

Stem Cell Update Roll on Capitol Hill Breakup Wakeup

# NEW MOBILITY

life beyond wheels

Accessible  
Cruises & Resorts

# PRECISION

## LEAD FROM ABOVE WITH THE TEK-RMD

### WORKPLACE MOBILITY NOW COMES WITH A VIEW

As the Quality Manager for an Air Force Precision Measurement Equipment Laboratory (PMEL) specializing in the calibration of mission-critical test equipment, Troy Yoho's world was changed when a skiing accident left him paralyzed three years ago.

"After my injury I found myself spending more and more time behind my desk and less time out on the floor interacting with my employees," said Troy. "Sitting in a chair all day also left me worn out by the time I got home," he added, "not to mention unable to focus for long periods at work. When I was first injured it was very uncomfortable going back to work because everyone was so much taller. We're a very technical group of people, and being unable to see what my team was working on had a definite impact on our relationship."

When he saw the TEK-RMD online, Troy was intrigued by the possibility of a vertical

mobility device that would allow him to do more at home. But as the manager of a 40,000 square foot laboratory with 50+ employees, Troy's focus quickly shifted to using the TEK as a means of improving his job performance.

"Using the TEK at work has changed my life," said Troy. "I spend half as much time at my desk, but am far more productive. And now I'm able to interact with my employees at eye level and stay engaged with them throughout the day. When you aren't on the floor and constantly engaged with the desk work being done, you kind of lose your team. The TEK has absolutely allowed me to take back control of my workplace."

You can learn more about the TEK-RMD and the entire line of mobility products available from Innovations Health by calling, visiting us online, liking us on Facebook, or subscribing to our YouTube channel.



(800) 659-4548

[www.InnovationsHealth.com](http://www.InnovationsHealth.com)

INNOVATIONS  
HEALTH



Robotic®  
Mobilization  
Device

# PLATFORM

MD



A special thanks to USAF contractor Goldbelt Falcon and the men and women of Hill Air Force Base near Layton, Utah, who are dedicated to protecting our way of life.

Retired Air Force veteran and T12 paraplegic Troy Yoho reviews the work of a calibration engineer from his TEK-RMD.



ERGOtrans®





# VaPro Plus Pocket

Touch Free Hydrophilic Intermittent Catheter

We're for the man who makes his dreams a reality.



We want to help you get there. The **VaPro Plus Pocket** hydrophilic intermittent catheter provides the right balance of ease of use and protection without compromising convenience or discretion.

Its ready to use, touch free catheter with integrated collection bag is designed for easy handling and to help keep germs away.

Request a sample\*: call 888.740.8999 or visit [hollisterpeoplefirst.com/vapro](http://hollisterpeoplefirst.com/vapro)



**Continence Care**  
People First

\*RX Only. Federal (USA) Law restricts this device to sale by or on the order of a physician or other healthcare practitioner licensed under state law to order this product. The Hollister logo and VaPro Plus Pocket are trademarks of Hollister Incorporated © 2015 Hollister Incorporated. 922923-1015

## FEATURES

**13 SCI RESEARCH UPDATE** It's been a long road, but human stem cell trials are finally here. TIM GILMER reports on the growing number of encouraging discoveries.

**18 MEET THE ADVOCATES** Get to know some of the rollers who will fight for our rights at the 5th Annual Roll on Capitol Hill at the end of this month. BY MAUREEN GAZDA

**23 LEFT HANGING IN LOVE** KATE MATELAN thought she had found the love of her life; then he left. She writes about coping and moving on when SCI issues are involved.



## COVER STORY

## ADVENTURE ON THE OPEN SEAS

28

The oceans cover 71 percent of the planet, so why not get out and explore them? ELLEN STOHL discovers Atlantis – not the mythic sunken city, but the Bahamas resort. IAN RUDER gets the lowdown on cruising from accessible travel experts Cory Lee and Ashley Lyn Olson. And LILLY LONGSHORE overcomes her fears to live out a Caribbean dream.

Cover Photo by PhotoAbility.net



## DEPARTMENTS

- |                |                       |
|----------------|-----------------------|
| 4 BULLY PULPIT | 42 UNITED SPINAL NEWS |
| 6 LETTERS      | 46 PARA/MEDIC         |
| 8 NEWS         | 48 OUTDOOR TRACKS     |
| 10 SCI LIFE    | 50 ERVIN              |
| 41 SPOTLIGHT   | 56 CRIP BUZZ          |



JUNE 2016

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 27, Issue 272, is  
published monthly by United Spinal Association, 120-34 Queens  
Blvd, #320, Kew Gardens NY 11415.

Copyright 2016, 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](http://www.newmobility.com)

## ( BULLY PULPIT )



### SCI Cure: Dreams and Reality

In this issue we revisit the “C” word — the seemingly neverending search for a cure for paralysis. For me, the quest began in 1966, 50 years ago, when biomedical engineering succeeded in helping paraplegics stand with electrical stimulation. But for many NM readers, the search is immediate and ongoing, as in now. Yet even in this era of stem cell research, epidural stimulation, treadmill walking and other experimental treatments, the cure still seems somehow distant.

But there are unmistakable signs of progress. At times it seems that all that is needed is to discover just one more piece of the puzzle, and then everything will fall into place, mystery solved. It is unlikely, though, that just one more discovery will result in a widespread cure anytime in the next five years. One of the biggest obstacles is the deliberate nature of the scientific process itself. Another is the way our health care system is slow to include new treatments. And a third is cost. Medicare and private insurance companies are unlikely to cover the cost of expensive operations or equipment for any but a small percentage of those of us with longstanding paralysis.

For our own peace of mind we should stop talking and thinking about the “C” word, and replace it with “AI” — and I don’t mean artificial intelligence. I mean Any Improvement. Any improvement is good. And that is the undeniable message that the latest research trials keep sending.

In this month’s feature on stem cell research (see page 13), we interview two recent U.S. clinical trial subjects whose gains over a one-year period following stem cell injections are not so much about small gains in finger dexterity and core strength — which they did report — they are more about overall health improvement: better blood pressure regulation, less

autonomic dysreflexia, better bladder control, breathing, temperature control. And one more — improved motivation — which is especially important when practical gains tend to come with rigorous physical therapy, exercise and treadmill walking.

The most dramatic gain was reported by Dr. Wise Young, ever the indefatigable SCI pioneer, who combined some serious treadmill walking with umbilical cord blood cell injections and three other factors he is known for — (you can read more about the complete protocol in next

**For our own peace of mind we should stop talking and thinking about the ‘C’ word, and replace it with ‘AI’ – Any Improvement.**

month’s issue) — and the result was 15 out of 20 subjects regaining some ability to walk with rolling walkers. These participants had chronic (14 years post-injury), complete spinal cord injuries.

Now that is encouraging.

We now have two very dramatic and exciting clinical trial results in the last five years. First came the surprising results of the epidural stimulation trials involving four motor-complete SCI subjects who suddenly regained the ability to stand, and later move their legs with some degree of control when their implanted stimulation devices were switched on. Now we have 15 more subjects with motor complete SCI walking with the help of rolling walkers. Interestingly, the one thing both trials had in common was treadmill walking as a way of optimizing the results.

AI. Wherever it leads, any improvement is good.

— TIM GILMER

# ( CONTRIBUTORS )



JUNE 2016

## CONTRIBUTING EDITORS

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



From his treehouse at an undisclosed location in the Pacific Northwest, Ian Ruder does his best to keep on top of the latest in technology, sports, and most importantly, food. After a long career as a freelance journalist, he found his home at *NEW MOBILITY*, where he is now a senior editor. He also manages United Spinal Association's social media accounts. When he's not eating, watching his beloved San Francisco Giants or rolling with his friends, he's probably doing something else really cool.

Ellen Stohl is a university lecturer, writer, wife, and mom, but there was a time when she never thought she would be. Thirty-three years ago a wet freeway and a dangerous curve taken at breakneck speed shattered her spine, and at the time, her dreams. Initially impacted by negative stereotypes, she quickly discovered her injury did not define her. Today, she is the proud mother of a beautiful 13-year old girl and a self-actualized woman whose education, experience and life story have given her unique opportunities and insights into living life fully.



## 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



Having sustained his SCI in 1980, Mark T. Race's motto is "get what you want out of life or just get old." When he isn't facilitating United Spinal's New Hampshire chapter and a peer support group for Granite State Independent Living, he is busy collaborating and advocating with partners like the YMCA, rehabilitation hospitals, the governor's brain/SCI advisory council and barrier-free sport organizations, to bring inclusion for SCI men and women. Mark is happily married with six grandkids and a seventh due in July. Mark lives in Loudon, New Hampshire, and enjoys gardening, photography, sky diving, water skiing and things that go fast.

Tiffany Carlson, from Minnesota, is the brains behind *NEW MOBILITY*'s *SCI Life*, having written more than 150 columns since 2003, each month giving readers three or four informational tidbits from our shared world. She sustained a C6 spinal cord injury from a diving accident when she was 14 years old. Writing and breaking stereotypes is her passion. She founded the longtime disability site, *BeautyAbility.com* and her work has been featured in *Penthouse*, *Playgirl* and *Nerve.com*. When she's not writing, Tiffany loves to cook and practice adaptive yoga.



I am excited about the new trend in advertising.



### Like Any Other Mom

I am excited about the new trend in advertising using real people, especially people with disabilities ["Is Ad Land Really Changing?" April 2016]. I was lucky enough to be in an amazing Minute Maid spot with my daughter last year. It was re-edited for 2016 and was just released. In it I am just a mom like any other mom. You can see it here: [www.minutemaids.com/blog/mom-doinggood/](http://www.minutemaids.com/blog/mom-doinggood/)

Ellen Stohl  
Northridge, California

### Twinking Mount Rushmore

Loved Mike Ervin's idea for more Mount Rushmores! [Ervin: "Mount Rushmore for Cripples," April 2016]. I'd like to add another category: Wheelchair and Ventilator Mount Rushmore. I came across these very famous folks while communing with my late husband, Paul Kahn (a playwright, poet and general Renaissance man). They changed their names (slightly) as they acquired more equipment. For instance:

Henri de Too Loose La Trach, 19th century artist (they didn't have Velcro in those days and his trach collar kept coming loose); Catheter Hepburn; Valve Kilmer; Saline Dion.

Ruth Kahn  
Boston, Massachusetts

### More Options

I noticed in the "Traveling Mobility Technology" piece by Mark Smith [Innovations, April 2016] that our GO-Anywhere Chairs were overlooked as an option. Traveling mobility is what we do and all we do! To see our portable shower and commode chairs, please visit [goesanywhere.com](http://goesanywhere.com).

Rick J. Goldstein, President and CEO  
Go! Mobility Solutions, Tucson, Arizona

### DME Overpriced

Any product classified as DME is way overpriced — wheelchairs are no exception ["Sticker Shock: Understanding DME Prices," April 2016]. Providers know how to game the system, and they do that well. But I will say this, I have had good service overall during the past 22 years with my five power chairs. One chair was a lemon, but the manufacturer replaced it after 90 days without complaint.

NM should have posted a sidebar to this article telling us how much ad revenue they receive from wheelchair companies. This advertising cost, after all, comes out of their readers' pockets when they buy chairs.

Dave Allen  
via [newmobility.com](http://newmobility.com)

**Editor's note:** *Dave, we did the math. Our top advertiser's annual ad costs, when divided by the number of wheelchairs they sell annually, adds \$5 to the cost of each chair. That comes to .0002 percent, or 1/5000th of the total cost of a wheelchair.*

### More than Price

I think there are some additional problems besides costs that also need to be addressed ["Sticker Shock"]. Funding guidelines estimate a five-year life span for power wheelchairs when in reality they are manufactured to be less durable, require more repairs and do not stand up to the use intended. Then when they need to be replaced before five years are up, or with a more durable model, it is denied. All around, end users are screwed.

Debra Stemmler  
via [newmobility.com](http://newmobility.com)

### Waiting Over Eight Months

In the last 10 years I no longer get repairs when needed, despite doctors' notes, prescriptions, etc. The DME companies have been uninterested, uncaring and their bot-

tom line is the money. I've been waiting for a power chair for over eight months despite going through all the required hoops. DME companies are corporations. And you won't necessarily get the chair that's best for your needs because the DME company doesn't tell you they don't sell it.

Pam Balidoy  
via [newmobility.com](http://newmobility.com)

### We Are Not the Enemy

Your article is right on track with the information you presented ["Sticker Shock"]. After reading the comments, I am sorry to say there is a lot of anger directed at the manufacturers and the dealers. I understand where some of this comes from, especially if the user had a bad experience. As you know, we [dealers and manufacturers] don't make the rules, but we are required to follow them. I appreciate your comment [asking readers] to get out and lobby their legislators to make the rules more accommodating to their needs. As suppliers we do it, but it would be nice if we had the support of the consumer. We are not the enemy.

Dave Kruse, ATP  
Portland, Oregon

### It's the Bean Counters

Between the government regulations and the necessity of manufacturers protecting themselves against prospective negligence lawsuits, the industry is weighted down with MBA bean counters ["Sticker Shock"]. I see the same problem while observing my wife's career in the medical field. She and others on the front line are focused on patient care, but they must function in an atmosphere of management (meaning the latest trend or theory pontificated by business schools). That's why my latest wheelchair cost more than a new car.

Gary Presley, via [newmobility.com](http://newmobility.com)

LoFric®

## A good start to CIC with LoFric Sense and LoFric Origo

The only catheter with Urotonic™ Surface Technology

Easy to grip and use with "no touch" technique

Clever and discreet packaging

LoFric® Sense™ for her



LoFric® Origo™ Coudé for him

A good start  
A good *life*

Contact us for

**FREE SAMPLES**

Call **1-855-456-3742**

or Email

[marketinglofric-us@wellspect.com](mailto:marketinglofric-us@wellspect.com)

[www.wellspect.us](http://www.wellspect.us)

   FOLLOW ONLINE AT "LOFRIC US"

wellspect  
HEALTHCARE

## Anticholinergic Meds May Cause Brain Damage

Older adults who use bladder-controlling anticholinergic drugs such as Ditropan, Detrol, Enablex, Toviaz, Sanctura and Vesicare may want to talk with their doctor about finding an alternative. According to a study published by the Journal of the American Medical Association (Neurology) on April 18, these drugs may cause brain damage, cognitive impairment and dementia. Other anticholinergic drugs include over-the-counter antihistamines such as Benadryl. Some antidepressants are also anticholinergic.

Although previous research has discovered a link between anticholinergic medications and dementia among older adults, this is believed to be the first study of those links using neuroimaging measurements of brain metabolism and atrophy.

"These findings provide us with a much better understanding of how this class of drugs may act upon the brain in ways that might raise the risk of cognitive impairment and dementia," said study author Shannon Risacher, Ph.D., in a press release. "Given all the research evidence, physicians might want to consider alternatives to anticholinergic medications if available

when working with their older patients."

The study's 451 participants were drawn from a national Alzheimer's project, and 60 of them were taking at least one medication with medium or high anticholinergic activity. Researchers used PET scans to measure brain metabolism and MRIs to scan brain structure, as well as cognitive tests. The cognitive tests showed participants taking the drugs performed worse on short-term memory and some executive function tests. The MRIs showed that people taking the meds had reduced brain volume and larger cavities inside the brain.

"These findings might give us clues to the biological basis for the cognitive problems associated with anticholinergic drugs, but additional studies are needed if we are to truly understand the mechanisms involved," Dr. Risacher said.

## Reeve Foundation Presents Sip-and-Puff Toys

A remote control car operated by a sip-and-puff headset. A voice-operated pitching machine that tosses pop-ups, groundballs and strikes. These are examples of Adaptoys, designed to be used by anyone in the family, including adults or kids with quadriplegia.

In hopes of bringing Adaptoys to market, the Christopher and Dana Reeve Foundation has launched a crowdfunding campaign at Adaptoys.org. "Technology has been such a powerful force for individuals with disabilities. However, there is a void when it comes to technology and accessible toys," said Peter Wilderotter, president and CEO, Christopher and Dana Reeve Foundation. "Adaptoys will help eliminate inequality by reimagining playtime for parents,

grandparents, siblings, uncles or aunts who are living with paralysis."

Former Rutgers football player Eric LeGrand agrees with Wilderotter. "I have never let paralysis slow me down. However, I look at my nephews and it can be frustrating when they want to play ball and I can't join the fun," says LeGrand, a quadriplegic living in New Jersey. "With Adaptoys, I can fully participate with my family and create new memories with my nephews so that they never feel as though their 'Uncle E' is sidelined at playtime."

"As a grandmother, you dream about playing with your grandchildren. But for people living with disabilities, playtime can be isolating and inaccessible. My granddaughter lit up when I was able to race cars with her," said Donna Lowich, who is also a quadriplegic living in New Jersey. "Adaptoys will allow me to be part of her childhood in a more meaningful way, and my only hope is that we can bring these accessible toys to many more families. Everyone deserves to play with their loved ones."

## Clinton, Sanders Confirm Support of Disability Integration Act

Although they may disagree on various foreign policy issues and argue about the future of climate change, Democratic presidential candidates Hillary Clinton and Bernie Sanders have come together in solidarity to help the disability community by confirming their support for the Disability Integration Act.

On Wednesday, April 6, Clinton released a statement endorsing the 2015 proposed civil rights legislation introduced by New York Democratic Senator Chuck Schumer, which aims to ensure that people with disabilities who need long term care be given the choice to live independently and receive care at home instead of being forced into institutions and nursing facilities. Later on the same day, Sanders signed



Eric LeGrand plays with his family using Adaptoys.

on as one of the five co-sponsors of the bill.

"As a young lawyer working for the Children's Defense Fund, I started my career fighting for the inclusion of children with disabilities in our schools. And I've never stopped fighting to break down the barriers that hold people with disabilities back," Clinton's statement reads. "In this campaign, I have committed to improving opportunities for people with disabilities to live in integrated community settings, consistent with the full promise of the Americans with Disabilities Act and the Supreme Court's historic *Olmstead* decision."

Similar to the ADA, the groundbreaking legislation intends to require that states and insurance companies provide home and community-based services as an alternative to institutionalization. National grass roots disability advocacy group ADAPT has been very vocal in its efforts to champion the DIA, and activist Bruce Darling said he couldn't be more pleased with the candidates' support.

"The ADAPT community is thrilled that Hillary Clinton released a statement supporting the Disability Integration Act and that Bernie Sanders has signed on as a co-sponsor of the legislation," he says. "This is the first time in history that candidates for president of the United States have acknowledged our nation's systemic institutionalization of Americans with disabilities as part of their campaigns and supported our cause. We will continue to press the other candidates to support this landmark legislation."

For more information on the DIA visit [www.disabilityintegrationact.org](http://www.disabilityintegrationact.org) or [www.adapt.org](http://www.adapt.org).  
— MAUREEN GAZDA

# Stronger Together



Invacare is a proud participant in Roll on Capitol Hill and applauds the consumers who are making their voices heard.

We may arrive as individuals, but the strength in numbers and shared real-world experiences are powerful forces for change.



©2016 Invacare Corporation. All rights reserved. Trademarks are identified by the symbols ™, sm and ®. All trademarks are owned by or licensed to Invacare Corporation unless otherwise noted. Form 16-075 160410.



## JOIN THE REV<sup>1</sup>OLUTION!

EXPERIENCE WHY ROWHEELING IS THE RIGHT WAY TO ROLL!



The benefits of ROWHEELING with REV<sup>1</sup> wheels combine to reduce the risk of shoulder-related injuries, which are common to over 50% of manual wheelchair users.



- Compatible with most manual chairs
- Reimbursed under HCPCS E2227

VISIT US AT [WWW.ROWHEELS.COM](http://WWW.ROWHEELS.COM) OR CALL (608) 268-9670



By Tiffany Carlson

**“If you put all your focus on keeping an open mind and positive attitude, happiness will find you.”**



### The Great Adventures of Joe Stone

When Joe Stone, 30, was a younger man, his heart was drawn to the mountains, so he left the flatlands of Minnesota for Montana. “I was opened to mountain biking, fly fishing, skydiving and eventually speed flying, and my goal was to always push myself as hard and far as I could.”

On August 13, 2010, his love of speed flying — where you use your feet to jump off mountainsides to catch air, wearing wings — bit back, and he crashed while doing a barrel roll. “I made a mistake or two, which created line twists and sent me spiraling down until I crashed at about 50 mph.” He broke several vertebrae and sustained spinal cord damage at C7.

After being flown back home to Minnesota, he threw himself into rehab with his main goal to be as independent as possible. “After about seven months I felt like I hit a wall in therapy and realized I needed to continue my rehab on my own.” He also started a handcycling regimen

that made it clear adapted outdoor recreation was his therapy of choice.

Stone’s next goal was to hand cycle the famed Going to the Sun Road in Glacier National Park, which he completed on his one-year SCI anniversary, after 14 hours of cycling. Since then, mountain biking has become another one of his top adapted sports.

After his injury he formed the Joe Stone Foundation — with a mission to merge adaptive sports with able-bodied sports whenever possible — and last year the foundation partnered with the Wydaho Rendezvous Mountain Bike Festival to bring adaptive athletes to the event. He also does motivational speaking.

His secret to moving on? Endless progression. “This can be achieved with an open mind and a positive attitude. If you put all your focus on keeping an open mind and positive attitude, happiness will find you.”

Meet Joe at [thejoestonefoundation.com](http://thejoestonefoundation.com)

### Gas-Powered Go-Machine

Many outdoor power chairs claim king of the hill rights, but the TracFab chair made by two cousins in rural Pennsylvania may be the rightful heir. The cousins’ brainchild was initially invented for their ailing grandmother. Wanting to help grandma explore the family property, they installed rubber tracks on her scooter.

This design eventually morphed into the modern-day TracFab, which has rubberized tracks and either a 30-inch or 36-inch base. It also has a model that runs on gasoline, making it powerful and long-lasting in the energy department. The 30-inch model can also fit in most vans,



which is unheard of in the 4x4 chair market. Other noteworthy features include its exclusive patent-pending adjustable seat suspension, which changes “on the fly” depending on the surface you’re on.

The TracFab also has removable armrests to make transferring a cinch — a nice touch to see on such a beefy machine. Cost: \$11,995 (30-inch model) to \$13,995 (36-inch model).

### Real Life Tinder

It seems anyone who is single has tried Tinder, the popular dating app, and this includes singles with SCI. Kristen Parisi, 30, a paraplegic, gave it a whirl ... and many men split once they realized she had a spinal cord injury. Instead of taking it sitting down, she spoke out about her experience for *Cosmopolitan*. Read it here: <http://bit.ly/1JWdxTu>



**Eric Cook** I love the independence this chair provides me. It's extremely well-engineered.



# iLevel<sup>®</sup> is independence.

 **K. Francis** So glad to see this. Technology has made it possible now we need to make it probable for everyone everywhere.

 **M. Henson** I'm just weeks away from getting this chair and I can't wait. I've had an opportunity to use a demo for a week and this chair is a game changer.

 **D. Heilman** Flipping fantastic! Everyone deserves to look at another eye-to-eye... not up or down.

 **L. Boccuti** This is so great. My husband felt claustrophobic in his chair in a crowd because he was so far down. This would have helped that so much.



• MOBILITY VENTURES •  
**MV-1**<sup>®</sup>

**The Road  
to Freedom  
Starts Here.**

**[www.mv-1.us](http://www.mv-1.us) • 877-MV1-FORU • 877-681-3678**



**PROUDLY MADE IN THE USA**

**Mobility Ventures LLC  
an AM General Company**

Designed from the ground up for universal accessibility, the Mobility Ventures MV-1 is built for wheelchair and scooter users who demand the safest vehicle on the market.

**Visit our [website](http://www.mv-1.us) to find your local MV-1 dealer and learn more about this revolutionary vehicle.**



• MOBILITY VENTURES •  
**MV-1**<sup>®</sup>

# U.S. STEM CELL TRIALS SHOW ENCOURAGING RESULTS

INCLUDING IMPROVED HAND FUNCTION, SENSATION AND BLADDER AWARENESS

BY TIM GILMER

I remember talking with Christopher Reeve at his estate in Pound Ridge, New York, in September 2002, a year following the 9/11 disaster that changed the world. He wanted to talk about a different kind of change — his view that a cure for paralysis was imminent and embryonic stem cells would play a central role. He was angry that congressional support was lacking.

Now, finally, human stem cell trials for those of us with SCI and other neurological diseases are in progress and yielding promising results.

It took until 2010, six years after Reeve died, for the first human clinical trials involving human embryonic stem cells to get underway in the United States. It never got past the phase one safety arm of the trials. The Geron Corp. ran into funding problems from private investors and abandoned the trials in 2011. The company's original plan was to enroll 10 subjects in the study with acute, neurologically complete SCI (just seven-14 days post-injury). Only four received injections of about 2 million cells each. So far, no substantive neurological or functional changes have occurred in any of the enrollees.

The early difficulties of selling the stem cell gamble gave rise to wide-ranging research involving other types of stem cells. In the United States, perhaps the most promising clinical trial today involving humans with SCI are the Pathway trials, which use cells



"I absolutely see myself improving nonstop."  
— Michael Fraser, a C6 quad, one year after receiving neural stem cell injections in the Pathway clinical trials in the U.S.

derived from brain tissue of donated aborted fetuses. I asked Dr. Stephen Huhn of StemCells, Inc., the lead Pathway researcher, to explain the difference between embryonic stem cells and fetal neural cells.

"These neural stem cells are multipotent, which means they can only be neural cells," says Huhn. They do not grow tumors in mice, which has happened with embryonic [pluripotent] stem cells since they can become any type of cell. The risk is much greater with embryonic than multipotent cells."

From Huhn's mice studies, neural

stem cells were shown to grow into three types of central nervous system cells — neurons, astrocytes, and oligodendrocytes. "These cells then make neurons and myelin," says Huhn. "We have seen it in mice trials, microscopically. And the mice, whose spinal cords had been transected, then regained significant ambulatory function."

## FROM MICE TO HUMANS

OK, enough with the paralyzed mice. We've heard their miracle cure stories for decades.

Bring in the humans.

## AND EVEN BIGGER NEWS FROM CHINA:

"At one year after treatment, 75 percent (15/20) of the research participants in Kunming recovered the ability to walk long distances in a rolling walker with minimal assistance . . ."

— Dr. Wise Young, on the unexpected results of umbilical trials in China (see page 16)

The Pathway trials began in 2014 with 12 enrollees, all paras with thoracic injuries from T4 to T11 (seven ASIA A complete, five ASIA B). This was a safety cohort, with no problems reported at the end of one year. Each para received an injection of 20 million stem cells, a tenfold increase from the earlier Geron trials. The StemCells, Inc. website offers further positive info, which can be expected since they hope to attract investors, but is nonetheless encouraging: “Post-transplant gains in sensory function below the level of injury were demonstrated in half of the subjects. Two subjects converted from a complete injury to an incomplete injury and it has been further observed that one subject with an incomplete injury has shown signs of voluntary toe movement.”

But there was no control group, so the question remains, what improvements might have taken place without the injec-

tions? We will never know, but Huhn did admit that the ASIA B group [complete motor and incomplete sensory] “had a better response,” as might be expected.

The good news is the next phase of the Pathway study involves 40 C5-C7 incomplete quads. I spoke with two enrollees of an initial safety cohort who received stem cell injections in March and April of 2015 and had their final evaluations this year.

---

**Before the trial Fraser could barely lift a key, and he couldn't do anything with it. "At the end of 12 months, I could pick up a key and turn it in a lock and pick up coins and put them in a slot."**

---

They were excited about their results so far.

Michael Fraser, now 24, injured in July 2013 from a diving accident, went to Shepherd Center in Atlanta for his rehab. While there, his diagnosis was C6 ASIA A (complete) at two months post-injury.

By the time he had completed rehab and enrolled in the Pathway study, his diagnosis had improved to ASIA B (complete motor, incomplete sensory), a prerequisite for the study. He had his stem cell surgery (injections) at the University of Pittsburgh Medical Center in April 2015.

“At the time of my surgery, I didn't have hand or finger function, but I could grasp things weakly using tenodesis (when the thumb and forefinger close together). It was all from lifting my wrist, no finger function. I had no sensation in my legs, no touch, but could feel deep sensation. Now I have much greater sensation and awareness, stronger proprioception [body awareness].”

But what excites him is his overall improvement in strength. “Especially with transfers,” he says. “Before the surgery I was using a transfer board and having difficulty. Always had trouble with my legs, someone would have to grab them and throw them in bed for me. Now I can elevate and transfer without a board and bring my own legs into bed independently, using my wrist under my knee.”

During the trial, participants were evaluated at three-month intervals on a number of practical tests — picking up a key, putting coins in a jar, grasping screws. Prior to surgery he could pick up a key with difficulty but not do anything with it. Progress took time over the course of a year, with noticeable gains between six and nine months. “My balance and arm strength started improving a lot. At the end of 12 months, I could pick up a key and turn it in a lock and pick up coins and put them in a slot.”

Does he think these kinds of improvements might have happened without the stem cell implants? “I definitely feel the stem cells accelerated my improvement, strength and sensation. And one of the things they didn't measure was the breathing aspect of it. There's been a very big improvement. I had diaphragm issues with coughing and choking. Now I have a strong cough and sneeze. And I no longer get cold all the time. Whatever the temp is, I'm good with it.”

He sees this as the beginning, not the



## National Disability Voter Registration Week

*July 11-15, 2016*

[www.aapd.com/REVUP](http://www.aapd.com/REVUP)

final result. “I absolutely see myself improving nonstop. I plan on pushing myself every day. Even before the trial I was pushing myself intellectually and physically.”

It will be interesting to check in with him in a couple of years to see if his progress is ongoing.

## C4 QUAD MAKES SIMILAR GAINS AFTER INJECTIONS

James Mason, injured in April, 2013, was tagged a C4 complete quad at first, but like Fraser, he improved to a C4 ASIA B classification before enrolling in the Pathway trial. He also rehabbed at the Shepherd Center, and in March 2015 received neural stem cell injections at Mount Sinai Medical Center in New York City.

“One of the main things was my blood pressure got a lot better,” says Mason. “Before the trials started I used to have to take one pill a day to treat low blood pressure, plus on days when I would be suspended in a harness over a treadmill, I took an extra pill so I wouldn’t get autonomic dysreflexia. At first I would almost pass out. Now I no longer take any BP meds, and I don’t have AD when on the treadmill, and this is with no BP meds. My heart rate is also better, not so slow, so I’m also weaning off that medication.”

Mason also participated in functional tests, like Fraser. Prior to injections, he could not pick up a key from a table. One month later it was about the same. “At three months I was able to pinch it and pick it up but dropped it right away. At six months I picked it up and almost inserted it in the slot. And at 12 months I went further and inserted it, but couldn’t turn it.”

In the last month or two, since his 12-month evaluation, he says he has been getting progressively stronger, with increased sensation. And his bladder control has improved. “Before the trial, when I would clamp off my indwelling catheter, I would not be able to tell when I had an urge to pee, and I would get AD. That would tell me I had to pee. Now I can clamp off my cath and feel the urge to pee when my bladder gets full, so I can unclamp it and pee. Also, before I had to have Botox injections for my bladder every few months. I haven’t had any injections since the stem cell injections.” It’s been more than a year and counting since he’s needed those Botox injections.

One of his biggest improvements, he says, is improved core strength, a major improvement for a C4 complete quad with some sensation. “I’ve always been motivated to work hard, but since the stem cell gains started happening, I’ve been even more motivated.” He maintains a busy workout schedule, working with a personal trainer one day a week on the treadmill harness, and also rowing, crawling and doing assisted pushups and other rehab activities. Wednesdays and Fridays he does FES bike riding for his legs. On Thursdays he does the FES arm bike and the Lokomat.

At home he uses a stim unit on his back and wrists, and he can literally feel the results in his abs. “I can feel my stomach muscles begin to fire with the back stim unit — not normal sensation — but I can feel it happening.”

Perhaps the most practical day-to-day improvement is that he is now transitioning from a power chair to a manual chair. He says he intends to keep working out. “My doctor feels that I may keep making progress for as long as another 10 years or so.”



Since stem cell treatment, James Mason has transitioned from a power chair to a manual chair.

An advertisement for Mallinckrodt Pharmaceuticals. On the left is a close-up, black and white photograph of a woman's face, looking slightly to the right. Her eyes are a striking, vibrant blue. The background is dark with a subtle geometric pattern of triangles. On the right, the text reads: "SEEING COMPLEXITY IN A NEW LIGHT." Below this, it says: "For nearly 150 years, Mallinckrodt has made complex scientific problems manageable, developing valuable treatments and diagnostic tools for patients who need them. We view challenges as opportunities. See how at [Mallinckrodt.com](http://Mallinckrodt.com)". At the bottom right is the Mallinckrodt Pharmaceuticals logo, which consists of a stylized 'M' made of colorful geometric shapes, followed by the text "Mallinckrodt Pharmaceuticals" and the tagline "Managing complexity. Improving lives." At the very bottom, in small text, it says: "Mallinckrodt, the 'M' brand mark and the Mallinckrodt Pharmaceuticals logo are trademarks of a Mallinckrodt company. © 2016 Mallinckrodt. June 2016".

# CHINA TRIALS RESULT IN WALKING

One of the most respected SCI researchers, Dr. Wise Young, has been involved for many years with organizing and overseeing research protocols and trials in China and other countries. As of the writing of this article, very promising trial results involving implantation of umbilical cord blood mononuclear cells [UCBMNC] into people with chronic complete injuries were in the process of being published in the journal, *Cell Transplantation*. NEW MOBILITY will publish a full feature article on this most recent work of Young in our July Issue.

In the meantime, Young, in a letter sent in May from the Keck Research Center, his academic and research home in New Jersey, reports the exciting and unexpected results of the trials.

Eight subjects in Hong Kong with chronic complete SCI received injections of 100,000 UCBMNC above and below the injury. None of them recovered motor function, but imaging of the spinal cords suggested that at least two had fibers that regenerated across the injury and the trial showed the transplants were safe. In the second part of the trial, in Kunming, 20 subjects received similar UCBMNC treatments but also underwent extensive locomotor training six hours a day, six days a week, for three to six months.

Young went on to write:

*"At one year after treatment, 75 percent (15/20) of the subjects in Kunming recovered the ability to walk long distances in a rolling walker with minimal assistance (If necessary, a person walked behind with ropes tied to the legs to prevent the knees from buckling.) Thirty-five percent (7/20) could walk without such assistance using either a four-point walker or crutches. ... When they went home, some of the subjects did not have devices or people to help them walk and several regressed. However, 35 percent continued*

*to walk and became household walkers, preferring to walk for distances up to 100 meters, but using their wheelchairs for longer distances. Another unexpected finding was that 60 percent of the subjects became completely independent including no longer needing any help for bladder and bowel function. In fact, 55 percent stopped using catheters."*

"We were quite stunned by these results," Young said in discussing the results with NEW MOBILITY. "We believe that there's an important lesson to be learned in the two papers. The stark difference between recovery in Hong Kong versus the recovery in Kunming, we believe, is due to the presence of the intensive walking program. ... In other words, if you don't exercise and do intensive walking training, you will not recover any function no matter what you transplant in.

"That's the point of our paper, and I think it's a very important lesson. In fact, it really opens up the question whether more therapies would work if people actually trained."



Dr. Wise Young is known for his involvement with SCI communities both in the U.S. and around the world.

**35 percent became household walkers.**  
**60 percent regained bladder and bowel function.**  
**55 percent stopped using catheters.**

## OTHER U.S. HUMAN STEM CELL TRIALS

At least two additional stem cell trials are either underway or have recently been completed. Neuralstem has completed a study on four ASIA A complete thoracic paras, levels T4-T12, all of whom were injected with neural stem cells as of July 2015. Each of the subjects was one to two years post-injury at the time of injection.

In October 2015, Dr. Joseph Ciacchi, lead researcher at University of California, San Diego, reported that at the three-month mark there had been no serious adverse events. In other words, the

goal of establishing the safety of the trial was apparently accomplished. The study was estimated to have ended by March 2016, with secondary measures of graft survival and immunosuppression results included.

On the functional side of the trial, an exploratory outcome that runs for 60 months (until 2020) will compare baseline and post-transplantation motor and sensory changes, as well as bladder and bowel function.

NEW MOBILITY made repeated attempts to speak with researchers involved in this study. Initial contact with a

nurse involved with the study succeeded, but no researcher was available for comment at press time.

A third stem cell trial brings us back to the beginning of this article.

When Geron Corp. suspended its embryonic stem cell trial in 2011, some company employees re-gathered to form a spin-off company, Asterias Biotherapeutics, with the intention of carrying out the aborted Geron trial and going on from there. A new study involving ASIA (complete) C5-C7 quads began in March 2015.

The new trial seeks to enroll 13 subjects from 14 to 30 days post-injury and

inject them with from 2 million to 20 million cells from the same source of embryonic cells that had previously been owned by Geron. The safety arm of the trial was scheduled to end one year from injection. Secondary outcomes measuring upper extremity motor levels are to be measured at one, two, three, six and 12 months from injection.

The estimated completion date of the overall study is June 2018. **MM**

## HOW TO ENROLL IN SCI STEM CELL TRIALS

**S**tem cell trials for people with SCI are still in the relatively early stages of development. In addition to the three studies listed below (one currently closed), a new study based on Dr. Wise Young's trials in China with umbilical cord blood cells will begin in the United States as early as the end of 2016, but more likely in 2017. For more on this see our July issue.

### CURRENT TRIALS

- StemCells Inc. (Pathway, C4-C7 complete and incomplete SCI). Study is ongoing and recruiting at least through September 2016, with 12 medical facilities participating. For complete list, go to: [tinyurl.com/z4ugjeu](http://tinyurl.com/z4ugjeu); [www.sciresearchstudy.com](http://www.sciresearchstudy.com)
- Asterias Biotherapeutics (SCIStar, C5-C7 complete, 14-30 days following injury). Study is ongoing and recruiting at six locations in United States. For specific locations, go to: [tinyurl.com/zv6po2p](http://tinyurl.com/zv6po2p); [asteriasbiotherapeutics.com/](http://asteriasbiotherapeutics.com/)
- Neuralstem Trials (T2-T12 chronic complete SCI): Study is ongoing but not currently recruiting subjects. No test results have been reported as of mid-May 2016. For more info go to [tinyurl.com/hr35vmq](http://tinyurl.com/hr35vmq); [www.neuralstem.com/cell-therapy-for-sci](http://www.neuralstem.com/cell-therapy-for-sci)
- Hundreds of clinical trials involving SCI have been or still are ongoing in areas other than stem cell research. For a current, complete list of U.S. SCI Studies, open and closed, all types, go to: [tinyurl.com/zsagpq8](http://tinyurl.com/zsagpq8).



**astellas**

## Changing Tomorrow, Together

**At Astellas, we believe we can make a real impact on the future.**

That's why we are fully committed to developing medicines that make a difference where they're needed most, in areas like oncology, urology, cardiology and transplant. It's also why we focus on bringing together a diverse group of people with a common goal: to help transform lives. Whether it's in the office, the laboratory or the community, **we're working together to change tomorrow.**

[in](#) [f](#) [t](#) @AstellasUS [www.astellas.us](http://www.astellas.us)



**TOPOLINO TECHNOLOGY**

Engineered For Life

203.778.4711  
[topolinotech.com](http://topolinotech.com)

 **Handmade in the USA**

# WHY WE *Roll*

## UP CLOSE AND PERSONAL WITH ATTENDEES OF THE 2016 ROLL ON CAPITOL HILL

BY MAUREEN GAZDA

At the heart of all advocacy efforts are the advocates themselves — the people who find the time to tell their stories and make their needs and voices heard. Since United Spinal's first Roll on Capitol Hill five years ago, hundreds of passionate wheelchair users and members of the SCI/D community have trekked to Washington, D.C., to make sure that their representatives understand the needs of our community. This June 26-29, attendees will storm Capitol Hill to carry on the fight for a wide range of issues, including: access to complex rehab technology, the Disability Integration Act, Medicare and Medicaid reforms, SCI research, accessible transportation and much more. With over 100 attendees registered so far, this year's group is already the largest in the event's five-year history, and the most geographically diverse, with rollers hailing from 32 states, Washington, D.C., and Puerto Rico. Before they tell their stories to America's policy makers, we thought we'd have them tell you why they are excited about rolling on our nation's capital.

### **Gary Karp**

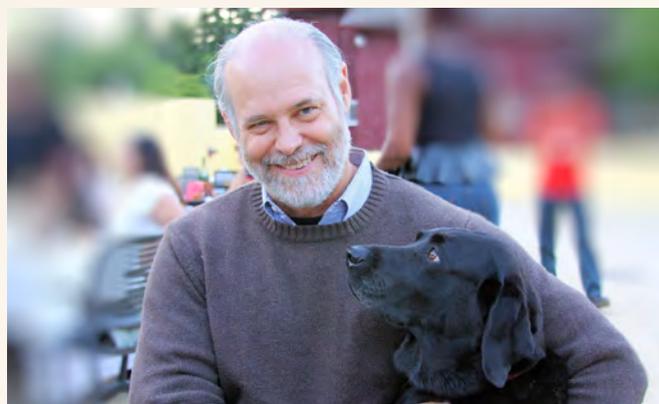
*Tempe, Arizona*

*United Spinal Board Member*

*First Time at ROCH*

A professional juggler, an architect, and an SCI hall of famer — those are just some of the roles Gary Karp has filled in his illustrious career. But topping his extensive resume is his 20-plus years as a notable author, motivational speaker and civil rights pioneer for the modern wheelchair user and disability community. A T12 paraplegic for over 40 years, Karp has traversed the country speaking at more than 70 colleges and universities, rehab centers and conferences, encouraging those with disabilities to realize their full potential and urging the nondisabled community to look beyond the wheelchair. He joined the United Spinal board earlier this year, and now he is setting his sights on Congress as a first-time attendee of the Roll on Capitol Hill.

"I'm looking forward to trying to shift the perspective of legislators to understand disability as a natural human experience that is much less about loss and limitation and much more about adaptation and possibility," Karp says. "We need



**Gary Karp**

the broader society to recognize that the capacity of people with disabilities of all kinds is being unleashed by a radical, historic transformation. We're getting stuff out of people's way, steps, lack of restrooms, limits in transportation and housing, doubts of employers that we can contribute on par with others. People have an innate right to pursue their optimal independence. It's actually no different from the democratic right to the pursuit of happiness."

Karp was injured falling from a tree in 1973 and found himself facing an inhospitable environment. Then 18, he had to be physically carried in and out of his architectural classes because the building was completely inaccessible. Incensed by the lack of accommodations for wheelchair users, Karp became his own advocate and launched a successful campaign to make the building and campus more wheelchair friendly. This was the beginning of Karp's fervent quest for widespread accessibility on behalf of the disabled population.

A debilitating hand injury cut Karp's architecture career short, and he went from designing plans for homes and buildings to pursuing his passion of helping others with spinal cord injuries design and rebuild a plan for their lives. He was inducted into the SCI Hall of Fame in November 2007 for his numerous contributions to the SCI community.

Karp is looking forward to ROCH and addressing congressional leaders about the importance and need for innovative



Hand on her chin, Alicia Reagan listens intently.

and reliable equipment to allow wheelchair users to achieve their full potential. “Since 1973, I’ve obviously been the beneficiary of an amazing level of advancement in wheelchair design,” Karp explains. “So I know how much of a difference the right chair makes in a person’s life. In fact, being denied the optimal chair costs people their potential — and so costs the rest of us their contributions. Even worse, someone in the wrong chair is prone to chronic health issues like skin breakdown, arm, shoulder, and back damage, if not undue fatigue and energy loss, compromising their quality of life.”

He says that state-of-the-art mobility equipment is invaluable and essential to creating a society where those with disabilities can contribute their talents. “They will be healthier and put less demand on the health care system, and they will work instead of being trapped in the entitlement system where they don’t want to be and don’t belong,” says Karp. “They will contribute more to their families, their communities, and in the workplace where they can bring their skills and creativity and productivity to bear. Family members will be freed of the demands of unnecessary caregiving and the financial burdens on the family.”

### **Alicia Reagan**

*Leesville, South Carolina*

*Blogger, Mom*

*Second Time at ROCH*

Alicia Reagan attended the 2015 Roll on Capitol Hill and can’t wait to get back to D.C. this summer. “After spending the day on the Hill, pouring your heart and soul into every conversation, you came back exhausted but it felt so wonderful,” she says. “You knew that your day had purpose and meaning and it was because of your story. That is a really good feeling.”

Reagan has lived with transverse myelitis since 2009. She says the birth of her son — her sixth child — four months after she became paralyzed, helped to renew her faith that her new reality was not a death sentence. “My life as a wife and momma to a bunch of kids changed drastically. But, one thing is the same. I am still happily married and now a mom to six wonderful children. Every day of life that is given to me is such a precious gift,” Reagan says.

Seven years later, Reagan has channeled her glass-half-full mentality into a successful blog called “This Enabled Life,” where she advocates on behalf of the disabled community and writes about her family, her faith, and the ups and downs of life in a wheelchair. “It has changed my life in many horrible and wonderful ways. I love to talk about it all. The good, the bad, and the ugly.”

This will be Reagan’s second year attending the Roll on Capitol Hill. She says the event is a way to actively make a difference and allows the disability community to express their needs, wants and concerns to government officials. “I am a passionate believer that we have no right to complain about any of our hardships unless we are willing to personally be a part of doing something about it. This is just one other way I can use my voice to help make changes for now and for the future,” she says.

“More people are realizing that if we do not get personally involved, changes will not happen. It is pretty addicting to go and be a part of something so important and fuel off of one another. Once it gets in your blood, you talk about it and then more want to be involved with you. I believe that is why it has grown and why it will continue to grow.”

In addition to advocating for things such as increased wheelchair accessibility, affordable adaptive equipment, health care, and jobs, Reagan says the event allows her to connect with others, learn about their lives and take a stand together.

“I love learning what others in the disability community are accomplishing in their advocacy efforts. I look forward to reuniting with friends, meeting with our legislators, and coming home prepared to tackle local issues,” she says. “It is so fun to meet others, hear their stories, watch them gain confidence in speaking up for themselves, and develop friendships that last all year long.”

“There were three other ladies that I was friends with on Facebook but we had never met in person,” explains Reagan. One of the nights we did a girl’s night and thoroughly enjoyed sharing stories, tips and ideas of our lives as women with disabilities. It was a cherished memory we all went away with.”

### **Namel Norris**

*New York, New York*

*Hip Hop Artist*

*First Time at ROCH*

Namel Norris, known by his stage name, “Tap Waterz,” is part of a successful hip-hop group called “4 Wheel City.” The group



Namel Norris

has gained global recognition and is committed to showcasing the talents and potential of those with disabilities. Having already made a mark on the music scene, Norris is looking forward to doing the same on Capitol Hill.

"I'm attending ROCH because I feel like I have a purpose and reason to be there, to represent the people who feel the way I do about disability issues," he explains. "I've had several trips to Washington, D.C., within the past months, which included a meeting in the White House, a performance on Capitol Hill and at the AAPD Awards Gala. Attending ROCH will be an extension of those experiences and give me the opportunity to further the groundwork laid down over the past months."

Norris sustained a T2 spinal cord injury from accidental gun violence in 1999. A teenager at the time, he initially struggled with his new limitations, but soon developed a positive attitude and went on to go to college and earn a degree in business management.

Through 4 Wheel City he has found a powerful voice. "Our mission is to inspire others with our music and story to never give up, to show the world that people with disabilities still have talent and deserve to be treated equally," Norris says.

Norris is excited to talk with congressional leaders about issues dealing with disability rights and gun violence, to name a few. "I am hoping to meet with my representatives and begin to build relationships with them that will lead to the changes I want to see in this country," he explains. "I'm looking forward to bringing more awareness to disability rights, gun violence, poverty issues, police brutality, and making new relationships



No stranger to advocacy, Namel Norris attended a meeting at the White House this past December to talk about disability and poverty.

with elected officials and other attendees."

An avid social media user, Norris is also looking forward to forging bonds and friendships with fellow ROCH attendees. "The social aspect is the icing on the cake of the ROCH," he says. "Mainly because it provides an opportunity to expand and share ideas even further, especially in these times of social media. I think it adds layers of potential for change outside of just the meetings themselves."

Norris feels fortunate to have the opportunity to take part in ROCH and hopes his voice can make a difference, even in a small way. "The fact that a person like myself from the streets of the Bronx will be attending to speak on behalf of my movement is a testament to why its longevity is important," he explains. "It gives those who would never have a chance to do such a thing a chance to make a difference."



Different models to meet specific needs!



For Home AND On-The-Road

Mobility Solutions

VA contract V797D-30180

## GO-ANYWHERE Chairs

"When Ya Gotta Go, We Go With Ya!"

- Safe, Practical, Convenient, Portable
- Won't rust, easy to clean.
- Simple to assemble; no tools required.
- Numerous optional accessories

Come See Our New Ultralight "Sport" Model!

[www.GoesAnywhere.com](http://www.GoesAnywhere.com) | [Sales@GoesAnywhere.com](mailto:Sales@GoesAnywhere.com) | 800-359-4021

## Daniela Castagnino

Washington, D.C.

United Spinal Resource Center employee

Fifth time at ROCH

She might be a United Spinal Association staff member, but Daniela Castagnino is attending the Roll on Capitol Hill for much more personal reasons. “As a disabled person myself, I have a vested interest in presenting our issues before Congress,” Castagnino explains. “The laws and statutes that Congress passes affect people on a daily basis, and our politicians need to understand that.”

Castagnino sustained a C4-5 level spinal cord injury from a car accident six months after she graduated from the University



Daniela Castagnino attended last year's ROCH with her boyfriend, Matt.

of Virginia. She soon realized she wanted to make a difference for the disabled population, moved to Washington in 2001 and ended up working for what has since become the United Spinal Resource Center.

As a staffer, Castagnino brings the unique perspective of having attended ROCH in previous years, and playing an integral part in the planning process year-round. She has enjoyed watching the event grow and improve. “We are better organized and have better representation from more states around the country,” she says.

Castagnino says ROCH has made major progress on a government level and has helped create positive momentum for the active wheelchair user. “It’s always heartening when you’re able to get endorsements or acknowledgments of support from a new congressperson,” she says. “These are the people we need to get on board with our issues if we want to instill change and improvements in the quality of life of our members.”

Working for United Spinal Association has allowed her to become invested in the many issues facing wheelchair users and develop close bonds with members. Along with striving to make a difference, the camaraderie is her favorite part of the event. She talks with members from across the country all year in her job and relishes putting faces to names and voices.

“I love meeting new people every year from all corners of our nation and reconnecting with those who have attended in the past,” Castagnino says. “Spending time with ‘real people’ every year tends to revitalize us and re-energize us for years to come.”

MI

# BOLD FOR LIFE

We are a bold, global pharmaceutical company and a leader in a new industry model – Growth Pharma. Our world-class team develops, manufactures and commercializes innovative branded pharmaceuticals and biologic products for patients around the world.

We are one team of dedicated employees, carving new paths, taking bold, decisive actions to deliver results and better outcomes for patients and providers.

[www.Allergan.com](http://www.Allergan.com)

 Allergan

DO YOU HAVE A RELIABLE SOLUTION TO YOUR BOWEL PROGRAM?

# CEO-TWO<sup>®</sup>

Laxative Suppositories



Use CEO-TWO<sup>®</sup> Laxative Suppositories as part of your bowel program. These unique CO<sub>2</sub>-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 suppositories .....NDC #0283-0808-11  
Box of 6 suppositories .....NDC #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](http://www.amazon.com)



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

# BREAKUP WAKE UP

BY KATE MATELAN



Illustration by Mark Weber

## *How Do You Cope When a Relationship Ends?*

**F**our years and a dog later, my ex-boyfriend somewhat unexpectedly ended our relationship. When we moved in together years prior, I changed my attendant care and got comfortable having an extra set of hands. After he packed up, and amongst balled-up tissues, I had worries beyond the single life. I came to the realization: a long-term, live-in relationship on wheels brings a whole new set of breakup dilemmas.

My ex moved out and left me hanging — not just as my boyfriend and best friend, but as the person I relied on for some daily help. Making dinner (parts of it), getting groceries with me, buttoning my blouses, helping me with a bandage on my back, moving couches to get a misplaced dog toy. Hell, he even lovingly and willingly helped me change over and over one night during a bout of stomach flu.

Despite everything we had been through,

“What have I learned? For one, my friends, family and current attendants are always in my corner — keep them close no matter what.”





he still felt the need to leave. I remember our sitting down to eat dinner on a Monday night — he kept moving the food around on his plate. Being that it was very unlike him to not be on a second helping of his favorite meal, I asked him what was wrong. “I think we need to take a break, Kate,” was all he could muster. At first I thought he was joking, but then his eyes had me believing every word. I instantly began to cry and wanted to throw up, yet somehow I asked, “Is this a break or are you leaving me for good?” As you can tell from the article thus far, it was for good.

I had a million questions. I thought this was the man I was going to marry. This was the guy I had lived with for two years. We bought a dog together. He was an uncle to my nieces and nephew, just without the official title. He was a second son to my dad. I was a part of his family! His life! I didn’t see it coming — he gave no indication that weekend, that morning, on my phone call on the way home from work.

Looking back, I know our relationship wasn’t in the best place. After a nitpicky fight, my ex told me he wasn’t feeling

happy about a month before our breakup, but he gave no mention after our conversation that he was feeling that unhappy. I assumed he was working on it or would reach out to me for help if he needed it. Apparently I was wrong. My ex said he needed time to work on himself, find his happy — he couldn’t do it together and he couldn’t commit to ever getting back together. “I can’t predict the future,” he said.

As devastating and complicated as my situation was, at least it happened before we had taken the next step.



Dave, 38, a C6-7 quad and father of three, saw his 10-year marriage take a nosedive soon after he was paralyzed and his third child was born.

“My marriage was strained before my injury. In our relationship, I was the easy-going guy and she was the controller. I think it was overwhelming for her to control everything and that was ultimately the final straw. I ended up being the lowest hanging fruit that could be expelled.”

PROTECTING  
ACCESS  
TO  
COMPLEX  
REHAB  
TECHNOLOGY

**NCART**  
National Coalition For Assistive & Rehab Technology

[www.ncart.us](http://www.ncart.us)

TELADOC

The **Relentless**  
Pursuit of **Better.**

[www.teladoc.com](http://www.teladoc.com) | #RelentlessPursuitofAccessibility

While his ex-wife wasn't as intertwined due to their rocky relationship, he picked up more hours with caregivers to compensate for her void. Dave also experienced another angle of a breakup when the lawyers got involved.

"Divorce proceedings lock you down from a financial perspective," he explained. "I had to postpone getting a car for over a year until the divorce was finished. Otherwise, the van would be considered an asset and divided in half. I felt like I was being held hostage on multiple levels."

Dependency is a tricky subject. Dave mentioned how you "feel abandoned at some point" when some of that is gone. In any relationship, we rely on our partner, physically and emotionally. For a chair user living with another person, the rules can be blurred and the dependency more real.

For example, I had my ex pull the dry laundry out of the top loader (the joys of apartment living), letting me do laundry at any time and in any order. Now, I have to make sure I have someone there at the end of the cycle, or have clothes that can

sit and not wrinkle until help arrives later. It might sound small, but it was monumental. I went from being unplanned to having to choose what gets washed and dried when.

The same freedom applied to something like my jewelry. I could wear whatever pieces I wanted to — necklace clasps

---

**"We rely on our partner, physically and emotionally. For a chair user living with another person, the rules can be blurred and the dependency more real."**

---

or tricky earrings were no match! I knew my ex would be there at the end of the night and could help me take off the day ... maybe even in more ways than one (if you catch my drift).

Beyond the actual help, he had been there on many more levels. On a Friday

night, I didn't have to have plans all lined up because he was going to be a part of the planned and unplanned adventures. I didn't have to worry if I was headed to a friend's house with steps; he could carry me and my chair.

I'm now mapping out my weeks and weekends, getting used to eating on my own, making sure I have the right muscle waiting to lift, dealing with an empty apartment without him and our pup. There was such an emptiness in my bed, not having him beside me, one arm wrapped around my chest and another rubbing my head.

Most importantly, he was my best friend, the person I told everything to. I shared my fears and entire medical life and history to him, something I had never felt comfortable doing with any other boyfriend, or really, man. He knew my vulnerabilities and had supported me on the good days and the bad. He laughed it off when I leaked pee from my belly button and made me smile when he jokingly called my medical drawstring bag a S.U.B. (Special Utilities Bag) for code (calling it anything else in public can be

**Proud to be a  
continued partner!**

*Working together,  
To empower each other.*

**verizon** ✓

Verizon.com/Responsibility

## The Para Ladder®

### A Stairway to Independence

The Para Ladder provides safe floor transfers for wheelchair users. Able-bodied users can go from the floor to standing position.

Minimize Staff Workers' Comp claims and insurance cost from lower back injuries resulting from lifting patients



**We Care Designs**

VA Approved • [www.paraladder.com](http://www.paraladder.com)  
877-288-4988 • U.S. & Foreign Patented



dicey). He offered advice and loved me unconditionally, even when my type A personality kicked into overdrive.

The impacts and layers to a breakup on wheels continue well past someone ending the relationship or moving out. I've lived it, and continue to live it, so there are unexpected reminders whenever I roll.

What have I learned? For one, my friends, family, and current attendants are always in my corner — keep them close no matter what. When my ex split, they were the first ones to help me fill the void, force me to eat a real meal, and pick up extra hours with my care. Even today I rely on them for the physical and emotional support that I lost. It's hard to depend on them in new ways or explain everything I'm going through, but I've allowed myself to ask for the extra help as I transition into my new normal. We're growing together — or at least that's what I tell myself. I also learned getting too comfortable with someone can bite you in the ass.

I can't believe a smart, successful

woman like me found myself where I am today. I'd like to think I am self-aware and that I surround myself with people who love me enough to work through the so-called "tough stuff." Maybe I was wrapped up in thinking we'd get through everything and that our love was no match for any bumps along the way.

Turns out, I was working on the relationship and he wasn't. It didn't become evident until I looked back after he left. I know I need an equal partner by my side because let's face it, love is work, life is work, and adding a chair in there is work. BUT all that work is worth it when it's with and for the right person.

Going forward, I think it's crucial to still blend two lives — that's part of any relationship! There's nothing wrong with adjusting your care and routine slightly, but be sure you can make a few nursing calls or small life changes if your relationship bottoms out. Invest in your other half and take care of yourself, or have more than one other half — if that's how you roll!

MM



*As founder of NBMS, I truly understand the challenge and complications you face for obtaining and using the right catheter. You see I not only supply catheters — I rely on them.*

*Sincerely,  
Joe Paladino*

## Not Happy With Your CATHETER SUPPLIES?

**WE TREAT OUR  
CUSTOMERS LIKE FAMILY.**

**One-on-one service. Every time.  
No call centers.**

*We accept Medicaid, Medicare  
and Independent Insurance*

**FREE Delivery**

**Call Today**

Local/Fax: 860-224-9017

Toll Free: 855-332-0285



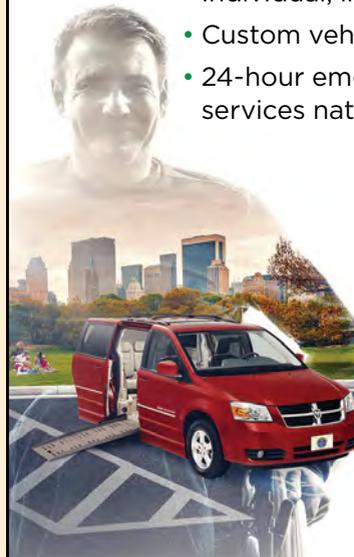
74 VINE STREET • NEW BRITAIN, CT 06052  
WWW.NEWBRITAINMEDICALSUPPLIES.COM

## Safety. Confidence. Dedication.

That's what a QAP-accredited  
mobility dealer can do for you.

The National Mobility Equipment Dealers Association's Quality Assurance Program™ ensures quality, reliability and service when modifying vehicles to be accessible for all with:

- Individual, in-person evaluations
- Custom vehicle modifications
- 24-hour emergency roadside services nationwide



**Put your safety first.  
Find a QAP-accredited  
mobility dealer near you.**



(866) 948-8341  
NMEDA.com  
Proud Sponsor of  
Roll on Capitol Hill



# CLAIM MORE

# S P A C E

WIN **\$10,000** TOWARD A NEW VMI VAN  
PLUS **GAS FOR A YEAR** 



## ENTER TO WIN!

Visit [vmivans.com](http://vmivans.com) or call  
a VMI Customer Advocate at  
**855-VMI-VANS** (864-8267)

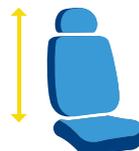
With flexible seating, ample headroom, and enough floor space to execute a full 360° turn, VMI vans offer enough room for the entire family, and allow even the largest power wheelchairs to maneuver with comfort and ease.



**BRING  
EVERYONE**



**USE ANY  
WHEELCHAIR**



**ACCOMMODATE  
ANY HEIGHT**



**MANEUVER  
360°**

# Discovering the Real Atlantis

## An *Almost* Accessible Island Resort

BY ELLEN STOHL

Somewhere under the deep blue sea, the mythic lost city of Atlantis may lie in wait, holding secrets beyond our imagination. But when it came time to plan my family's trip last summer, my husband, daughter and I were happy to settle for the more real — and much more commercial — Atlantis Resort, a gigantic tourist wonderland just off the coast of Nassau in the Bahamas.

Since its inception in 1998, Atlantis Resort has spread to cover almost every inch of the aptly named Paradise Island's 1.1 square miles with every conceivable tourist draw, from Broadway-caliber theater to turquoise lagoons where you can swim with dolphins, to nearly 20 water slides and beautiful beaches where you can sop up the sun. The tourist map you receive when booking a trip is so dense with attractions, restaurants and shops as to be almost overwhelming.

Trying to wrap my head around the resort's accessibility and the best ways to maximize our four nights and five days considering my needs as a manual wheelchair user proved daunting. Luckily the resort has published an extensive access guide with answers to many of the common questions about accessible rooms, attractions and more. It's important to note that the Bahamas are not part of the United States and are not required to comply with the Americans with Disabilities Act. Unsure of the implications of this reality, I touched base with John Sage, a T4 incomplete para who has spent considerable time in the region running his accessible travel services, Sage Travel-

ing and Accessible Caribbean Vacations. "In the Caribbean there is not always ideal accessibility, but there is the right attitude," he said. "Most people are eager to please and will often come up with creative solutions to help someone with a

disability get where they need to go or do what they want to do." He finds Nassau and Paradise Island to be more accessible than many other Caribbean destinations, but warned that "the main island and Paradise Island have hills. Also, in addi-



Ellen Stohl, her husband, David, and her daughter, Zoe, enjoyed their Atlantis stay.



John Sage

tion to the steepness of natural features, the bridge from the cruise terminal to Paradise Island is long and high and too difficult for a manual wheelchair user to push over by themselves.”

## Finding Paradise

Choosing the right accommodations is always important, but even more so at Atlantis. Why? Because the island is huge (for a wheeler) and there are no accessible shuttles to help you get from place to place. Routes are paved and there are accessible paths of travel to all exhibits, but some exhibits require a specific route for accessibility, and they are not always clearly marked. Most guests use the resort shuttle to cover the mile-long island’s many routes, but wheelchair users are out of luck. As Sage says, “Getting around in a manual chair can be tiresome and time consuming.” We often found ourselves running late for reservations and questioning our decision not to stay in the centrally located Royal Towers.

Of the resort’s hundreds, if not thousands, of rooms to choose from, only 30 are deemed “accessible,” with safety bars, lowered sinks and roll-in showers — 12 housed in the Royal Towers. We chose to stay at The Reef, one of the two luxury towers at the west end of the island. The suites at The Reef offer full kitchens. After reading many travel reviews about the high cost of food at the resort, I figured getting groceries from town and cooking our own food would save us money and balance out the higher-end accommodations. Staying at the luxury level hotels, The Reef or The Cove, also gets you access to a private beach and pools. My hus-

## The Curious Case of Accessible Caribbean Transportation

Between cruises and flights, getting to Atlantis and other Caribbean resorts is relatively easy and cheap. Getting around on the islands once you’re there? Well, that’s a whole other matter.

Like many resorts, The Atlantis offers a variety of shuttle services to the main island, including an accessible van. However, it costs \$288 roundtrip for the accessible van shuttle. It does include transport for up to eight adults. Compare that with the \$33 cost of an individual roundtrip on a bus. If you have a large party, maybe you can justify the \$288 — maybe — but if there are less than eight passengers, the cost of the short ride feels a bit unfair. Limos, town cars, and SUVs are also a choice, but they are as spendy as the accessible van and require the ability to transfer.

After speaking with John Sage, the founder of Accessible Caribbean Vacations, about his experience, I learned that accessible vehicles anywhere in the Caribbean are hard to come by due to the high import tax on vehicles. “There are only three wheelchair accessible vans between Nassau and Paradise Island, and rarely are all of them operational at the same time. Additionally, the demand for accessible vans can be huge when cruise ships arrive. If you need a wheelchair accessible van in Nassau, be sure to book it weeks or months in advance.” Accessible Caribbean Vacations offers several shore excursions to Atlantis if you’re visiting Nassau as part of a cruise destination, and all of them include fully accessible van transportation.



What trip to the Caribbean would be complete without swimming with dolphins?

band is not a big fan of crowds and neither am I. Navigating through hordes of tourists in a wheelchair can get tiresome, so having an option to relax away from the hustle of the bustling Aquaventure Park was on our “must have” list.

Our suite at The Reef was experiencing electrical problems, so we were upgraded to a room at The Cove. I was offered an accessible room, but it was on the first floor and I didn’t want to give up the view. So we stayed on the 19th floor and had a spectacular view. The room was not labeled as accessible, but it was very roomy. With only a shower bench from housekeeping, I was easily able to complete my activities of daily living with minimal assistance from my family.

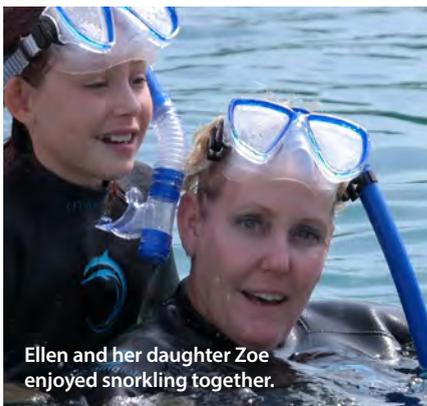
With a few more adaptations and pieces of adaptive equipment, the room could become fully accessible to all guests except those with the highest level of mobility issues.

## So Much to Do, So Little Time

To plan our agenda we revisited our “must have” list. Swimming with dolphins was a must for me and my daughter, while my husband insisted we find time to snorkel and relax — beach or pool side. All of us wanted to experience the wild water slides and amazing marine life and see the iconic Tony Ben-



It was as if the dolphin knew Stohl needed extra support to swim across the lagoon.



Ellen and her daughter Zoe enjoyed snorkeling together.

nett with Lady Gaga on the Atlantis Live stage. There were so many possibilities that my head was spinning each time I tried to execute the perfect vacation plan and maintain a realistic budget.

This resort has something for everyone. A Vegas-esque casino, 11 swimming pools, gorgeous beaches, gourmet restaurants and awe-inspiring water experiences for every age and ability. The resort is also home to the world's largest open-air marine habitat, which includes 14 lagoons with more than 250 species and 50,000 aquatic animals, including giant rays, sawfish, piranha, barracuda, tropical fish and more.

There is also a marina village filled with shops, 40 different restaurants, bars and lounges, and Aquaventure, a 141-acre lushly landscaped area full of thrilling water experiences and slides.

Aquaventure is home to Dolphin Cay, a state-of-the-art dolphin education center and interaction habitat. Dolphin Cay offers a number of options for guests who want to get up close and personal with the dolphins. We chose the Deep Water Swim based on the Access Guide's clear

indication that it was open to guests with special needs so long as they inform the staff in advance of their booking.

When we showed up, the staff was incredibly helpful and open to suggestions. We got to touch, kiss, feed and swim with the dolphins in their habitat. The final thrill was Dolphin Cay's signature "foot push," where a powerful dolphin propels you across the lagoon for an amazing rush. The "foot push" requires guests to straighten their legs and hold them stiff, something I cannot do. That didn't deter me or the trainers. They tried locking my knees with a life vest, and when that did not work, one of the trainers had me ride piggyback so the dolphin had a strong set of limbs to push. It was a magical experience, communing with such intelligent creatures and gliding across the lagoon. The dolphins were so in tune with my needs that as I was being propelled, another dolphin swam beside me. It was as if they knew I needed extra support.

Sage, a veteran of many dolphin attractions, was not surprised. "You can swim with dolphins at a variety of locations throughout the Caribbean, but when I was there, the Atlantis staff was willing to accommodate and work with people who have disabilities," he said. "Not all places are open or comfortable doing that."

On top of all the water and beach-related options, Atlantis has a theater, a nightclub, a comedy club and a larger event space, called Atlantis Live. It just so happened that Tony Bennett and Lady Gaga were playing at Atlantis Live during our stay. Tickets were about the same as they were for the Hollywood Bowl, and

they were actually still available at the Atlantis venue.

Wanting to ensure accessible seating, I contacted the box office, only to be told that the Silver seating area isn't wheelchair accessible, so I was limited to two seats in the accessible Gold area at the Silver price. I let them know that I appreciated the price accommodation, but I calmly explained that there were four of us traveling and we'd like to enjoy the show together. In the end it all worked out as we got the needed companion tickets and enjoyed a memorable night.

We almost missed out on another of our favorite attractions, The Dig, because we could not find the accessible entry point. Thankfully, we persevered. The Dig is a maze of underground passageways and tunnels offering underwater vistas into the boulevards and streets of the ruins of the lost city, and it is where the myth of Atlantis truly comes alive. We got to explore the ancient laboratories of the legendary Atlanteans and marvel at their inventions of electricity, flying machines and submarines.

The Dig also features an interactive touch tank aquarium, as well as over 100 venomous lionfish, 500 piranhas, iridescent jellyfish and six-foot moray eels. There are also special environments that hold nine species of enormous groupers.

Beyond these three attractions, my family and I divided our time between hanging out at the beach, snorkeling, swimming and relaxing, and the Aquaventure park.

## Water, Water Everywhere

I absolutely loved the beaches and the ease of obtaining a beach wheelchair. The ocean breeze along the shore countered any trace of humidity and the weather consistently hovered in the high 70s and low 80s. The water was a comfortable 80 degrees, so I could spend hours snorkeling along the shallow shoreline. Covered lounge chairs, lined up in rows only a few feet from the water's edge, made going from the sea to sunbathing an easy jaunt, especially since there was always a staff member around to help out. Unlike many American theme parks and resorts, staff is not restricted from assisting guests.

Inspired by the can-do mentality, we

decided to add the Snorkel the Ruins experience to our agenda even though the Access Guide indicated that “Participants must be able to stand up; step down into the exhibit; walk along a sandy, rocky floor; and snorkel in 15 feet of water with sharks, rays and schooling fish.” I didn’t think anyone would actually be walking in 15 feet of water, they’d be swimming; so we decided to press our luck. I was right — the tour guides had no problem helping my husband transfer me to the ground and navigate me down the two steps into the Ruins Lagoon. Everyone wore life vests as we were led through the unique underwater vistas swimming alongside sleek sharks, spotted rays and brilliantly colored tropical fish.

Aquaventure park boasts 20 water slides, two river rides, 11 pools, three unique beaches, and a seven-acre snorkeling lagoon. Several pools have zero access entry points, and water wheelchairs are available on request. The chairs are designed to help transport guests into the water where they can transfer into the pool or onto a raft.

Our favorite attraction was The Current, a mile-long rapid river that propelled our inner tubes through churning rapids, lazy stretches and three and four-foot waves. This attraction also allowed easy access to the Power Tower conveyor belts that lead to four of the featured water attractions: The Fall, The Drop, The Abyss and The Surge. Most of the water slides require the ability to climb stairs, but guests can access both The Falls and The Drop tube rides via a conveyer belt. This means that once you’ve had help

transferring into the raft, you can be conveyed up four-stories without walking at all. This can NOT be done alone and should only be attempted if you have good upper body strength and the ability to sit upright and hold on tight.

Water levels were low our first few days on the rapids, so the conveyer belts were closed. They finally opened on our last day, giving me a chance to ride. From four stories up, the view was amazing. I could see the entire Atlantic Ocean stretched out before me for miles. The conveyer belt dropped our two-person tube into a small stretch of free flowing water that led to the slide. Many guests disembarked to move their tubes along more quickly. This wasn’t an option for us; I couldn’t walk and if my husband got off, we risked flipping. Once the ride staff knew I couldn’t walk, they provided the assistance we needed by pulling us along. My heart raced, I had not been on a waterslide since before my injury over 30 years ago. The gate opened and SWOOSH, down we went at an exhilarating speed that ended with a gigantic splash.

The wide grin on my face at the end of the ride is a fair representation of my overall experience at Atlantis. Other than the lack of accessible shuttles, I was extremely surprised by the level of access. Public restrooms, restaurants and room amenities (if not numbers of accessible rooms) at Atlantis were on par with ADA designs in the United States, and other resort venues were quick to provide access and additional support if need be. Based on my experience, while the resort may not comply with the letter of the ADA, I would say it does a good job of following the spirit of the law. NM

## Resources

- Atlantis Resort, 800/Atlantis; [www.atlantisbahamas.com](http://www.atlantisbahamas.com) (call 242/363-3000 for disability-related needs)
- Accessible Caribbean Vacations, 888/490-1280; [www.accessiblecaribbeanvacations.com](http://www.accessiblecaribbeanvacations.com)
- Sage Traveling, 888/645-7920; [www.sagetraveling.com](http://www.sagetraveling.com)



New ostomy bags help prevent complications, improving quality of life.

[LifeChangingInnovation.org](http://LifeChangingInnovation.org)

MEDICAL TECHNOLOGY  
**life changing  
innovation**



The “Snorkel the Ruins” attraction was listed as inaccessible, but Stohl made it work.

# NEW FDA CLEARED

WHILL Model M

Advanced motion and complete terrain coverage come with medical support to fit your needs.



Arm Support



High Back Support



Low Back Support

Call (844) 699-4455 | Visit [www.WHILL.us](http://www.WHILL.us)

WHILL Model M CAUTION: Federal law restricts this device to sale by or on the order of a physician.

04/16 320-01451-MKT-04



**t**he warm ocean breeze blowing through your hair. The translucent blue sea surrounding you as far as you can see. Exotic ports and exciting adventures awaiting your beck and call. And all the amenities of a luxury resort floating right along with you—there’s nothing quite like experiencing the open seas on a cruise ship. For many wheelchair users, cruising is the preferred mode of travel. Unlike air travel or a road trip, there’s no need for transferring in and out of aisle chairs or endless packing and unpacking.

When you add in the growing number of new cruise ships (seven new ships started sailing in 2015 with 15 more scheduled for 2016-17), the improved accessibility that many offer and the availability of reasonably priced excursions, there’s no good reason to keep putting off that cruise you keep talking about. To help motivate you and give you the inside scoop on how best to book and enjoy your accessible trip, we’ve enlisted two of the most knowledgeable pirates this side of the Caribbean — Cory Lee, of Curb Free with Cory Lee, and Ashley Lyn Olson, of wheelchairtraveling.com. Between the two of them, they’ve traveled the world and the seven seas (well, maybe not all seven, but close enough) and dealt with every kind of access obstacle and opportunity. We had a wide-ranging conversation covering everything the prospective cruiser would want to know. The conversation has been edited for length and clarity. You can find much more on cruising and accessible travel on their respective websites, [www.curbfree-withcorylee.com](http://www.curbfree-withcorylee.com) and [www.wheelchairtraveling.com](http://www.wheelchairtraveling.com).

—IAN RUDER

# Make the Most of Your Accessible Cruise Experience:

## A Q&A WITH THE EXPERTS



**nm:** Let’s start with an easy one: Give me your best quick sales pitch for why I should go on a cruise.

**CORY:** I think cruising is the most successful way to travel. Everything you could possibly want to do is on the cruise ship, and you don’t have to try to find an accessible taxi to go to dinner or go see a show. Other than a little planning for the ports, everything else is already taken care of, and you can usually get cruises for a pretty cheap price. It’s also a great way to see a bunch of different places in a short time. You can check places out and decide where you want to go back.

**ASHLEY:** Everybody is friendly with one another and having a great day, no matter what they’re doing. Everybody’s smiling and happy and wanting to have a little chit-chat for the most part. It’s great.

**nm:** OK. You guys sold me. I booked



my cruise. The ship says it’s accessible but I’m going to call ahead anyway because I always do that when I travel. What should I ask them about?

**CORY:** I always ask about the width of the doorway, because one time I asked for a wheelchair accessible room when I was cruising to the Bahamas, and they said that the room was completely accessible with a roll-in shower, but when I actually got there, my wheelchair would not even fit through the doorway. We ultimately worked that out, but really just try to ask for anything that would make your stay as comfortable as possible.

**ASHLEY:** Ask if you can get pictures of a room so you can understand what the space is going to be like. Ask about the bathroom access, ask about the bed height, ask if you need a Hoyer. When you’re on board the ship, the maintenance staff is usually good about trying to come up with creative solutions to your needs. Also, make sure every

deck is accessible. When you're there and you've paid all this money and you just want to lie out by the pool and have that whole cruise boat experience, that "I'm hanging off the rails" experience, and you can't go to the top level — that would be very disappointing to me.

**nm:** As far as the planning goes, between different destinations, different excursion offerings, which season you go, and what kind of ship you choose, there's a ton of things to consider when you're

booking an accessible cruise. Of all the things to think about, what's the biggest consideration when it comes to planning a really good accessible cruise?

**ASHLEY:** It's really what kind of experience you want. Do you want to have something where you're getting off at a port every single day and going on a little adventure, or just getting off at a port and hanging out at a beach and not really doing much? Are you looking for a tropical warm getaway? Do you care about sight-

seeing? It just depends on you as a traveler, what do you want? What do you want to see? What are your interests?

**CORY:** Make sure you consider the weather. Cruising in hurricane season may sound like a terrible idea, but I have done it and it's actually been pretty great — and no rain!

**nm:** You mentioned the hurricane season. Are there any things like that as far as booking or planning that can save you additional money? Is it cheaper to go during the hurricane season?

**CORY:** Oh, yeah. It's definitely a lot cheaper to go in September or October, during the hurricane season. You can get Bahamas cruises out of Florida for as low as \$180 per person for a four-day cruise. Which is insanely cheap because all of your meals, entertainment, and everything is included. It is a risk that you have to take, but I've done it a couple times and always had a great time. So if you're looking for a bargain, I would definitely consider it.

**nm:** What about destinations? Is there a region or a specific type of cruise that you've been on or have heard is just awesome? Or one that maybe is not the best for wheelchair users?

**CORY:** Anywhere in the Caribbean is generally pretty good. It does vary. So with western Caribbean, I've had a lot of luck. I mean, all of those were docked. But in the eastern Caribbean there are a couple that I think are tendered with some cruise lines. The Bahamas are really great, and it's easy because it's quick to get there and cheap. But the Mediterranean can be a bit challenging, as far as ports.

**ASHLEY:** I'm going on an Alaska cruise, and I've heard good things about them. The Mediterranean is a fantastic cruise route, but a number of the ports are challenging, especially for power wheelchairs. The same goes for Mexico.

**nm:** What would you say to the first time cruise goer who is worried about being hundreds of miles out at sea for an extended period of time?

**CORY:** I've never actually used them, but

## 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](http://www.conceptsinconfidence.com)

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

\*one time discount per customer



20 YEARS OF EXPERIENCE

## AN ADVOCATE WHO'S BEEN WHERE YOU ARE

# MICHAEL F. MAHONEY

ATTORNEY AT LAW



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

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

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

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

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

\*Massachusetts Lawyers Weekly

**LAWYERS WEEKLY  
LARGEST VERDICTS  
& SETTLEMENTS\***  
2013, 2014 & 2015



[MichaelMahoneyLaw.com](http://MichaelMahoneyLaw.com)



1-877-224-2040

Hablamos Español

### 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. Nuprod's exclusive compact modular design allows the system to fit showers of nearly any size. Log on to [www.nuprodx.com](http://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. Nuprod's, 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!



**Tub, Toilet and Shower Access Systems**

[www.nuprodx.com](http://www.nuprodx.com) (855) 220-5171

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

there are medical professionals on cruise lines that can help you out if you get sick or injured on the cruise. And they're on pretty much every cruise line, I think. I really don't know a lot about it, but it's worth checking out.

**ASHLEY:** Pack extra, no matter where you travel to, so you are prepared for a longer stay if anything happens. The reality is you never know, but cruises are pretty safe. You could be going for a stroll outside your house and something could happen. So you can't be scared to leave your home forever.

**nm:** So coming back to excursions, have either of you guys had a bad excursion or off-ship experience where it wasn't accessible or didn't go how you'd planned?

**CORY:** Usually excursions that are offered by the cruise lines are not fully accessible. It does take some good research skills to find one in any destination or port of call. So I usually just get on Google and start researching to find one or plan my own. I've actually gotten really lucky, and ev-

ery excursion that I've been on has been fantastic. They do usually cost more, though, so if you get an excursion from a cruise line, it may be only \$50 per person. But to book a private accessible short excursion with a company away from the cruise line, it might be \$200-300 for the day. So it is a lot more expensive.

**ASHLEY:** Generally overall, I feel like what cruises offer is just so limited. And what they do offer is pretty center of the road - super safe activities. When I book something, I want it to be executed as it's promoted. If it's advertised that I get to go into a historical building or see a waterfall then it better be so. And I want a pic.

**CORY:** One really important thing that I always ask is whether the ports are docked or tendered. Because if it's docked, then you can just kind of roll off the ship with the ramp once you get to the port. And if it's tendered, then you've got to get on a little dinghy boat, which sometimes is accessible and sometimes isn't.

**nm:** Have either of you guys done the

tendered ports and gone through that experience?

**CORY:** I did one a few years ago to Co-coCay, a private island in the Bahamas, where you only get to visit it if you're with that cruise line. The ship parked way far away from the island, and we got on this little bitty boat. It was actually a ramp, just a really long ramp that went onto the small tender boat. And it took us to the island. But it was completely accessible, the sand was really packed well, so my wheelchair did not have a problem at all, even rolling on the beach and all around the island. So it really worked out and was a great day.

**nm:** It sounds like what you two are both kind of saying is, the more preparation you put into planning the excursions, the better, but still be prepared for the unexpected.

**ASHLEY:** Part of the cruise appeal is the: "Oh joy, I don't really have to plan anything!" But if you're going on a seven to 10 day cruise that has a stop almost every single day, you're going to want to get off at some point and do something. The land excursions are my favorite part! I love experiencing a new place and way of life. Many onboard activities have schedules, some things may repeat but not everything, so you're still going have to do some kind of planning, whether you're staying on the ship the whole time or not.

**CORY:** I do not want to be stuck on the ship at all. I mean, by the time we actually get to a port, I'm pretty desperate to get off the ship. Make sure that there are tour companies within those ports that offer accessible tours, or if it's offered by the cruise line or whatever. But make sure of all of that before you even book the cruise.

**ASHLEY:** Think about what you want to do in the first place. Do you just want to drink and eat the whole time and just go to shows, and you really couldn't care less about getting off the boat? That could be a very nice vacation and exactly what someone needs to really wind down and relax. But some people, like Cory and I, who are super eager to get off the boat, we just can't wait. We want to have an adventure of some kind.

nm

**WE ARE UNITED**  
Share the Journey.

It's FREE to join, and member benefits include New Mobility!

**JOIN US!** United Spinal Association knows that disability is a shared experience that affects you, your family, friends and communities. Fortunately, we are stronger together, and United Spinal brings decades of expertise to help: information, peer mentoring, advocacy and much more. Become a member today and **Share the Journey.**

**800.404.2898 • unitedspinal.org**

**United Spinal Association**



# Realizing a Caribbean Dream

BY LILLY LONGSHORE  
PHOTOS BY STEPHANIE ALLEN PRODUCTIONS

After her paralysis, Lilly Longshore thought her dream of visiting the Caribbean Islands was out of reach. But with good help and good planning, her dream came true.



Everywhere Lilly went, there were good people offering to assist her.

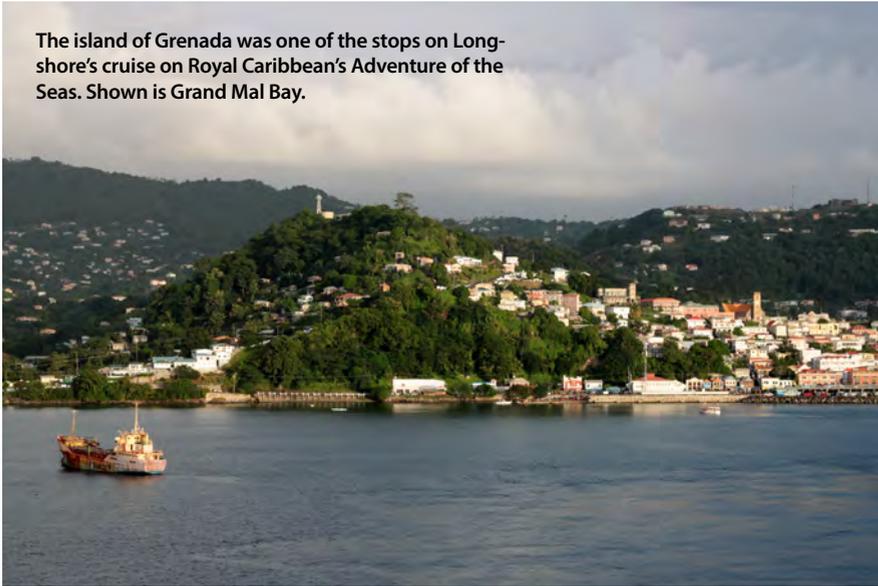
Before I broke my neck, I had visited the Cayman Islands and vowed that someday I'd return to see the remaining islands of the Caribbean, the Virgin Islands and the West Indies. After I broke my neck I put my dream trip off for years, not wanting to struggle with likely wheelchair inaccessibility. Finally last year, after several friends were diagnosed with life-altering diseases, I decided it was now or never. I figuratively jumped into the blue waters with both feet.

I braced myself for disappointment but did my research to better my chances of success. An ounce of prevention is worth a pound of cure, as the expression goes.

I selected a cruise on Royal Caribbean's Adventure of the Seas, a ship recommended by accessible travel author Candy Harrington. Then I made dozens of phone calls starting 10 months in advance, interviewing potential tour companies that could and would assist me with my specific needs. I wanted to do more than look at the tropical sea from a vehicle window. I wanted it in. After just one bump, I reaped the rewards of my efforts. Good planning and good people made it possible for me to fulfill my dream.

Harrington was right — the ship was wonderfully accessible and the service was splendid. My first stop in St. Thomas offered plentiful, accessible shopping where I snatched up unique Island Christmas gifts for friends and family. But I was dead wrong on my excursion choice. There was no way I could safely board the large catamaran for my snorkel trip. And I so wanted to snorkel. Deeply disappointed, I left my travel companion, Stephanie, to go without me and I headed back to the ship.

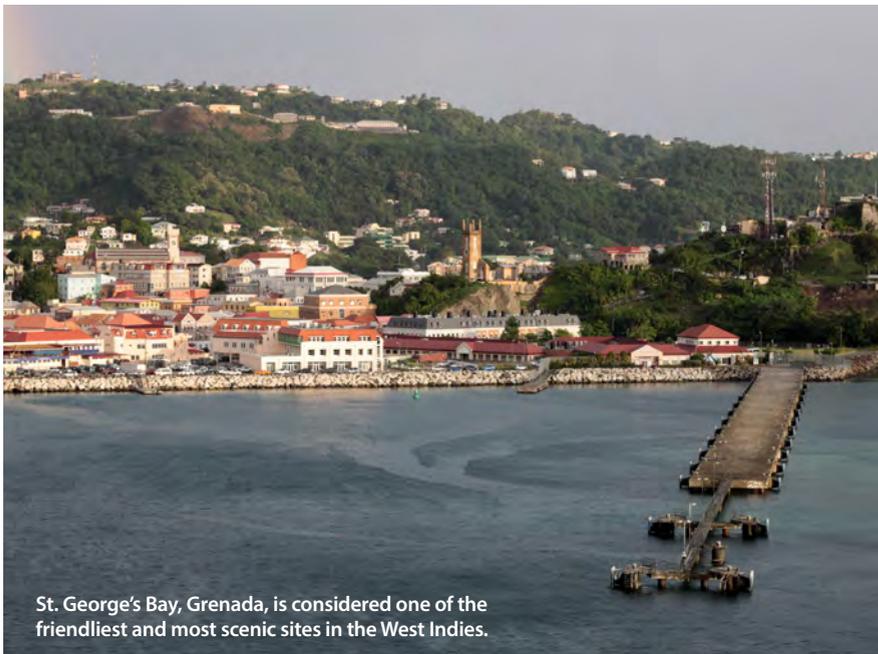
The island of Grenada was one of the stops on Longshore's cruise on Royal Caribbean's Adventure of the Seas. Shown is Grand Mal Bay.



Grenada's Spice Island Tour offers tourists an up close look at cacao trees and more.



The tire art livened up St. Lucia.



St. George's Bay, Grenada, is considered one of the friendliest and most scenic sites in the West Indies.

So when we got to St. Croix, I was hell-bent on getting into that water. This time, I approached it from the beach area of the Sand Castle on the Beach Resort. I rolled to the edge of their deck and pushed myself to my feet. With one arm around Stephanie's shoulders and the other around the shoulders of a stranger, I shuffled across 20 feet of uneven white sands and into the warm, blessed waters of the Caribbean Sea. I had arrived!

I bobbed up and down on the gentle swells for about an hour, reveling in the freedom and motion, breathing the salty air. Only when my fingers shriveled like prunes did I reluctantly prepare to leave the azure sea. I was well aware that getting out would pose more problems than getting in.

Stephanie grabbed my gait belt from the pack on my chair. Seconds later, three tourists from New York appeared at my side. "My mom had a stroke and had to re-learn to walk," one man explained. "I saw the gait belt and thought you might like help." I rode a swell to get my feet under me, then gratefully used two men's shoulders as crutches to hobble back to my chair. After I sat, the third man washed the sand from my feet!

In Antigua, the service and kindness of the tour guides at Stingray City warmed my heart. I sat in my chair at the edge of the grass, discussing with Stephanie my options of how to get across the sand to the speedboat docked 20-some feet away. A huge, strong man came up to me and said, "Put your arm around my neck," in a

soothing Island accent. Thinking I would use his and another's shoulders as crutches, I did as he asked. I was stunned when he scooped me up in his arms like a bride and carried me away. "You have no idea how much I weigh!" I sputtered in shock. "You have no idea how strong I am," he responded. I stopped arguing. He was solid, steady as rock as he stepped into the boat with me in his arms and placed me safely on the seat.

Nigel, the boat captain, whisked us away, gliding across the glassy bay in the speedboat to the stingrays. I was again carried from the boat and into the water, where I moved almost normally. I swam with the rays, fed them and snorkeled around the bay. Nigel, whose two uncles use wheelchairs, made sure I saw and did everything.

In St. Lucia, I selected Dive Fair Helen tours, which proved to be an excellent choice. It didn't matter that there were few ramps. The men just picked me up in my chair and carried me to where I needed to go, this time onto a 39-foot Sea Hawk dive boat. They helped me in and out of the water as needed.

I snorkeled for two hours during the

excursion, with a lasagna lunch during a break. Organ pipe sponges and purple urchins attached to the reef seemed inches away as I looked through the crystal clear water. Swimming through a school of dazzling tropical fish, I realized I had achieved a great personal goal in this paradise.

Grenada, the Island of Spice, was the final stop before cruising back to our port of origin in Puerto Rico. The fact that I was only 99 miles from Venezuela was enough to give me an adrenaline rush! I hadn't been that far from the United States in 20 years!

Grenada's Spice Route was my only land excursion. Mandoo Seales [of Mandoo Tours], our tour guide, was articulate and sincerely cared about the environment of his island home. "Our spices all come from trees," he explained. "The trees are planted mixed together — it is best for the soil." I saw cinnamon, nutmeg, clove, allspice, bay and cocoa trees. Our group toured an old, rustic nutmeg factory built by slave labor hundreds of years ago. A steep ramp led to the entrance, which I needed help to ascend. The smell of fresh, grated nutmeg, cinnamon and clove hit me as I entered, delighting my senses. Although I couldn't access the entire plantation and factory grounds, I experienced, saw and smelled enough that I was well pleased with the excursion.

The next day, we were off, heading back to San Juan, Puerto Rico. I trusted that due to good planning and good people, even more adventures awaited me there. NM



Longshore gets up close and personal with sting rays at Antigua's Sting Ray City.

abbvie

INNOVATION DRIVES  
OUR SCIENCE.  
HUMANITY DRIVES  
OUR PURPOSE.

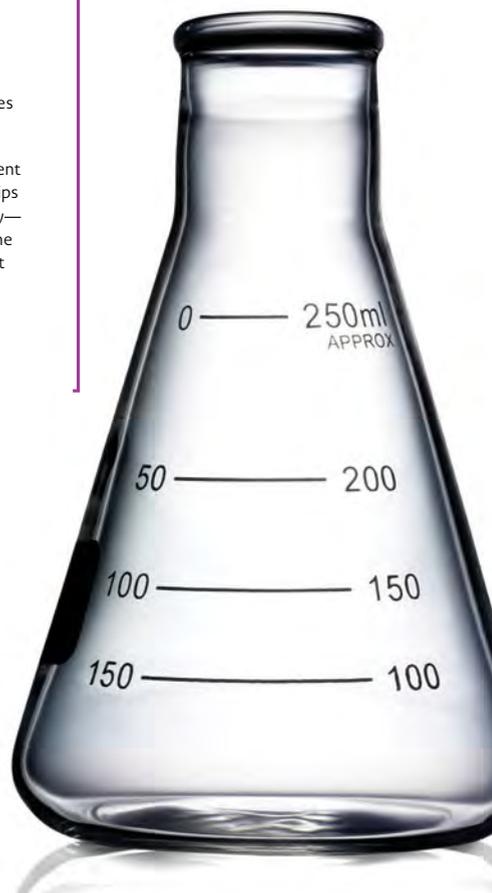
**To address healthcare challenges across the world, we unite a biotech spirit with the strength of a successful pharmaceutical business.** The result is a biopharmaceutical company combining science, passion, and expertise to improve health and healthcare in new ways. Making a remarkable impact in people's lives is more than our promise. It's our purpose.

This focus—combined with our commitment to developing multi-stakeholder partnerships and our ability to deliver medicines globally—means that more people living with even the most complex, chronic diseases can benefit from our efforts.

[abbvie.com](http://abbvie.com)

We are proud to support the United Spinal Association.

PEOPLE. PASSION.  
POSSIBILITIES.



## Resources

- Dive Fair Helen, 758/451-7716; [www.divefairhelen.com](http://www.divefairhelen.com)
- Mandoo Tours, 473/440-1428; [grenadatours.com/half.htm](http://grenadatours.com/half.htm)
- Royal Caribbean Adventure of the Seas, 866/562-7625; [www.royalcaribbean.com/fin-dacruise/ships/class/ship/home.do?shipCode=AD](http://www.royalcaribbean.com/fin-dacruise/ships/class/ship/home.do?shipCode=AD)
- Sand Castle on the Beach, 800/524-2018; [www.sandcastleonthebeach.com](http://www.sandcastleonthebeach.com)
- Stingray City Antigua, 268/562-7297; [www.stingraycityantigua.com](http://www.stingraycityantigua.com)



## 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.opensesamedoor.com](http://www.opensesamedoor.com)



## REGISTER BY JUNE 30 TO SAVE \$100

Academy of Spinal Cord Injury Professionals, Inc.<sup>™</sup>  
 Many Minds. One Vision.



# NASHVILLE

EDUCATIONAL CONFERENCE & EXPO

STAYING IN TUNE WITH TRENDS IN SCI

**SEPTEMBER 4-7, 2016**  
 OMNI NASHVILLE HOTEL AND MUSIC CITY CENTER  
[WWW.ACADEMSCIPRO.ORG](http://WWW.ACADEMSCIPRO.ORG)



# HOPELESS

PhRMA is a proud supporter of the United Spinal Association.

We are committed to helping patients live longer, healthier lives.

FROM **HOPE** TO **cures**

**PhRMA**  
 RESEARCH • PROGRESS • HOPE  
[fromhopetocures.org](http://fromhopetocures.org)



**QUANTUM®**  
**iLevel®**  
 power chairs

Quantum Rehab® is committed to preserving and protecting access to complex rehab technology and mobility independence for all Americans.

866-800-2002 | [www.ilevel.rehab](http://www.ilevel.rehab) | [www.quantumrehab](http://www.quantumrehab)

    /quantumrehab

## MY TAKE

Concord is an old, historic city that recently went through a metamorphosis via revitalization, in which the city brought the entire Main Street up, literally and figuratively, to the present. The entrances to all the Main Street shops and stores are now level with the street. They are aligned with beautiful granite — “the rock of ages” — with better ramping and curbing. These materials last forever.

The implementation of universal improvement in accessibility will be completed in two phases — and the second phase is already under way. It is a beautiful and much needed enhancement, certainly a step in the move towards universal access for all. Before this transformation, only a few shops were accessible for chair users.

## PLACES TO GO

Loudon, just north of Concord, is where I live and is home to the New Hampshire Motor Speedway. There are three huge annual events with something going on every weekend. Motorcycle week is in June, with the 93rd Annual Motorcycle Loudon Classic and the Weirs Beach “get together.” For NASCAR followers, in July and September we have two annual NASCAR events. Our sleepy town grows from a population of 6,000 to 250,000, and it’s all wheelchair accessible.

A trip to Crotched Mountain’s accessible trails in Greenfield is an all-time favorite and beautiful to visit. The longest accessible trails in the country can take you up to view a panoramic vista or down near a beaver meadow with erratic glacier boulders strewn around the primitive forest.

“Live Free or Die” — When I relocated to New Hampshire, there weren’t many barrier-free recreational organizations in the state. New England Healing Sports Association was established in 1970 for individuals with disabilities. However, it was limited in services provided, and equipment was medieval compared to today. Now it’s a different recreational scene. Northeast Passage came onto

## SKINNY ON THE CITY

Concord, population 42,000, is centrally located in New Hampshire, the Granite State, approximately an hour from the ocean and an hour from the White Mountains and Mount Washington. Between the Capitol Center for the Arts on Main Street and a drive up Mount Washington, there is always something to do. And if you can’t find something to do in the 603 (sole area code for the state), Boston is just over an hour south.



Learn about the New Hampshire Chapter on next page

the scene in 1990 and currently travels with staff and equipment not only in N.H., but throughout New England. New England Disabled Sports, Crotched Mountain Adaptive Recreation Sports and Adaptive Sports Partners of the North Country Inc., are a few more barrier-free organizations around the state. [Outdoorsagain.org](http://Outdoorsagain.org) and [accessoutdoorsne.org](http://accessoutdoorsne.org) both offer plenty of resources for adaptive hunting and fishing or just getting back in the woods. You can even go skydiving at two places within an hour’s drive.

## GETTING AROUND

The city of Concord has an accessible fixed route bus service (CAT) and para-transit for those not near a route. In addition Granite State Independent Living operates a small fleet of vehicles that mainly serves people with disabilities in outlying areas. COAST has its own fleet of accessible buses that serve the coastal areas, as does the most populous city in the state, Manchester.

## HEALTH CARE AND SUPPORT

Renowned teaching hospital Dartmouth-Hitchcock Medical Center is about as good as it gets. Other hospitals

and rehabs throughout the state are well known for their specialty. Concord Hospital is known for its cardiac expertise.

While in Concord, visit Granite State Independent Living, where New Hampshire National Spinal Cord Injury Association is located. As a nonprofit organization and New Hampshire’s only Center for Independent Living, GSIL stays close to its roots with a focus on its five core services — education, information, advocacy, support and transition — for people with disabilities and seniors.

## MUST SEE, MUST DO

Main Street is where you will find our state’s capitol building, the nation’s oldest in-use state house. From 1819 to the present, the legislature still occupies its original chambers. It is fully accessible, with beautiful architecture, paintings of past dignitaries, and the only capital building that the public can access and actually watch a legislative session or a house bill voting.

## New Hampshire: Partnering for Success

As Carol Conforti-Adams recovered from being paralyzed in a 2002 car accident, she began to feel a desperate need to do something with her life. She was in her 40s and had spent a large portion of her career working in the hospital business, focusing on promoting health and wellness. She had seen first-hand the potential value of social exercise groups when she launched an award-winning program for seniors called HOP (Healthy Old People). As she began to understand the needs of the wheelchair-using community, she wondered whether a similar program could work for it.

The result became Wheelchair Health in Motion, a unique blend of peer support groups and exercise that is quickly spreading throughout New Hampshire. The New Hampshire chapter of United Spinal collaborates closely with WHIM, and chapter president Mark Race is one of the seven trained peers who leads a regular weekly group at HealthSouth Rehabilitation Hospital in Concord. He got to know Conforti-Adams when she served on an advisory committee for the chapter. He says the program's mix of socializing and exercise can be nothing short of life changing. "I've seen people come in who looked like they were beaten down by life and turn around in a couple of months and leave with a newfound confidence in life," he says. The benefits go beyond confidence and attitude. Race mentions one attendee with cerebral palsy who started coming. "At the time, he had a tracheotomy and a vent," he says. "Through exercising and learning about



proper nutrition and exercising at home, he is no longer vent dependent."

The free sessions consist of an extensive regimen of upper body stretches and exercises specifically designed for wheelchair users. Peer leaders receive training and are given a 100-page manual that Conforti-Adams developed for the program. "We spent a lot of time developing a manual, and we made sure it was reviewed by neurologists, physical therapists and occupational therapists," she says. "That was really important to me because of my background in health. We wanted to make sure that the exercises we were promoting were actually beneficial to people with spinal cord injuries."

"The great thing about WHIM is that anybody can do it," says Race. "There's a lot of repetition, but in a fun way. Everybody does it to the level they can. Whether you do a little or a lot, you just have to start."

Conforti-Adams has been thrilled to



From handcycling to hiking to watersports, WHIM is always coming up with fun activities for its members to enjoy. It's WHIM's mix of socializing and exercising together that proves to be nothing short of life changing.

watch the program expand to four locations and serve a growing number of people, with as many as 15 attending some of Race's Concord sessions, but she still sees room for growth and improvement.

"It hasn't yet surpassed what I expected because I'd love to have more community," she says. "It has brought me more awareness about how difficult it is for people to get out there because of their social and economic situations."

With no local accessible public transportation options, Race says many attendees rely on local independent living organizations for rides, even though they only receive as few as two rides per month. "The chance to be among their peers, to work out and to have fun is a huge draw," says Race, who works as the peer support supervisor for Granite State Independent Living.

WHIM is currently offered in four New Hampshire locations, but Conforti-Adams says she is open to and excited about the possibility of expanding the program beyond the Granite state's boundaries.

"I fully believe it's something that can be duplicated with a small amount of time and energy," she says.

For more information on Wheelchair Health in Motion, call 603/938-2562 or visit [www.sheinh.org/index.php/whim](http://www.sheinh.org/index.php/whim).



The WHIM group rests after a hike on the Crotched Mountain accessible trail.

# SUREHANDS® Recreational Lifts

provide transferring options to enhance the enjoyment of leisure activities

*Whether at a sports club, stable, recreational facility, mountainside or marina, or even in your own backyard, take the struggle out of accessing your favorite fun-time or rehab activity.*



- Aquatic activities
- Sailing
- Outrigger canoeing
- Bass fishing

- Mountain or road cycling
- Therapeutic horseback riding
- or just enjoying a hot tub or swimming pool in your own backyard



**SUREHANDS LIFT & CARE SYSTEMS**

**1-800-724-5305**

website: [www.surehands.com](http://www.surehands.com)

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

Each year, over 2.5 million people develop pressure ulcers and face weeks in bed recovering. The physical and emotional pain can be devastating. Fortunately, there is a solution. The self-contained **SofTech** cushion system.

Designed to help treat and prevent pressure ulcers, **SofTech** uses internal air bladders that automatically inflate and deflate to actively change pressure points up to 60 times per hour while offloading full-time under an existing pressure ulcer.



**NEW  
from  
Aquila**

**DON'T PUT UP WITH PRESSURE  
ULCERS ANY LONGER.**

**CALL OR VISIT US ONLINE TODAY.**

Call Aquila for details

**AQUILA** CORPORATION  
Seat Cushion Systems

**AquilaCorp.com**



**866-782-9658**

## Mission

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

### SPINAL CORD RESOURCE CENTER

*Questions? We Have Answers!*

800/962-9629

[www.spinalcord.org/  
resource-center](http://www.spinalcord.org/resource-center)

### WHEELCHAIR MEDIC

*Expert Wheelchair Repair*

**Fort Totten, NY:**

718/352-1623

**Castle Point, NY:**

845/831-2000, ext. 5394

[www.wheelchairmedic.com](http://www.wheelchairmedic.com)

### VETERANS SERVICE OFFICE

*Veterans' Benefits Advocacy*

**Philadelphia, PA:**

215/381-3037 or 800/807-0190

*M-F 8:30 a.m. to 4:30 p.m.*

[www.vetsfirst.org](http://www.vetsfirst.org)

### CONGRESSIONAL LIAISON OFFICE

*Disability Policy Advocacy*

**Washington, DC** 202/556-2076

#### ALASKA

**Providence Alaska Medical Center**

Anchorage, AK; 907/562-2211

#### ARIZONA

**Barrow Neurological Institute at Saint Joseph's Hospital and Medical Center**, Phoenix, AZ; 602/406-3000

**HealthSouth Rehabilitation Hospital Spinal Cord Injury Program**, Mesa, AZ; 480/567-0350

#### CALIFORNIA

**Casa Colina Centers for Rehabilitation**, Pomona, CA; 866/724-4127, ext. 3900

**Dignity Health - Northridge Hospital Medical Center**, Center for Rehabilitation Medicine, Northridge, CA; 818/885-8500

**Rady Children's Hospital San Diego** - Division of Pediatric Rehabilitation Medicine, San Diego, CA; 858/576-1700

**Sharp Rehabilitation Center**, San Diego, CA; 858/939-6709

#### COLORADO

**Craig Hospital**, Englewood, CO; 303/789-8800

#### CONNECTICUT

**Gaylord Specialty Healthcare**, Wallingford, CT; 203/284-2800

**Hospital for Special Care**, New Britain, CT; 860/827-2761

**Mount Sinai Rehabilitation Hospital**, a Saint Francis Care Provider, Hartford, CT; 860/714-3500

#### DISTRICT OF COLUMBIA

**Medstar National Rehabilitation Hospital**, SCI Program, Washington, DC; 202/877-1000

#### FLORIDA

**Brooks Rehabilitation Hospital**, Jacksonville, FL; 904/345-7600

**Pinecrest Rehabilitation Hospital** at Delray Medical Center, Delray Beach, FL; 561/498-4440

#### GEORGIA

**Emory University Hospital Center for Rehabilitation Medicine**, Atlanta, GA; 404/712-7593

**Rehabilitation Hospital Navicent Health**, Macon, GA; 478/201-6500

**Shepherd Center - Southeastern Regional SCI Model System**, Atlanta, GA; 404/350-7645

#### HAWAII

**Rehabilitation Hospital of the Pacific**, Honolulu, HI; 808/531-3511

#### ILLINOIS

**Marianjoy Rehabilitation Hospital**, Wheaton, IL; 800/462-2366

**Memorial Medical Center**, Springfield, IL; 217/788-3302

**Rehabilitation Institute of Chicago** - Midwest Regional Spinal Cord Injury Care System, Chicago, IL; 800/354-7342

**Schwab Rehabilitation Hospital**, Chicago, IL; 773/522-2010

#### INDIANA

**Rehabilitation Hospital of Indiana**, Indianapolis, IN; 317/329-2000

#### KANSAS

**Mid America Rehabilitation Hospital**, Overland Park, KS; 913/491-2400

#### KENTUCKY

**Cardinal Hill Rehabilitation Hospital**, Lexington, KY; 859/254-5701

**Frazier Rehabilitation Institute**, Louisville, KY; 502/582-7490

**Gateway Rehabilitation Hospital**, Florence, KY; 859/426-2400

#### LOUISIANA

**The Gilda Trautman Newman Rehabilitation Center** at Children's Hospital New Orleans, New Orleans, LA; 504/899-9511

**Touro Rehabilitation Center - SCI Rehabilitation**, New Orleans, LA; 504/897-8560

#### MASSACHUSETTS

**Spaulding Rehabilitation Hospital**, Charlestown, MA; 617/573-2770

**Weldon Rehabilitation Center at Mercy Medical Center**, Springfield, MA; 413/748-6840

#### MARYLAND

**Adventist Rehabilitation Hospital of Maryland**, Rockville, MD; 240/864-6132

**International Center for Spinal Cord Injury at Kennedy Krieger Institute**, Baltimore, MD; 888/554-2080

**University of Maryland Rehabilitation and Orthopaedic Institute**, Baltimore, MD; 410/448-2500

#### MICHIGAN

**DMC Rehabilitation Institute of Michigan**, Detroit, MI; 313/745-1055

**Mary Freebed Rehabilitation Hospital**, Grand Rapids, MI; 800/528-8989

#### MISSOURI

**SSM Rehabilitation Hospital**, Bridgeton, MO; 314/768-5200

**The Rehabilitation Institute of Kansas City**, Kansas City, MO; 816/751-7812

#### MISSISSIPPI

**Methodist Rehabilitation Center**, Jackson, MS;

601/981-2611

#### NORTH CAROLINA

**Carolinas Rehabilitation**, Charlotte, NC;  
704/355-3558

**Cone Health Inpatient Rehabilitation Center**,  
Greensboro, NC; 336/832-8153

**Roger C. Peace Rehabilitation Center**,  
Greenville, NC; 864/455-3779

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

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

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

#### NEBRASKA

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

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

#### NEW HAMPSHIRE

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

#### NEW JERSEY

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

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

#### NEW YORK

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

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

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

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

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

**Sunnyview Rehabilitation Hospital**, Schenectady,  
NY; 518/382-4560

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

#### OHIO

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

**Miami Valley Hospital - Rehabilitation Institute  
of Ohio**, Dayton, OH; 937/208-8000

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

#### OKLAHOMA

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

#### OREGON

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

#### PENNSYLVANIA

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

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

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

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

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

#### SOUTH CAROLINA

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

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

#### TENNESSEE

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

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

#### TEXAS

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

**Houston Methodist Hospital**, Houston, TX;  
713/394-6000

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

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

**The University of Texas Southwestern Medical  
Center - Rehab Unit**, Dallas, TX, 214/493-0597

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

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

#### UTAH

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

#### VIRGINIA

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

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

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

#### VERMONT

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

#### WASHINGTON

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

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

#### WISCONSIN

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

## Organizational Members

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

**Life Beyond Barriers Rehabilitation Group**  
Rockford, MI; 616/866-6859

**Miami Physical Therapy Assoc., Inc.**  
Miami, FL; 305.444.0074

**NeuroWorx**  
South Jordan, UT; 801/390-0760

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

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

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

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

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

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

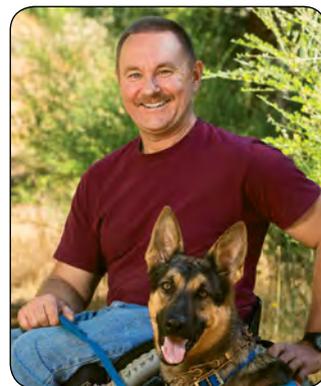
**Project Walk - San Jose**  
San Jose, CA 408/596-2844

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

**Project Walk - Walnut Creek**  
Walnut Creek, CA, 925/234-4400

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

Interested in becoming a hospital  
or organizational member? Please  
contact Nick LiBassi at  
718-803-3782, ext. 7410  
or [nlibassi@unitedspinal.org](mailto:nlibassi@unitedspinal.org)



By Bob Vogel

## Charcot's Spine, a Potential Long Term Complication of Spinal Fusion

**Q.** *I am 52 and in my 25th year as a T6-7 complete para. I have Harrington rods from T3 to T10. About a year ago I noticed I was leaning to the left side of my chair and couldn't seem to sit straight. I also started hearing a grinding sound in my lower back, and my leg spasms increased to the point where it was interfering with my daily life.*

*My doctor ordered a set of spine X-rays and then a CT scan. She said the results showed that I had "Charcot's arthropathy" and showed me my X-ray. It looked like half of my T12 and L1 vertebrae had disappeared — just vanished. Two weeks later I had surgery that included cutting and removing the lower part of my rods at T8 and adding new rods from T8 to L3. It was a big surgery — and so far so good, I'm sitting straight, and the grinding noise and muscle spasms are gone.*

*Prior to my diagnosis I had never heard of Charcot's arthropathy and I'm still trying to wrap my head around what it is. How common is it among people with SCI? A year after I was injured I was going to have my rods removed. Would it have made any difference?*

— Stacy

**C**harcot's arthropathy (also called "Charcot joint") is the progressive destruction caused by repeated trauma to a joint that doesn't have sensation. When it occurs in the spine, often referred to as "Charcot spine," it causes one or more vertebrae — below the level of fusion — to become progressively reabsorbed (disappear), which

creates a false joint that often causes instability, scoliosis (sideways curve) or kyphosis (outward curve of the spine).

Charcot joint was initially coined by Jean-Martin Charcot, a neurologist in the 1800s, to describe degenerative changes in a joint that had lost sensation due to diseases of the day like leprosy and syphilis. These days the term Charcot is usually associated with diabetes, as in "Charcot foot," which describes progressive joint damage that a person is unaware of due to sensation loss. The person then keeps walking on the foot until the joint is destroyed and the body absorbs the bone.

To get the lowdown on how Charcot's happens in the spine, I turned to Dr. Douglas Garland, an orthopedic surgeon and former director of neurotrauma at Rancho Los Amigos Rehab Center. Garland explains that Charcot Spine is caused by a combination of spinal fusion, loss of sensation below the fusion, and repeated, excess stress on the vertebrae below the fusion.

The spine has 24 articulating vertebrae (joints) that enable us to bend and twist. A fusion reduces the number of joints and the bending/twisting load is transferred to the remaining vertebrae. Garland explains that a fusion, whether done with rods, a cage, or other device, becomes a lever arm, just like the arm of a tire iron. The longer the fusion, the greater the lever arm force, which places a higher bending and twisting demand on the fewer remaining ver-

tebrae. "When I was at Rancho I would warn those with SCIs about doing impact sports, because part of the spine is now fused and it puts more stress on the discs and vertebrae below," says Garland. "Plus you can't feel if you are stressing it too much. If you could feel it, you would self-limit. The pain would cause you to stop."

"It is the fused vertebrae, not the rods, that change the dynamic of the spine," explains Garland. "Unless they are bothering you, there is no evidence that removing rods is any better than leaving them in. In general rods should not be removed because it is difficult to tell if a proper fusion has occurred, and it is a difficult surgery."

"Charcot spine is caused by wear and tear in the vertebrae below the base of the fusion — the vertebrae that don't have sensation," says Garland. "Repeated trauma causes micro fractures and the body starts to absorb the vertebrae, leading to a false joint. The trauma also causes huge amounts of bone deposit, almost like heterotopic ossification." Charcot joint usually forms one to two segments below the spinal fusion.

A web search of Charcot spine pulled up seven journal articles on the subject published between the years of 1997 and 2015 that show corresponding findings. Symptoms of Charcot spine varied and included one or more of the following: localized low back pain, loss or increase of spasticity, audible noise (grinding or clicking) with motion of

the spine, change in seating position — leaning to one side, or leaning forward with a rounding of the back (kyphosis). Also, episodes of severe sweating and autonomic dysreflexia. The average onset of Charcot spine symptoms was 27 years post-injury and ranged from 10 to 41 years, according to a five-patient case study in the September 2005 issue of *The Bone and Joint Journal*.

Early diagnosis and treatment of symptomatic Charcot spine is important, says Garland, especially if it is causing scoliosis or kyphosis, because it is a progressive disorder. The more it progresses, the more difficult it becomes to straighten out. Diagnosis is made with an X-ray and followed up by an MRI or CT scan to rule out osteomyelitis (bone infection). Treatment usually consists of using rods and screws to fuse the vertebrae together and straighten the spine.

All five of the Charcot spine subjects in *The Bone and Joint* article underwent fusion at a three year follow-up. They all reported good relief of their symptoms and were able to return to their previous level of activity.

“Just as important as knowing when to treat Charcot spine, is knowing when to leave it be,” explains Garland. “If a Charcot joint is present in the spine, but there are no symptoms and the spinal column remains lined up, it should be left alone. In those cases it helps with flexibility. It should be monitored with a yearly X-ray, and as long as things remain stable and there isn’t a big gap and no deformity, it should be left alone.”

The main takeaway of all of this is awareness and risk analysis. “If you have a long fusion and are doing impact sports, you put yourself at risk of having Charcot spine,” says Garland. It is a balancing act of knowing the risks of certain sports and activities and making informed decisions.

How common is Charcot spine? A common thread among several journal articles on Charcot spine is that although it is rarely reported in journals up to now, Charcot spine will probably be seen more frequently because those of us with SCI are living longer and have active lives. This makes it important for

physicians to be aware of the condition. It is even more important to us to be aware, since we know our bodies better than anybody.

## Resources

- Characteristics and surgical management of neuropathic (Charcot) spinal arthropathy after spinal cord injury: [www.thespinejournalonline.com/article/S1529-9430\(13\)01362-4/abstract?cc=y](http://www.thespinejournalonline.com/article/S1529-9430(13)01362-4/abstract?cc=y)
- Charcot’s Arthropathy of the Spine: A Late Complication of Spinal Instrumentation: [www.bjjprocs.boneandjoint.org.uk/content/87-B/SUPP\\_III/401.3](http://www.bjjprocs.boneandjoint.org.uk/content/87-B/SUPP_III/401.3)
- Charcot Joint in a Paraplegic History: [www.spineuniverse.com/professional/case-studies/sekhon/charcot-joint-paraplegic](http://www.spineuniverse.com/professional/case-studies/sekhon/charcot-joint-paraplegic)
- Charcot Spine after Remote Cervical Spine Injury: [www.omicsgroup.org/journals/charcot-spine-after-remote-cervical-spine-injury-2167-1222.1000191.pdf](http://www.omicsgroup.org/journals/charcot-spine-after-remote-cervical-spine-injury-2167-1222.1000191.pdf)
- Charcot spinal arthropathy: an increasing long-term sequel after spinal cord injury with no straightforward management: [www.nature.com/articles/scsandc201522](http://www.nature.com/articles/scsandc201522)

# 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](http://www.clarkehealthcare.com)

**Gilead is a proud  
supporter of  
New Mobility.**



For more information, please visit [www.gilead.com](http://www.gilead.com).  
© 2016 Gilead Sciences, Inc.

# OUTDOOR TRACKS

## Glacier Skywalk Adventure



By Kary Wright



Photo Courtesy of Brewster Travel Canada



The Glacier Skywalk is not scary at all, lied Kary Wright to his wife.

I zoom to the edge and stop, quickly glancing back reassuringly at the others, like all of us fearless leaders do, then nervously turn back to the abyss. My heart is in my throat; I slowly ... bravely (?) ... wheel out onto the clear walkway, stop and look down. Below my footplate is clear glass ... and nearly a thousand feet of sky ... and then rocks (gulp). Beside me is a handrail with more clear glass. It feels like I'm suspended in the air. My wife, Terryll, follows with her cameras.

"A little scary isn't it?" says she.

"Not bad," I lie. "Are you getting pictures?"

"Yes," she replies, "but this is a little unnerving."

Like a lot of people, I'm not a big fan of cliffs, balconies, roofs, etc. In my first life

BC (Before Crash, back when I was nondisabled) I flew airplanes, an ultra-light that was like a lawn chair with wings, a hang glider and a parasail. Maybe it makes me a control freak, but in my head if I felt it could be steered, then there would be a solution if a problem arose, and I was confident that all possible situations were rehearsed in my mind. I was on high alert and never got injured in these "well-planned" endeavors. Looking back, I think, man, over-confident or what? Based on results, I never anticipated every calamity as well as I thought, and as a result I'm a quadriplegic from a car accident! When it comes to structures, ropes, and anything you can fall from, I still get the creeps. I guess it stems from having to rely on the builders and designers to make it safe, and there is no plan B if

they're wrong.

We had seen advertisements years before of the skywalk over the Grand Canyon, but never had the opportunity to experience it. It seemed too far away and remote. Then during the winter we saw an ad on television for a new Skywalk opening in the Rocky Mountains a few hours from home, close to our favorite campground near Jasper, Alberta, in Canada. The thought of wheeling on it made me nervous ... perfect!

Right away I started scheming on how to arrange the adventure, how to tactfully bring up the subject in the best possible light so as to gently entice the affected parties into wanting to go.

"Can we try that ... huh ... huh ... huh ... can we?" I

hinted in my subtle way.

"Sure, ya gotta," laughed Terryll, knowing full well she'd hear me a gazillion times until she gave in. "Let's book a campsite. Is it wheelchair accessible?"

"It has to be, it's new." I reply.

"Isn't that a little scary, being that high up with a clear floor?" she asks, looking at the pictures.

"Yes, it probably will be, but that'll make it exciting. It's good to conquer a fear once in a while," I reassure myself.

A quick internet check confirmed that all was well, and the whole facility was totally accessible. You simply park at the Columbia Icefields Glacier Discovery Center between Banff and Jasper, and go inside to get your tickets. Then you hop an accessible bus for the short trip to the Skywalk.

## Wheeling on Air

We arrived on a warm and sunny spring morning. After we purchased our tickets, we were ushered out to a waiting bus. Within a minute or so I was on board, the rest of the passengers were loaded and we were off. The driver gave an informative narration of the area as she drove, and about 10 minutes later we were parked next to the curb beside the canyon. The bus driver, a real funny screwball I might add, had the ramp out and was gesturing me out the door.

"Where's the red carpet?" I say dryly.

"For who?" she replies with a grin ... *touché!*

We unloaded and were given a telephone-like device that gives a recorded information session at different stations as you amble along the discovery pathway. There were also park employees along the way with interpretive displays on various subjects. We learned all about the glaciers that were just a few miles down the valley. At another display we heard about the different birds of prey found in the area.

All the while we were working our way closer and closer to the skywalk. It did look a bit intimidating. It is a semi-circle section of the path, protruding out from solid rock, seemingly suspended

with little support. I was getting a bit nervous as we approached, but I sure wasn't letting on! — *Pshaw, nothing to this* — I portrayed, rolling ahead to try it.

At first it was scary having nothing between you and the distant rocks but see-through glass, but after a few minutes, the beauty of it took over! There was a beautiful aqua blue river rushing from the glaciers to the left, crashing along over huge boulders and exiting miles down the valley to the right. The sides of the mountains were covered with pine trees up to the treeline, and then it was rock, snow and ice above that.

Below we noticed a couple of white fluffy things slowly moving along the cliffs. Closer inspection revealed a mountain goat and its baby. What a treat! We were now familiar with the situation, and we were in awe of the scenery. It was no longer scary. A fear challenged!

If you're looking for a wheelchair-friendly, safe, awe-inspiring adventure, you can't beat the Glacier Skywalk!

## Frequently Asked Questions

### Where is the Skywalk located?

It is located in the heart of the Canadian Rockies, between Jasper and Banff in Alberta. You park at the Columbia Icefield Glacier Discovery Center. Accessible shuttle buses leave every 15 minutes to the Skywalk.

### How long can you stay?

They recommend 45 minutes or so, but we were told that we could stay as long as we like.

### Where can I find more information on the Glacier Skywalk?

At Brewster's website — [www.brewster.ca/activities-in-the-rockies/brewster-attractions/glacier-skywalk/#/0](http://www.brewster.ca/activities-in-the-rockies/brewster-attractions/glacier-skywalk/#/0)

**KEMPF**

# Drive any car with both hands on the wheel!

"The controls are seamless. You cannot even tell if the hand-controls are OEM or not. It looks factory done... The throttle ring seems as if it belongs on the steering wheel. It's well worth it."

"I've always driven with the 'old school, push and pull' type controls for the past 23 years and I actually like this DARIOS system much better. It was easy to adapt to. The learning curve is very short."  
P. P., CA

**DARIOS**  
Digital Accelerator Ring and main right hand brake

**GAP**  
WARRANTY  
LIFETIME WARRANTY

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

[www.kempf-usa.com](http://www.kempf-usa.com) - Call: 1-888-4-KEMPF-US (453-6738) for a free DVD and free brochure.



By Mike Ervin

I'd be pretty suspicious about a kid being mentored by a degenerate like me.

## Why Mentoring Scares the Crap Out of Me

I always get a bad case of the creepy crawlies when someone approaches me about being a mentor for a young criplet. I'm very reluctant to sign up.

I don't know what scares me about it. Maybe it's because there is something so unsettling about the title of mentor. It's a lot of pressure. A mentor isn't just a person you hang out with. A mentor is a person you hang out with so they can impart their wisdom and bestow upon you valuable life lessons that accelerate your personal growth. So maybe I'm afraid that the criplet will hang out with me expecting to receive valuable life lessons, only to realize that I'm just another schlump. But then again, I suppose when a kid who looks up to you figures out that you're just another schlump, you've taught that kid a valuable life lesson. But I don't think that's how the mentor thing is supposed to work.

Or maybe I'm afraid the kid's parents will find out that I'm mentoring him and that surely won't turn out well. I think I know me pretty well, or at least well enough to know that if I had a kid I'd be pretty suspicious about him being mentored by a degenerate like me. Really, if there was a law requiring everybody who shouldn't be mentoring your kids to register with the police,

you'd see my mug front and center.

Or maybe I'm afraid that the kid they send for me to mentor will be pretty much like I was as a teenager. Back in those days, I was an inmate at a state-operated boarding school for cripples. They sent an older guy in a wheelchair to mentor me. He was a graduate of the school. (We inmates referred to graduates as parolees). We hung out a couple times but my reception of him was lukewarm. It wasn't his fault. It's just that it was like a dud blind date or an arranged marriage. No spark.

This mentor was sent to me so I could ask him all of my burning questions. But as a teenager I only had one burning question: How do I get laid? It's the same burning question every teenager has. It's no different when you're crippled. One of my quad friends became a quad as a teenager. She got run over by a car. And she says after she woke up in the ICU with a halo screwed into her skull and tubes coming out of every orifice, she realized the magnitude of what happened and her first thought was, "Will I ever get laid again?"

I didn't feel like asking my one burning question of the guy who was dispatched to mentor me. I guess I didn't think he had the answer, or at least not the answer I wanted to hear. I'll tell you

who I wanted to be my mentor. I wanted Hawkins, one of the inmates. He was just a couple years older than me, but I figured that guy really knew how to get laid. First, he was one of those jock paraplegic wheelchair basketball player types, and those guys were at the top of the cripple food chain when it came to getting laid. They were the alphas. He also gave off a kind of badass Jesse Jackson vibe and the ladies ate up that stuff, too. I never brought myself to ask Hawkins to kindly reveal unto me the secret of getting laid. I'm sure I feared he would either laugh or tell me if I want to get laid all I have to do is become a jock paraplegic wheelchair basketball player who gives off a kind of badass Jesse Jackson vibe.

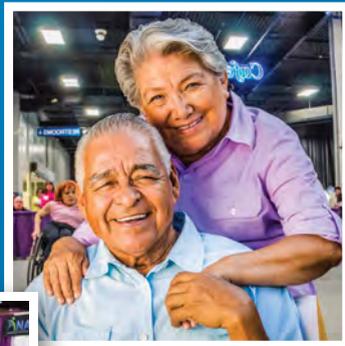
But that's really what it comes down to. I don't want to be a mentor because I know that once we get past the small talk, my criplet mentee will ask me for tips on getting laid. What will I say? "Well, kid, you wanna know the key word? Volume. I approach getting laid like telemarketing. That's my strategy. I figure if I make my sales pitch enough times over and over, sooner or later someone will buy what I'm selling."

And then I'll pat my criplet on the back, wish him well and send him out into the jungle.

# Abilities EXPO

Serving the Community Since 1979

## Discover the Latest Products Meet New Friends Talk with Experts Family-Friendly Experience



- Newest Technologies
- Life-enhancing Products
- Sports for All Abilities
- Informative Workshops
- Disability Services
- Essentials for Seniors
- Fun & Games for Kids
- Creative Adaptive Dance
- Devoted Service Animals

**FREE**  
ADMISSION

**www.AbilitiesExpo.com**  
Register online for priority access

Chicago / June 24-26, 2016  
Schaumburg Convention Center

Houston / August 5-7, 2016  
NRG Center

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

Bay Area / Nov. 18-20, 2016  
San Jose Convention Center

DC Metro / Dec. 2-4, 2016  
Dulles Expo Center

Los Angeles / March 24-26, 2017  
Los Angeles Convention Center

New York Metro / May 5-7, 2017  
New Jersey Convention & Expo Center

## Do you have a leak in your air cushion?

Don't replace it or attempt repairing it yourself with a temporary patch. It's not worth the risk!

Let the experts at AT&R repair it for you. Repairs are fast and 100% guaranteed.



Most repairs are just \$75 (plus shipping)

**AT&R**

For shipping instructions call 844-754-3305 or e-mail: [advancedtechandrepair@gmail.com](mailto:advancedtechandrepair@gmail.com)



### 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



Challenge Circuit

### 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](http://WWW.APEXEQ.COM) • 800-851-1122

# wheelchair MEDIC

a program of United Spinal Association

**WE'RE MOBILE SO YOU CAN BE TOO!**



Wheelchair Medic commutes to your location whether your home, hospital or care facility to provide affordable repairs to keep you mobile.

Our technicians will work with you on the phone to provide customer service to those inquiring about their wheelchair, scooter or mobility device.

Servicing New York City, Long Island, North Eastern New Jersey, Rockland, Orange, Dutchess, Putnam Westchester

- REPAIRS AT YOUR HOME OR LOCATION
- REPAIRS AT OUR FACILITY WITH PICK UP AND DELIVERY
- YOU DROP OFF AND PICK UP AT OUR FACILITY

**718-352-1623**

[www.wheelchairmedic.com](http://www.wheelchairmedic.com)

## Like Us on Facebook!

Join the conversation — we want to hear from you! Tell us how we're doing, let us know about what's important to you and see what others are saying. Like our Facebook page and get updates on the latest topics with just a click of your mouse.



[www.facebook.com/newmobility](http://www.facebook.com/newmobility)

**INCREASE & ENJOY YOUR SUMMER MOBILITY WITH DIESTCO ACCESSORIES!!**

Bags • Covers  
Ramps • Canopies  
Flags • Cupholders  
Cane, Crutch, O2 Holders

And Much Much More!!



**Enjoy Protection from the sun with DIESTCO's WEATHERBREAKER CANOPY**

Find Out More Visit Us At **DIESTCO.COM**

**DIESTCO MFG. CORP**  
1-800-795-2392  
WWW.DIESTCO.COM

**Ferti Care® Personal**  
& introducing the new **VIBERECT**



VIBERECT

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

**JUMP START YOUR SEX LIFE**

**FERTICARE PERSONAL**

- The Ferticare 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)

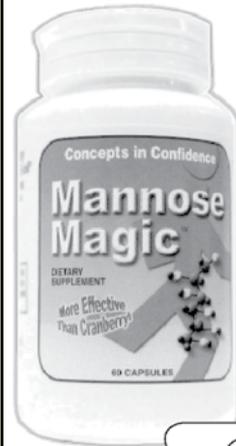


**Orion Medical Group, Inc.**

(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](http://www.medicalvibrator.com)

**Don't Become ANTIBIOTIC RESISTANT**



**Fight and Prevent UTI's**

**Flush Away E-Coli**



**Concepts in Confidence**  
60 capsules for only \$24.95

[www.conceptsinconfidence.com](http://www.conceptsinconfidence.com)

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



**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](http://www.sportaid.com)  
1-800-743-7203

**What does your wheelchair mean for your quality of life?**

Tell Congress to support legislation that protects your access to mobility and other essential home medical equipment.



Get the Facts. Get Active.  
[www.AAHomecare.org/Consumers](http://www.AAHomecare.org/Consumers)



With a strong local focus, and assignments from most insurance companies, we aim to be the most responsive and innovative complex wheelchair company to do business with. We're here to move lives forward for years to come. Visit [Numotion.com](http://Numotion.com) or call 800.500.9150.



American Airlines 

## As nonstop as you are.

As the world's largest airline, we're taking you to the destinations that matter most. And with our oneworld® partners, that's more than 1,000 cities across the globe. So, where's your next stop?



American Airlines, the Flight Symbol logo and the Tail Design are marks of American Airlines, Inc. oneworld is a mark of the oneworld Alliance, LLC. © 2016 American Airlines, Inc. All rights reserved.



**mv-1.us • 877-681-3678**

Designed from the ground up for universal accessibility, the Mobility Ventures MV-1 is built for wheelchair and scooter users who demand the safest vehicle on the market.



## Did Your Address Change



If so, please provide **NEW MOBILITY** with your updated information so you will not miss a single issue.

Full Name, Street Address, City, State & Zip Code are needed for both the old & the new address.

Please allow 6-8 weeks for this change to be processed.

Please mail to:  
120-34 Queens Boulevard, Suite 320  
Kew Gardens, NY 11415

Or submit your request electronically to:  
mkurtz@unitedspinal.org or at  
www.newmobility.com

Or call: 800-404-2898 x7203

## Help is Just a Click Away!

When faced with the challenges of living with a spinal cord injury or disease (SCI/D), the right resources and support can make a world of difference.

United Spinal Association's Affiliate Service Providers provide the full spectrum of clinical care, products and services, with an emphasis on SCI/D. Search our valuable online directory at <http://providers.spinalcord.org/> to discover service providers near you that specialize in optimizing the health, independence and quality of life of people with SCI/D.



Visit our directory at <http://providers.spinalcord.org/>

If you have any questions, contact our Resource Center staff at <http://www.spinalcord.org/ask-us/> or call (800) 962-9629.

Quickly connect with top providers specializing in:

- vehicle & hand controls • therapeutic & bathroom equipment • urological supplies • scooters • wheelchairs • ramps
- assistive devices, and many other disability-related products and services.



**FOR SALE**

**Barely used Edge HD Scooter Chair**  
\$2,000 – Golden Avenger Scooter \$900 – Both negotiable. Call Michael at 631-968-9154

**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](http://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](mailto:wlb21666@hotmail.com)

**Wheelchair PowerAssist.** Smart Drive MX2, with attachments for folding and rigid wheelchair. Like new, \$2,500.00. Mario 305-246-0060 or [mariotbasti@gmail.com](mailto:mariotbasti@gmail.com)

**Deerfield Beach Florida** – Deer Creek Golf Course 17th hole condo. Two Bedroom, two bathroom with a roll in shower. Fully wheelchair accessible. Furnished or unfurnished. \$129,000. Call 516-435-8231 or 516-698-2960

**USA Jeans makes pants** designed for sitting. Call Darlene at 800-935-5170 or visit [www.USAJeans.net](http://www.USAJeans.net)

**Jump start your sex life** and get expert advice at [medicalvibrator.com](http://medicalvibrator.com) or call 714-649-9284 we also specialize in fertility and incontinence.

**SHOW ME YOUR FACE** a novel by Goldie Gendler Silverman. Molly struggles with her feelings for Kevin, a very attractive paraplegic wheelchair user. Is he the man of her dreams, or a nightmare? Stanley K. Yamell, M.D., a disabled physician, called SHOW ME YOUR FACE "...a well-paced, compelling novel of attraction, emotional abuse, and self-discovery, all set against a backdrop of disability." **Available on Amazon or Kindle**

**Monarch Mark 1A** Automotive Hand Controls. \$225.00 E-mail: [phddvm@hotmail.com](mailto:phddvm@hotmail.com)

**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](http://www.placidaccess.com)

**VACATIONS**

**On The Beach Los Cabos, Mexico**  
Custom accessible Villa in the Village of Los Barriles, Walk/Roll to restaurants, shops, markets. Watch Whales and Dolphins. Swim, snorkel and fish, right out your back door. The Villa is completely wheelchair accessible boasting a huge roll-in shower & roll-under sinks. Monthly, weekly, or short term vacation rental. U-Tube Virtual tour! <https://youtu.be/yN5chLwJvI> Voted "Best Accessible Vacation EVER" (by those who stay here). Visit [www.vrbo.com/434500...](http://www.vrbo.com/434500...) read the reviews! NEW! For larger groups or weddings [www.vrbo.com/669234...](http://www.vrbo.com/669234...) 7,000 sq ft! 2 roll-in showers, all accessible! 1-866-727-7986 (toll-free)

**Ocean-front condo, wheelchair friendly,** sleeps six, pool, boardwalk to beach. Rents daily, weekly, monthly. St. Simons Is., GA. [bmmk4@frontier.com](mailto:bmmk4@frontier.com) 419-569-6114.

**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](http://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](mailto: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](http://newmobility.com/classifieds)

United Spinal Business Member Updates

Gold

**Abbvie**, [www.abbvie.com](http://www.abbvie.com), 800/255-5162

**Hollister Inc. is excited to launch the VaPro Plus Pocket hydrophilic intermittent catheter. No need to compromise protection for discretion. Learn more:** [www.hollister.com/vapro](http://www.hollister.com/vapro)

**Wellspect HealthCare is offering FREE samples of LoFric® intermittent urinary catheters, proven to reduce the risk of long-term complications. 855/456-3742, [www.wellspect.us](http://www.wellspect.us)**

Silver

**AdvaMed: Urologic disorders significantly affect QOL for men, limiting intimacy and self-esteem. Advanced medtech offers long-term solutions, allowing those affected to live healthier, happier lives.** [www.lifechanginginnovation.org](http://www.lifechanginginnovation.org)

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

**Astellas Pharmaceuticals**, [www.astellas.us](http://www.astellas.us), 800/888-7704

**Asterias Biotherapeutics: Now enrolling. Take a look!** [www.scistar-study.com](http://www.scistar-study.com)

Supporters

- Coloplast
- Comfort Company
- KD Smart Chair
- EZ Lite Cruiser
- Girards Law Firm
- Michigan Auto Law
- Scoutaround
- Surehands Lift & Care Systems
- Synapse Biomedical

For more information on how you can support United Spinal and become a business member, please contact Megan Lee at [mlee@unitedspinal.org](mailto: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.*

### THERE IS NO REPLACEMENT FOR MY WHEELCHAIR

When Gina Schuh wrote “My Wheelchair is My Legs, When it Breaks it IS an Emergency!” for [Pushliving.com](http://Pushliving.com), the Gilbert, Arizona, C5-6 quad with a law degree may have set off a revolution. Here is an excerpt:

My wheelchair replaces my legs because they retired in 2003. I rely on it for 100 percent of my daily mobility. THERE IS NO REPLACEMENT FOR MY WHEELCHAIR. Time to pee? Not without my wheelchair. Time to cook dinner? Not without my wheelchair. Time to go to the doctor? Not without my wheelchair. Plans to explore the world? Not without my wheelchair. Have a life? Not without my wheelchair. My wheelchair is my greatest accessory . . . and the worst. My wheelchair can either enable me to be mobile or disable me even more.

Just imagine breaking your leg, going to the doctor, and they tell you it will be almost a year before you can have surgery and you are forced to deal with it because you have no other option. Even three months would be insane! Well, that happens to wheelchair users all the time. When our wheelchair breaks, there is an utter lack of urgency for maintenance and chair replacement. Assistive technology providers have zero accountability for grossly negligent business practices including charging for services or parts that were never provided. Yeah, check your bills, friends.



Most people think about the mobility side of having a broken wheelchair, but it comes with an emotional side. When you can't get out of your house because of your wheelchair, you feel as though you live on a deserted island, isolated and alone. It's terrible that people are forced to wait months for replacement parts and repairs. THERE IS NOTHING on my end that I am doing to delay time. Money? I've got it. Prescription and doctor's letter of necessity? I've got it. Insurance? I've got it. I would be willing to drive to another state to get my wheelchair! Still, it is out of my control, and I am forced to deal with these monopolies who use insurance to manipulate the system.

Read Schuh's whole post at [pushliving.com/voices-of-the-community-my-wheelchair-is-my-legs-when-it-breaks-it-is-an-emergency](http://pushliving.com/voices-of-the-community-my-wheelchair-is-my-legs-when-it-breaks-it-is-an-emergency)

We shared Schuh's blog on *NEW MOBILITY's* Facebook page on May 9, and the response was overwhelming. Here are a few comments:



**Frank McMahon:** No question. A broken chair is worse than a broken car.



**Katerine MacFie:** Your experience sounds like my last dealings with [my provider]. Not only did I have to do pretty much everything for them,

but cushion and seat selection consisted of 15 seconds on one option before they decided to go with that. I heard nothing unless I showed up in person, and even then they rarely knew what was going on. After I finally got my chair, I was treated like a burden. I gave up and started looking into ordering a seat cushion that doesn't hurt and discovered every billable item on my wheelchair was, on average, 150-200 percent the listed MSRP on the manufacturer's website.

If I could order from ANYONE else or do it myself, I would in a heartbeat. Hell, I did my own measurements for my current chair. Except insurance picks who I go through. It's complete crap.



**Julie Curry:** I think it's lame we, the wheelchair user, the insurance payer, have to use only the wheelchair provider THEY choose for these OVERPRICED repairs. So, if we are not satisfied with the quality of service we are SOL. Fifty dollars an hour for repairs!?! This is ludicrous. Oh and I must add, these providers are NOT open on weekends.



**Michael Bernhart:** Being a quadriplegic, I live in my wheelchair and with it being specialized I cannot get spare parts on eBay like someone commented here. I have to wait and wait. It is an emergency and stricter standards are needed.



**Sue Vilchez:** Time we take it to the Capitol, peeps ... get ready to ROCH 2016. Check out United Spinal Association Advocacy Alliance ([www.unitedspinal.org](http://www.unitedspinal.org)).



SOLID BACKUP.  
WHENEVER.  
WHEREVER.

**ERGONOMICALLY DESIGNED**  
for you and your lifestyle, our seating  
system eases the strain on your lower  
back and is ideal for long days of great  
activity...on the court and off.



A Stealth Product 

A white, stylized signature of Mark Zupan.

Mark Zupan

[adirides.com](http://adirides.com) | [stealthproducts.com](http://stealthproducts.com)

**TX**  
SERIES 2

**RIGID RIDE.  
FOLDING  
FRAME.**

