxative Suppositories



Use CEO-TWO® Laxative Suppositories as part of your bowel program. These unique CO₂-releasing suppositories allow you to control your bowel function and prevent constipation and related problems, such as autonomic dysreflexia. Regain confidence in social and work situations by avoiding embarrassing accidents with CEO-TWO!

Many laxatives and suppositories are not reliable and are unpredictable. Having secondary bowel movements when you least expect it with such products is not at all uncommon.

CEO-TWO works reliably within 30 minutes. These unique suppositories are even self-lubricating, making their use as easy and convenient as possible.

- 3 year shelf life
- Reduces bowel program time to under 30 minutes
- Water-soluble formula
- Does not cause mucous leakage
- Self-lubricating
- No refrigeration necessary
- Individually wrapped and easy to open
- Unique tapered shape makes retention easier, providing satisfactory results every time

ORDERING INFORMATION:

Box of 2 suppositoriesNDC #0283-0808-11
Box of 6 suppositoriesNDC #0283-0808-36
Box of 12 suppositories.....NDC #0283-0808-12
Box of 54 suppositories.....NDC #0283-0808-54



ORDER BY PHONE

1-800-238-8542
M-F: 8:00 a.m. – 4:30 p.m. ET



ORDER ONLINE

www.amazon.com



CEO-TWO is a registered trademark of Beutlich® Pharmaceuticals, LLC. CCA 469 1114



imagine
possibilities

NEVER COMPROMISE ON EXCELLENCE

Enter to Win a VMI Van Down Payment!



VMI's In-Floor Conversion: Maximum Mobility. Zero Compromises.

Now you have the chance to win a down payment toward your very own VMI wheelchair van.*

Enter today and get on the road to a more mobile tomorrow.

**Down payment valued at \$12,000 to be applied on the purchase of a new wheelchair van conversion.*

When you choose a VMI van, you compromise on absolutely nothing:



STYLE



COMFORT



SPACE



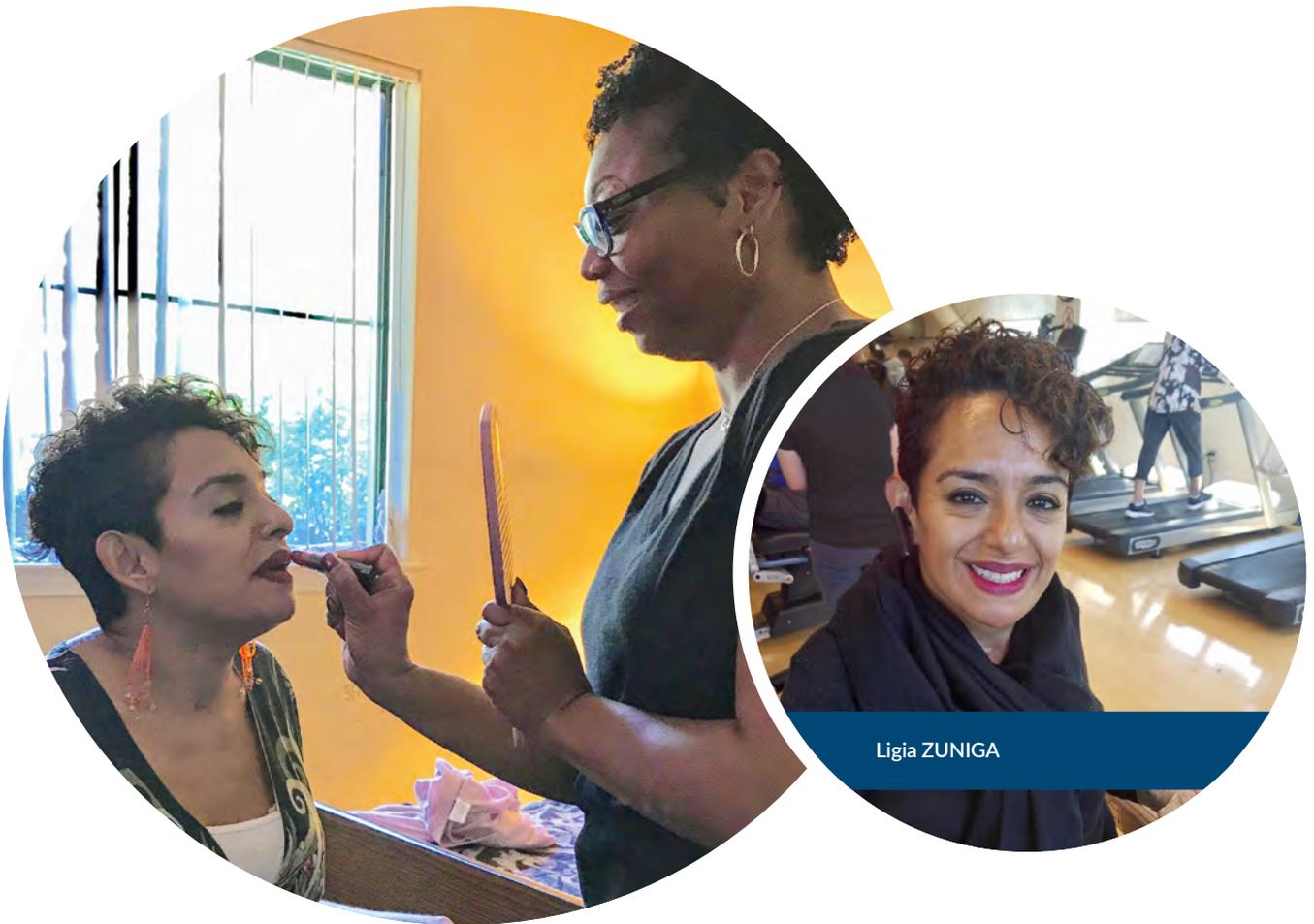
MOBILITY

ENTER ONLINE:

VMIVANS.COM

ENTER BY PHONE:

855-VMI-VANS
(864-8267)



Ligia ZUNIGA

The Business of Managing Your PCAs

BY ALEX GHENIS

Many of us need some help during the day, and some of us need a lot. We get that assistance from people all around us — our family, friends, coworkers, random good Samaritans and of course, personal care attendants. Personal care attendants in the morning, personal care attendants in the afternoon, personal care attendants in the evening, and personal care attendants at night ... once to turn to the right and once more to turn to the left.

We need to hire qualified staff, build professional relationships, train em-

“ I got to go to movies all the time, went out whenever I wanted, and used the bathroom whenever I needed. ”

ployees, coordinate shifts, ensure tasks get done, keep things friendly and track hours and money so people get paid. It can be frustrating. Sometimes, exhausting. Managing it all can be the equivalent of running a small business — one that your life depends on. Your success really comes down to getting a few key things right: the hiring process, organizing shifts, human relations and payroll.

FROM FAMILY TO PROFESSIONALS

Olivia Davis, 26, has muscular dystrophy and has relied on caregivers her whole life. Growing up, her parents provided most of her care. “I lacked a lot of independence because I had to rely on them,” she says. She couldn’t stay out late, hang out with friends, or do all the stupid high school things that teenagers do. Her folks burned out from the work, creating some stress in the family dynamics. It was time for a change.

In 2010, shortly after Davis graduated high school, her parents hired her first PCA. “The attendant would come to my house and hang out from 10 a.m. to 5 p.m.,” she says. “It was really awesome because I got to go to movies all the time, went out whenever I wanted, and used the bathroom whenever I needed.” Her parents still did morning and evening shifts — which were still stressful to an extent — but having some relief during the day gave them more freedom and Davis more independence than she had before. It was the first step toward handing over the business to Davis.

The next step came when Davis transferred to UC Berkeley and enrolled in the Disabled Student’s Residence Program. The program taught independent living skills, including personal attendant management, to freshmen with disabilities. “The DSRP taught me how to hire, fire and manage attendant care, and was one of the most important things I’ve learned in life,” she says. Unfortunately the program was eliminated last year due to budget cuts.

For Ligia Zuniga, 37, the stress of relying on friends and family after she was paralyzed in a car accident eight years ago also proved difficult. As a C5-6 quad on one side and a C3 quad on the other, Zuniga relied heavily on her mom, children, friends and other family members for her care after she was discharged. Balancing work schedules, her care needs and family dynamics proved too much. “Relationships stay the same, it’s just the circumstances that change,” she says. “And that affects the quality of your care with your family or your spouse or your children.”

Eventually she found somebody for the mornings, which were her tougher shifts. Now she lives with her partner, while regular care attendants come through, and her mom still helps on occasion.

FINDING HELP

There are more than a few ways to find new attendants. Classifieds, print or online ads, job sites, Facebook walls and groups, word-of-mouth, flyers, and, of



At first Zuniga relied on friends and family, but now hires help as well.

course, acquaintances, are all good sources. Davis has had good luck with advertising on Indeed.com. “I posted an ad there and I’m still getting responses, even though I’ve already found somebody,”

The number one cause of pressure injuries is constant unrelieved pressure.

Aquila’s SofTech cushion interrupts constant pressure, automatically alternating 60 times per hour.

Live life on your terms, choose Aquila.

The choice is easy.

Medicare Code E2609

Your custom cushion built in 3 weeks!

AQUILA CORPORATION
Seat Cushion Systems

AquilaCorp.com **866-782-9658**

she says. “These are really short shifts that I thought no one would want, like half hour shifts.”

Davis has quite the list of shifts: two hours for the morning and breakfast, an hour for cooking dinner, another for getting into bed (with slightly longer shifts on shower nights), and an overnight where she is turned once and her attendant stays for around four hours. She gets 283 hours per month from the state, divvied up between nine and 10 hours per day, and she uses every one of them. People want jobs, so even a quick \$6 shift can get replies galore when they are put in the right place.

I have a similar deal — several hours in the morning, midday help when I need it, dinner and night routines, and my roommate being on call in case something happens in the middle of the night. Having a plan in case of last minute cancellations or to find backups on short notice is a must. I have a texting group, Davis has a Facebook group just for her attendants, and some people keep a list of vetted people to call. It’s vital to have some sort of a backup plan in case somebody gets sick or needs to head out of town — nobody wants to sleep in their chair or be stuck in bed all day.

Many of us need to track hours to make sure people get paid correctly, whether it’s out of our own pocket or the government’s. Both Davis and I use Microsoft Excel, with some tables and a couple formulas to double-check how many hours somebody has worked in a week or month. It’s even possible to keep a file on the Cloud so you can access it on your phone, because who knows when some random shift will come up or you need to check logistics on the road. Everybody has a strategy that works for them — a sign-in sheet, a Word document, a monthly calendar with puppies on it — and it never hurts to play around and see what works best.

One place you can’t play around is with finances. Zuniga learned that the hard way. Like many quads, she was employed before her accident, financially stable with savings in the bank. Her savings actually impeded her from getting the level of personal attendant care she needs, as she had more than the \$2,000 allowed by her state’s asset limit. “Nobody tells you about the money piece,”



Olivia Davis has luck finding personal assistants to fill all of her shifts, even the 30-minute ones.

“ If you treat the work lightly and joke around, it may come at the cost of things not getting done. ”

she says. She later learned that a special needs trust would have enabled her to keep her money and still enroll in In-Home Supportive Services without problems. Instead, Zuniga funded all her care and went bankrupt, her savings vanishing until she qualified for California’s Medicaid program. Today, Zuniga is eligible and enrolled in IHSS and, like Davis, receives the maximum amount of hours and uses all for her care.

THE FUZZY LINE

With the logistics out of the way, you can focus on what is often the most difficult aspect of running your new small business — finding the right balance between professionalism and friendship.

Most employment is clearly work first and fun second. But with personal care, it can feel like a fuzzy line. After all, with regular jobs, you are often around a group of people in a business setting and at least some managerial structure. With attendant work, though, it’s all one-on-one and it can be hard for things to not get blurry. Davis puts it perfectly, “This is an intimate job and it’s hard to hold a professional relationship with someone who is wiping your butt every day and showering you.”

You might be spending two or three hours together in the morning, in the bathroom or taking a shower or getting dressed or eating breakfast or watching the news or ... well, the list goes on. If it’s all work and you don’t get along, that makes for some boring and awkward shifts. If you treat the work lightly and joke around, it may come at the cost of things not getting done. Then, if you

become best friends on the job, it can be difficult to hold people accountable out of fear of ruining a friendship. This little conundrum is a tricky balance, to say the least.

Should you decide to hire acquaintances or friends, be prepared: It can end in ruined, or at least diminished, friendships — but other times, it can be just fine. As Davis says, “Sometimes it works and sometimes it doesn’t.”

I’ll be honest, I’ve hired many friends and acquaintances. In doing so, I discov-

ered the value of healthy communication about where things are at on the job, what stresses might be coming up, and establishing boundaries between work and friendship.

A JOB FIRST

No matter what, attendant work should be like any other employment — it’s a job first. Many find it helpful to simply have things written down. Davis has a contract that outlines what she expects: If you are

running more than 10 minutes late, let her know as soon as possible; if you are going to be taking time off, let her know as soon as possible; and don’t bring in drama. “A lot of it is just basic knowledge, but it’s good to have it on a piece of paper so that they see it and sign it and know what is expected from the job,” she says.

Being specific about what you want and need is critical. “Leg stretch first, then ankle, not the other way around.” “Green cup for my coffee, brown one for the smoothie.” “Make sure you scrub the entire bathroom, especially that one spot on the right-hand corner.” “Tilt the tray up. No, down a little. No, back up. No, tiny bit down. Almost there. Aaaaaand, good.” This may sound nitpicky, but if you want your life to run the way you’d like, being accurate in your requests is the way to go.

“*Seeing other people as human beings always helps.*”

This point was hammered home by attendants I spoke with. “Tell us why you want things done a certain way,” says Hannah Karpilow. Karpilow has been working as a personal care attendant for the last 35 years, and, like many, derives great satisfaction from the job. “I like feeling appreciated and useful and helping people, and it just feels natural,” she told me. She says she would rather be doing helpful things than just sitting around on the clock. Even if a checklist is all the way done, she usually looks for a task or two that could be completed before she leaves.

While this all may sound easy in concept, feelings of frustration, resentment, and even passive-aggressive anger can develop. I’ve certainly felt the need to snap at guys in my crew, then realized I have a responsibility in the workplace to stay calm, be a constructive manager, and keep a comfortable working environment. Respectful language, positive feedback and active direction can guide attendants through the process to finish tasks just the way I want. It’s also good to give feedback if an attendant is being unhealthy in their work or communication. “In my experience, keeping an open mind has helped me, and seeing other people as human beings always helps,” says Zuniga.

Do you Believe in Magic?

Bowel & Bladder Basics are our Business!

Urological Supplements

Cran Magic +™

bladder, kidney & urinary health.

Mannose Magic™

maintain a healthy urinary tract- flush away E.coli.

Suppositories

The Magic Bullet™

safe & sure! Faster acting, water soluble suppositories.

Bowel Supplements

Magic Cleanse™

promotes fuller movements with greater ease (and less time).

Enzyme Magic™

better digestion= better elimination.



www.conceptsinconfidence.com

2500 Quantum Lakes Dr. #214
Boynton Beach, FL 33426
(800) 822-4050

*one time discount per customer

Vetting Potential Hires

BY ROXANNE FURLONG

After years of using services to hire personal care attendants — and having to work with whomever shows up — I've developed a system to vet potential PCA hires, help avoid toxic hires and find the best employees. It takes about 10 minutes and screens out anyone with a criminal or otherwise unsavory background.

When I find someone, I conduct an initial phone interview prior to a meet-and-greet in my home. During this call, I get their last name so I can do a preliminary background check before we meet, and then I follow that up by going through my PCA service, which will do a state background check.

With their first and last names, I head to my state's online courts system and check civil, family and probate court records, then criminal, traffic and petty case records. After years of vetting, I draw the line if there are several recent civil suits against a person for non-payment of rent or store credit; shoplifting convictions; DWIs within four years; and more than a fair share of speeding or other moving violations. If I know or can find the applicant's partner — if they have one — and that person has a questionable record, I cross them off my list.

After that quick check, I head over to Google and enter their first and last name in quotes plus the state of residence. Here, I search through a few pages of listings to find an address, spouse/partner or any social network with which they may be involved and, again, use my own criteria of what I deem unemployable. Full disclosure: If my potential em-

ployee is brandishing a gun in their selfie, we wouldn't be a good fit.

Using this system, I have dodged a bullet four times within the last nine months. In one case, I found newspaper articles about a prospective employee who lived in a high-income area. Yet, I found that she and her husband have been sued by several credit companies, have numerous parking violations, that their home is a known meth house in foreclosure, and that she harbored a man who'd recently killed a police officer. I found that another woman I was going to meet and greet was convicted of sexting 15-year-old boys at our local high school, and another woman's fiancé had a rap sheet a mile long with several assaults, armed robberies and stolen vehicle convictions.

I've learned the hard way that my system is only good if I follow it. Recently, I found a woman who already was hired by my service. I did my online search and found she had a shoplifting conviction four years prior but let it go thinking she'd passed the company background check through the state. She worked one 4.5-hour shift then doctored her timesheet to 24.75 hours. That's when I flashed back to her huge duffle bag of a purse flat out on my dining room table in the morning and her lugging it out plump and full when she left. We are missing our \$140 fireplace remote control and who knows what else.

No system is perfect, and it is important to follow our own judgment, but this method has worked more often than it hasn't. Hopefully it will help you avoid problem employees.

Find your state court records here: www.ncsc.org/topics/access-and-fairness/privacy-public-access-to-court-records/state-links.aspx.

IT'S TOTALLY DOABLE

Managing the caregivers you need can seem like an overwhelming task, but as Davis and Zuniga and others have learned, it is totally doable. After her tough time adjusting to life as a quad, Zuniga built connections with other people with disabilities to find out how to do things better. "There's no easy transition into this type of life," she says. "Be open to as much advice as you can and to different ways to look for

people to hire." The ideas and steps in this article will help, but don't stop here. The disability community has untold knowledge about how to live independently, from finances to benefits to transit and personal care. Seek it out.

With a respectful approach, attention to detail and some hard work, you can develop your small personal care business into a thriving success that ensures you get the care you need and the happiness you deserve.



Are you really using the BEST catheter for YOU?



Call Liberator Medical
1-800-247-9397



- Cure Ultra™**
- Pre-lubricated
 - Small, flexible package
 - Smooth, polished eyelets
 - Not made with DEHP, BPA or natural rubber latex



- External/Condom**
- Available in 100% silicone and latex
 - Hydrocolloid adhesive option wicks away moisture from skin



- Pocket Catheter**
- Available in extra long, 25 inch length
 - Eliminates the need to transfer or use additional extension tubing



Call a Urology Specialist today to sample from these and many other catheters:
1-800-247-9397

BAIRD | LIBERATOR
MEDICAL

1-800-247-9397
www.FreeCatheterSamples.com

*Conditions apply. Samples have nominal value.
BMD/DMES/0417/0324

OUTDOOR TRACKS



By Kary Wright

'Rescue' Dog

Summer is here. My favorite time of year. Now is the time to get out the T-shirt and hat (for those of us who are follicly challenged), grab the dog and go outside. The great outdoors calls — you can hear the sound of the song-birds newly returned from their southern vacation with tunes practiced and on key. Frogs are croaking their approval of their release from the icy winter prison. The trees have dressed in their summer finest, with eye-popping green leaves. A soft breeze carries a welcoming hint of freshly mowed lawn to your nostrils. It gently picks up speed like a summer breeze will, and ... oh man ... it's strong ... crap! ... there goes my hat!

The definition of frustration is being a quadriplegic alone on an outdoor excursion with your dog when a gust of wind slaps you in the back of the head and knocks your favorite hat to the ground. Now what?

Usually I would wheel back home, get my trusty piece of rope with bungee cord — taped together temporarily “for now” (meaning 20 years ago), and return to the scene of the calamity, then fish around until the hat is hooked and lifted back into my lap. Then I return with the rope to its safe place before I drop it on the ground, too. I suspect that over the years I've provided hours of entertainment for others while I do the “funky chicken” around and around trying to hook my hat, telephone, whatever. And then there's the TV remote. That sucker will lie just out of reach after I knock it off the table, changing the channel to a soap opera when I'm home alone for the day and just about to catch the last lap of the Daytona 500. It might as well be on the moon as on the floor!



A smart dog plus a smart trainer equals practical tricks, such as the dog learning to pick up dropped items like a hat.

You get the idea. It is a major inconvenience dropping some important item when you are a quad and can't pick it up.

I had the brainwave years ago that a service dog would be amazing. The only problem was, they are very expensive and the waiting list was years long. I looked around the room and ... hmm ... our yellow Labrador was peacefully sleeping on the floor. She looks like a service dog, seems to be friendly, retrieves a tennis ball and stick like a champ ... I wonder? I had no idea how to train a dog at that time, and spent hours and hours trying, but couldn't get her to pick up anything but balls and sticks.

One day there was a glimmer of hope. I dropped my phone while home alone. I asked her to pick it up, and she did. She walked right over and set it in my lap! I couldn't believe it; life was going to be so much easier with a service dog. Imagine the time I would save. We'll be a team — I drop stuff and she picks it up! She sat



down and wagged her tail expectantly, I praised her profusely. Then when I didn't throw it, she grabbed the phone out of my lap and set it on the floor, lay down and went to sleep, never to pick anything up for me ever again.

Ten years and one dog later, we have a golden retriever. Hmm ... the brainwave returned, I decided to try again, this time a little smarter. Looking up “service

dog training” on YouTube revealed many great videos. The key was to start slow and use treats to reward any advancements. At first a treat is given if they even look at the item (we used my hat). Then she progressed to touching the hat, then mouthing it, then picking it up. We got her closer to the goal by holding out with the treat until she hit the next level. It was literally no more than 10 minutes and Ginger was reliably picking up my hat and setting it in my lap!

Back to the windy summer day: Ginger looks at my hat on the lawn, then makes eye contact with me as her ears perk up, as if to ask a question.

“Would you pick it up for me?” I say quietly. Dogs have excellent hearing, so it’s good to get them used to a quiet voice; then you won’t need to shout commands.

Her ears drop and her tail wags as she runs to my hat. She picks it up, runs back to me and drops it in my lap with a smile.

“Good girl!” I say to exuberant tail wags.

She bounces away while looking back at me, as if to say “C’mon, let’s continue our adventure!”

It is surprising the added freedom from something as simple as being able to pick up the things you’ve dropped. My outdoor excursions are much more worry-free. I now go clean the lawn before mowing by getting her to pick up sticks, balls, bones, toys etc., and bring them to me. It’s incredible that a mere 10 minutes following the proper training methods have shown Ginger what I wanted, and now I have an eager helper nearby at all times.

I still test her a few times a day to make sure she remembers. She has picked up hats, cuffs, sunglasses, pencils, pens, a credit card (she showed real tenacity in that challenge), a cell phone, remote controls, firewood, a quarter, and my personal favorite ... my straw when it fell out of my wine glass!

Frequently Asked Questions

1. How did you learn about dog training?

I watched a YouTube video on training service dogs.

2. How long did it take to train Ginger, the dog, to pick things up?

Following the video, it took about 10 minutes until the first retrieve, and she continues to improve every day.

3. Did you do all the training yourself?

Not at the beginning. You may need somebody who can reward your dog quickly at first. You reward them for just looking at the item in the beginning, and I’m clumsy and slow with treats, so it’s hard for me to reward at the moment she does the right thing. Now Ginger realizes that it takes time for me to reward, and she’s OK with that.

4. What kind of dog will work?

I’m not a dog expert, but I’ll bet most dogs will work for treats. Ours is a golden retriever and wants to help, so maybe she’s a little quicker than some.



Assistance Dogs Provide Access to the World



**International Assistance Dog Week
August 6–12, 2017**

Organize or take part in an International Assistance Dog Week event. For more info and materials visit:

www.assistedogweek.org

Apogee Essentials

Intermittent Catheters

Depend on quality, comfort and value from a name you trust: Hollister Incorporated.



Available in non-lubricated and lubricated hydrophilic coated catheters.

For a free sample, visit hollister.com/apogeeessentials or call 888.740.8999



The Hollister logo and Apogee Essentials are trademarks of Hollister Incorporated. © 2017 Hollister Incorporated.



By Allen Rucker

“All this new mainstream media interest in disability is a heartening sign that we are becoming more visible.”

Disability is Hot

This just in ... all over this great country of ours, disability is becoming an ever-more-popular topic in mainstream media. The kinds of in-depth, penetrating stories you would normally find in disability studies journals or fine publications like this are popping up in the daily newspaper. This borders on exciting.

No longer are these pieces centered on kids with disabilities who do seemingly incredible things. “He can even speak Russian!” “Who ever heard of a miniature golf champion in a wheelchair?” You will now come across thoughtful, incisive writing on disability in *The New York Times*, *The Washington Post*, *The Los Angeles Times*, and even the haughty pages of *The New Yorker*. Some of the time, the subject matter can surprise you. *The Post* had a piece recently entitled “Digital Disabilities — Text Neck, Cellphone Elbow — are Painful and Growing.” I’m getting frozen shoulder syndrome just pounding this keyboard all day. It ain’t paralysis, but like the man said, it’s painful.

The NYT leads the current onslaught of *litterature d’invalidité*. Since August of last year, they have published a weekly essay on disabilities in the opinion section of the Sunday paper. The beauty is that they are all written by people who have disabilities. *The Times* is merely the vehicle.

Here are two completely differ-

ent stories to illustrate my point. One showed up in the NYT a few weeks ago and is in the running for all-time favorite. It’s called “Stories About Disability Don’t Have to be Sad,” written by a precocious middle-schooler, Melissa Shang, who has a form of muscular dystrophy called Charcot-Marie-Tooth Disease. Her point is simple: “My story is not a sad one.” She hates that young people, in particular, see disabled kids as “miserable people to be pitied.” She wrote a book about a disabled kid who loved her life. One professional reader rejected it by saying that the character didn’t suit such a light-hearted story. Where’s the hospital bed? The rejection, the loneliness, the “I’ll show them” winning the 100-yard dash?

Shang hates all that. She wants scenes in the school cafeteria with her buds, not hospitals. She wants everyone in earshot to “see disabled kids as friends, people to gossip with, to take selfies with, and go see movies with. ...” She wants kids to play with a disabled classmate and say: “She’s just like me! And she’s happy, too!” From the mouths of children. ...

A good distance from Shang’s POV is a recent *New Yorker* piece called — get ready — “Are Disability Rights And Animal Rights Connected?” The subject of the piece, Sunaura Taylor, who has arthrogryposis, which causes joint contractures, sees the treatment of the disabled much like the treatment of

animals. Both are viewed as “lower on the chain of being,” dependent, helpless and, in a pinch, expendable. As a kid, she was taunted that “she walked like a monkey and ate like a dog.” As an adult, she decided to embrace her animal nature. “I feel animal in my embodiment,” she says, “and this feeling is one of connection, not shame.”

I love animals, too, but don’t identify with them with the same ideological fervor that Taylor does. At the end of the piece, she mentions that she and her dog with back problems, Bailey, share an abiding affection. Now this I get.

In an article I wrote about disability and advertising for NM last year, my very favorite ad was from Kleenex, told in the first person, about a guy in Florida who’s paralyzed and a dog he and his wife found discarded like trash on the side of the road. The dog, “Chance,” is paralyzed, too, and for the rest of the ad, he dons his harness and red wagon for back legs and just tackles every moment with insane energy and enthusiasm. His love of life is an instant antidote for self-pity.

All this new mainstream media interest in disability is a heartening sign that we are becoming more visible. I recommend you keep your eyes open for other well-told, genuinely insightful stories of the same ilk. If the one you come across has a high-octane dog dragging a red wagon, please send me the link.

Experience Abilities Expo!



Achieve greater independence through:

- Latest products and services
- Expert-led workshops
- One-on-one engagement
- Revitalizing sports
- Kid-friendly fun
- Adaptive dance
- Service animals
- Daily living aids for seniors

FREE
ADMISSION

www.AbilitiesExpo.com
 Register online today. It's free!



Boston
 September 8-10, 2017

San Mateo
 October 27-29, 2017

DC Metro
 December 1-3, 2017

Toronto
 January 19-21, 2018

Los Angeles
 February 23-25, 2018

New York Metro
 May 4-6, 2018

Chicago
 June 29-July 1, 2018

Houston
 August 3-5, 2018



**It's not what you push ...
It's what pushes you!**

SG-A601 \$102

Z4 \$288

AZ-1 \$279

Portable Hand Controls
& Spinner Knobs

Get your **FREE** catalog today!
www.sportaid.com
1-800-743-7203



QUANTUM
Q100 Bathchair

NEW SEATING!

- Pressure relieving
- Injection Molded foam
- 25% better than ensolite
- Outlasts steel or aluminum
- Multi-configurable tub/shower/toilet
- Options: Carry case, flat or commode seats, free standing leg support
- Optional leg support shown on product above

ChallengeCircuit
multi-exercise weightlifting machines

7000

- Ab Crunch • Single-dual curls
- High bicep curl
- Single & dual tricep pulldown
- Tricep extension • Lat pulldown
- Multi-level row
- Bench & incline press
- Pec fly • Dumbbell pec fly
- + MORE

NEW EXERCISES!

VA Approved • Limited Lifetime Warranty
WWW.APEXEQ.COM • 800-851-1122

**JUMP START YOUR
SEX LIFE**



VIBERECT

- Treats men with erectile dysfunction
- Treats SCI men with ejaculatory dysfunction.

**\$200 OFF FERTICARE
10% OFF VIBERECT**
(OR ANY OTHER PRODUCT WE SELL)

FERTI CARE® PERSONAL

- The Feticare personal treats men with ejaculatory dysfunction and woman with orgasmic dysfunction/ vaginal dryness.
- FDA approved/ VA approved.
- Inexpensive alternative to fertility clinics.
- Can also help with incontinence thru Kegel Exercise.

(Not FDA approved for sale inside the USA for incontinence)

Orion Medical Group, Inc.
(Full D.M.E. Pharmacy Specializing S.C.I.)
Tel. 714-649-9284 / 1-888-64-ORION (67466)
Fax. 714-594-4038
info@medicalvibrator.com
www.medicalvibrator.com

SUN PROTECTION

Stay cool & comfortable
ALL SUMMER LONG

The original
**Weatherbreaker®
Canopy.**



"...kept our daughter cool and sunburn free for our entire trip."
—JOHN S.

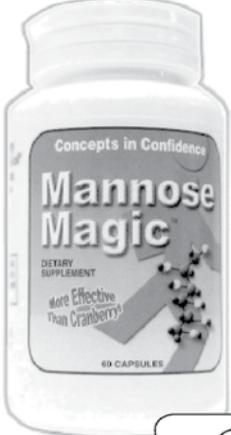
Available at your local VAMC & mobility dealer.

MADE IN USA!

1.800.795.2392
DIESTCO.COM

  /diestcomfg

**Don't Become
ANTIBIOTIC
RESISTANT**



**Fight and Prevent
UTI's**

**Flush
Away
E-Coli**

Concepts in Confidence
60 capsules for only \$25.95

www.conceptsinconfidence.com
2500 Quantum Lakes Dr. #214
Boynton Beach, FL 33426
(800) 822-4050

FOR SALE

Chairman HD3 Electric Wheelchair

Excellent condition. Used for 1 yr. This chair tilts, reclines and elevates Max weight 400 lbs. For additional information contact 973-934-1391 for photos. Asking \$3800.00

Nationwide Wheelchair Van Rentals.

For the next time you want to get out, vacation, doctors appointment, or try before you buy. Learn more at www.BLVD.com

Over 1500 wheelchair Accessible

Vehicles for sale at one website. A complete selection of New, Used and Pre-Owned wheelchair vehicles from dealers and private parties nationwide. Check it out today. www.blvd.com

40' ft 2000 Beaver Patriot Motor Home.

NEW Low Price! Immaculate – REALLY LOADED!!! – only 84,000 miles! LIKE NEW, ONLY \$70,000. 2 slide outs, Caterpillar Diesel, Pusher 3126B Truck Engine, SuperArm, Roll-In Shower / HC Bathroom, Hand Controls & Digi-Pad. Call or e-mail for any additional info and pictures. Cell (951) 218-4023 ~ Ask for William. Email: wlb21666@hotmail.com

USA Jeans makes pants designed for sitting. Call Darlene at 800-935-5170 or visit www.USAJeans.net

ISO

Gentleman looking to get a letter from a penpal. Write to Gary Cooper, 600 E. Perry St. Rossville, Kansas 66533

VACATIONS

Florida Keys! Accessible 2 /bedroom Waterfront Home, Large Bathroom with Roll-In Shower. Spectacular View, Resort Amenities included. 561-627-1941. www.placidaccess.com

NEW - Voted "Best Accessible

Vacation EVER" (by those who stay here). Visit www.vrbo.com/434500... read the reviews!

New Zealand disability vehicles, hand control cars, left foot accelerator cars for hire. Explore New Zealand – we make it easy! We are happy to pass on our former clients' recommendations of accessible activities and accommodation. See www.freedom-mobility.co.nz Old

Orchard Beach, Maine First floor entirely wheelchair accessible. House sleeps 10. Visit www.dunegrasscottage.com

VACATIONS

On The Beach Los Cabos, Mexico

Ultimate accessible vacation. Get out of the cold! On the beach, totally seamless and barrier free. All the toys, power beach chair, accommodations, pool, and boats are completely wheelchair accessible. Designed and constructed by a C-6/7 quad. Visit www.vrbo.com/669234 <http://www.vrbo.com/910690> <http://www.bajaenterprises.net/>

Ocean-front condo, wheelchair friendly,

sleeps six, pool, boardwalk to beach. Rents daily, weekly, monthly. St. Simons Is., GA. bmmk4@frontier.com 419-569-6114.

Cape May farmhouse near beach. First

floor entirely wheelchair accessible. Sleeps eight. Visit www.beautifullyaccessible.com for more info and reservations.

Accessible Journeys

making the world more accessible since 1985

Holland's Spring Tulips

Rhine River Cruises

Barcelona & Madrid

Venice & Ljubljana

Accessible Italy by train

Vietnam-Thailand-Cambodia

Kenya-Tanzania-Zambia-South Africa

800.846.4537

www.accessiblejourneys.com

TO PLACE A CLASSIFIED AD IN NEW MOBILITY

Call 800-404-2898, ext. 7253 or email your request to mlee@unitedspinal.org

Print Rates:

- \$1.30 per word
- \$1.00 per word for USA Members

• Boxed Ads - \$105 per inch

• Pre-Payment Required: VISA, MasterCard, AMEX, Discover

• All Paid Print Classifieds get a 1 month FREE Web Classified

Online Only Rate:

- 1 month = \$16
- 3 months = \$36
- 6 months = \$72
- 9 months = \$108
- 12 months = \$144

newmobility.com/classifieds

A SPECIAL THANKS TO THOSE THAT SUPPORT



PREMIER LEVEL

Wellspect HealthCare's LoFric® Origo™ is designed to provide safe, hygienic and convenient catheterization – and is NOW available in STRAIGHT TIP! Contact us for FREE samples. 855/456-3742 or www.wellspect.us

LEADER

Abbvie, www.abbvie.com

Hollister: The Onli hydrophilic catheter from Hollister is designed to provide a hassle-free and mess-free experience. Request a sample at 888/740-8999 or hollister.com/onli

ASSOCIATE

AdvaMed: Failure of a wound to heal can have a profound effect on QOL. MedTech has helped evolve wound treatment, reducing complications and improving QOL. www.lifechanginginnovation.org

Allergan: www.botox.com

Hill-Rom: Trusted in the hospital, trusted at home. Call a Patient Advocate today. 800/833-4291, homecare.hill-rom.com

NMEDA: NMEDA provides adaptive transportation solutions for you, your family, or caregivers. Contact your local NMEDA Dealer today: 800/833-0427, www.nmeda.com

SUPPORTERS

Cure Medical, <https://curemedical.com>

The Krist Law Firm, P.C., www.houstoninjurylawyer.com

Michigan Auto Law, www.michiganautolaw.com/ personal-injuries/back-injury/spinal-cord-injuries

Rare Patient Voice, www.rarepatientvoice.com

Trusted Mobility, www.trustedmobilityrepair.com

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.

Photo by Jacquelyn Martin



“OUR LIVES AND LIBERTY SHOULD’N’T BE STOLEN TO GIVE A TAX BREAK TO THE WEALTHY. THAT’S TRULY UN-AMERICAN.”

— ADAPT ORGANIZER BRUCE DARLING

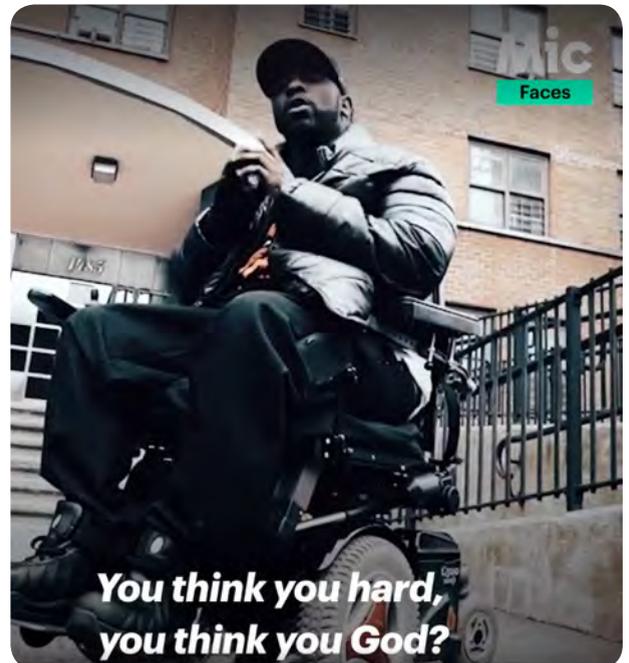
ADAPT organizer Stephanie Woodward was forcibly removed from Sen. Mitch McConnell’s office and arrested on June 22, along with 42 other protesters, during the fight to defeat the GOP health care plan, which would have devastated Medicaid.

COMPETING WITH KIDS FOR THE ACCESSIBLE STALL

I am not exactly certain when having children became a disabling condition, but based on all the baby changing stations now located in almost every female accessible stall, it must’ve happened in the past 15 years or so. ...

Sometimes the wait is brief, but other times, as was the case a few months ago at the Pilot gas station, there are four or more children occupying that accessible stall while mom scrambles to dress and undress each one, periodically pulling a wild toddler back from escaping under the door. When my turn finally arrives, the stall is often left with a disgusting mess to navigate through.

— Competing with Kids for the Accessible Stall, newmobility.com/2017/07/competing-kids-accessible-stall/



Millennial journalism site Mic featured rapper and anti-gun-violence advocate Name! "Tapwaterz" Norris in a video viewed over 84,000 times (www.facebook.com/MicMedia/videos/1570391059650345).

The Struggle is only
Part of the Story



INQLINE™

INTEGRATED WINCH & RETRACTOR SYSTEM

PASSENGER ONBOARDING AND PASSENGER SECUREMENT
ALL-IN-ONE



INQLINE is a fully tested, heavy-duty winch and restraint system featuring dual automatic retractors that double as front tie-downs; making it the ideal solution for both passenger onboarding and passenger securement.



CONTROLLED STEERING • DUAL INDEPENDENT RETRACTORS • IMPROVED RIDE QUALITY
SPEED, SAFETY, SIMPLICITY

LEARN MORE AT: [QSTRAINT.COM/INQLINE](https://www.qstraint.com/incline)



permobil

POWER WHEELCHAIRS

REACH FOR MORE.

Your world isn't one dimensional. Your seat elevator shouldn't be either. ActiveReach™ technology is the ultimate advantage in accessing your environment. By combining 14" of seat elevation and up to 20° of forward tilt, Permobil's ActiveReach™ technology enables you to reach beyond obstructions, into high cabinets, and can even assist in transfers. Truly putting your world within reach.

M5 FEATURING **ACTIVE REACH™**

FOR MORE INFORMATION VISIT WWW.PERMIBILUS.COM

Configurations may vary. Please consult with your clinician and refer to your Owner's Manual for further details.