

Parenting, Year One Gulf Coast Jewel Aging with Siblings



NEW MOBILITY

life beyond wheels

## The Paralympics: Highs and Heartbreak in Rio



TO  
SUBSCRIBE,  
CLICK HERE

 United Spinal  
Association

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

DEC 2016 \$4

# TOPPER OF THE TREE





## REACH FOR THE STARS WITH THE TEK-RMD

Performance artist and T-9 paraplegic Tresa Honaker, founder and artistic director of the AirAligned aerial dance group and the AirAligned Academy, puts the finishing touches on the Christmas tree at her Sacramento, CA studio. The TEK-RMD from Innovations Health doesn't just stand Tresa up, it lets her move gracefully while standing and allows her to perform a wide variety of activities that were currently out of her reach.

(800) 659-4548  
[www.InnovationsHealth.com](http://www.InnovationsHealth.com)  
[www.facebook.com/InnovationsHealth](http://www.facebook.com/InnovationsHealth)



INNOVATIONS  
HEALTH





THE ALL-NEW 2017 VMI CHRYSLER  
**PACIFICA**



unrivaled interior space · in-floor power ramp · interchangeable front seats  
**mobility without compromise**

VMI's Chrysler Pacifica provides freedom and flexibility so you can live  
your life the way you always imagined.

contact us to learn more:  
[vmivans.com](http://vmivans.com) | 855-VMI-VANS

# CONTENTS

VOLUME 27 NUMBER 279

December 2016



## FEATURES

### 17 BABY SOLUTIONS

STEPHANIE ARRACHE has gotten a crash course in parenting from a wheelchair since welcoming her first child in January. She shares the secrets to success.

### 20 A SUNNY SOUTHERN SOJOURN

MANATEES, snake birds and alligators help WILL SIERRA find inspiration on a relaxing accessible adventure to the Florida Gulf Coast.

### 40 JUST THE SIX OF US

CINDY HALL RANII reflects on how her SCI has impacted aging with her five siblings.



## COVER STORY PARALYMPICS: RIO 2016 24

Fear of Zika, budget woes and safety concerns didn't keep the world's top disabled athletes from rocking out at the 2016 Paralympics. Ace photographer LOREN WORTHINGTON captures the highs and lows of the games from behind the lens of his camera, while SETH MCBRIDE provides an inside peek at life as a U.S. Paralympian. Finally, EMILY ROSE YATES reports on the legacy of the games.

Cover Photo by Loren Worthington  
Contents Photo by Karla Worthington



## DEPARTMENTS

- |                      |                        |
|----------------------|------------------------|
| 4 BULLY PULPIT       | 14 EAT WELL, LIVE WELL |
| 6 LETTERS            | 35 SPOTLIGHT           |
| 8 NEWS               | 42 OUTDOOR TRACKS      |
| 10 EVERYDAY ADVOCACY | 44 RAISING A RUCKUS    |
| 12 SCI LIFE          | 48 CRIP BUZZ           |



DECEMBER 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](mailto: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 279, 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



## Focus on Our Strengths

Sixteen years ago this month I edited my first issue of NEW MOBILITY. The total number of stories and columns that have been published in NM since that time is pretty close to 2,000, and what amazes me is there seems to be no end to unique stories about wheelchair users and others with serious mobility limitations.

A major theme is that most of the stories have been less about problems and more about successes in adapting to lifestyle changes. More about courage and persistence than tragedy or failure. And this has taught me something about human beings in general. I believe we all possess an innate ability to adapt and survive, but we only discover this latent potential when confronted with personal tragedy and long odds. Faced with a daunting future, we set about trying to invent a new one.

It takes time to adjust, but eventually each of us embarks on a journey to find solutions to our everyday challenges. Every day we wake with the same limitations, or in some cases new complications, but we persist in our quest to make the most of it. And we learn what it takes. Those lessons shape us, strengthen us and refine our character.

The odd thing is that the mainstream public often sees us as weak and pitiable, living lives of lesser value. I have come to believe that what they are really seeing is a self-reflected image, a projection of their own inability to recognize *their* innate strengths. So they regard us in ways that reflect their fears and insecurities. Movies often portray us (using fictional characters played by nondisabled actors) as pathetic beings who would be better off dead. Doctors and nurses see us as people who need fixing. And government programs focus on our limitations rather than our potential.

Now, with a new president soon to take office — a man who showed little interest in us as voters and who mocked a disabled reporter — we have a new challenge to overcome. Already (as I write this in mid-November), we have seen massive protests from other minorities who feel threatened as well. In the major city nearest where I live, Portland, Oregon, a protest march devolved into a riot

I believe we all possess an innate ability to adapt and survive, but we only discover this latent potential when confronted with personal tragedy and long odds.

when anarchists joined in and vandalized businesses to the tune of over \$1 million. It was not a pretty sight, and the protesters, no matter how valid their fears, lost face, and more importantly, respect.

As a unique minority group, we need to focus on our strengths, our underused potential and our hard-earned adaptability. We need to advocate for programs and laws that emphasize what we have to contribute to society, not what we want society to contribute to us. We need to represent ourselves not as angry or needy, but as a growing resource, a population worthy of private and public investment.

Now is the time to remind ourselves and the powers that be that our civil rights, signed into law by a Republican president and enacted overwhelmingly by a bipartisan Congress more than 26 years ago, reflect our national strength, not our weakness.

— TIM GILMER

# CONTRIBUTORS



DECEMBER 2016



Stephanie Arrache is a criminal defense attorney by day, blogger at paraplewhat.com by night. When not in court, she is passing along tips for living with paralysis and anecdotes to help others better understand life on wheels. She was born with a tumor on her spine that ultimately led to her paralysis in 2013. She is also a motivational speaker, writer and photographer. In her free time you can find her at the gym. She lives in Palm Springs, California, with her husband, infant son, and two dogs. Follow her on YouTube and Instagram (@paraplewhat).

Emily Rose Yates is an accessibility consultant and a freelance writer, trainer and blogger based in the UK. Besides authoring Accessible Rio de Janeiro for Lonely Planet, she is currently working on Disabled Access Day 2017, encouraging disabled people and their loved ones to get out there and try something new, wherever that may be in the world. She regularly writes about sex and disability and has led a TED Talk and been featured on BBC Three. Find out more at [www.disabledaccessday.com](http://www.disabledaccessday.com) or follow her on Twitter at @EmilyRYates — or on her website at [www.emilyroseyates.co.uk](http://www.emilyroseyates.co.uk)



Paralyzed from the waist down at 15, Sue Shepard went on to graduate from college and is currently very much involved with United Spinal's Rochester Spinal Association chapter as a board member/vice president and peer mentor. She also serves on the board of Rochester Accessible Adventures. She is a guest speaker on spinal cord disease perspectives, rehabilitation volunteer, disability advocate, and most importantly to her, a loving wife and mother. Sue strives to be a true champion for family-inclusive activities that maximize the quality of independence for those living with spinal cord disease.



California native Will Sierra [a pseudonym] has been using wheels for mobility since sustaining a C4-5 spinal cord injury. He has worked in information technology for 20-plus years. When not working, he enjoys traveling with his wife and visiting national and state parks. Besides travel, his interests include nature, geography, history and lifelong learning. In recent years, Will has traveled around the southwestern, eastern and southern United States, as evidenced by this issue's article on a Florida Gulf Coast Wildlife Park. Will and his wife live in Washington state.



## CONTRIBUTING EDITORS

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

## COMMUNITY PARTNERS

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

## Ms. Duckworth deserves the honor of being named NEW MOBILITY's Person of the Year.



### Tammy is Deserving

My friend Dan Bauer feels this piece in NM about Congressperson Duckworth was very informative ["Tammy Duckworth: Our Champion in Congress," October 2016]. His recommendation: Ms. Duckworth deserves the honor of being named NEW MOBILITY's Person of the Year.

*Patricia Hendren (for Dan Bauer)  
Louisville, Kentucky*

### Chill Mitchell

I was there the night he had his accident, I called 911, I got down on the ground and tried to comfort him ["Actor Chill Mitchell Conquers Hollywood," September 2016]. I made the police know who he was and saw them perk up when I said he was an actor on *The John Larroquette Show*. His grandmother and my dad were cousins. I am so happy to see how he has not allowed what happened to handicap him.

*Patricia Aiken Nelson  
via newmobility.com*

### Chill's Attitude

"No time for crying. I can do that later."  
Love it ["Actor Chill..."].

*Kareema Lee Marie  
via newmobility.com*

### Rx for Diabetes

Unless induced by chronic steroid use, type 2 diabetes is generally thought to be caused by the inability of the pancreas to make sufficient insulin to regulate glucose metabolism when insulin resistance is present in muscle, liver, and fat cells ["Diabetes and SCI: Control Your Carbs and Exercise," October 2016]. What drives insulin resistance? Physical inactivity, excess abdominal fat, certain foods, poor sleep, stress, tobacco use, and chronic inflammation, among other things. Knowing your risk for T2D can

help you prevent or delay the onset.

*Diabetes Community Action Coalition  
Fulton County, Georgia*

### SCI Not the Cause

It is misleading to say SCI increases the risk of diabetes ["Diabetes and SCI..."]. It is the secondary weight gain that is the cause. If rehabs would spend time educating people about this risk and how to avoid it, you would see it decrease.

*Carole Herbster  
via newmobility.com*

### My Parking Solution

My husband made a great gadget for me [... Van Parking Spaces"], a traffic cone about 18 inches high. He attached a rope to it about 10 feet long and attached the other end to the front passenger seat. He bought adhesive black letters with a reflective background, so they are visible night and day, that say "RAMP." I pull that cone out whenever I must take two spaces to park because a van-accessible space isn't available. It has worked 99 percent of the time.

*Diane Mettam  
via newmobility.com*

### Smaller Parking Spaces

With reduced widths of handicapped parking I can no longer "enter" or navigate "leaving" my van ["What Happened to Van Parking Spaces," Everyday Advocacy, September 2016]. There is not enough room with my power chair with my side ramp deployed. I can't navigate. Very, very frustrating. It actually takes away the independence I once had. There is no reasonable excuse.

*Jim Beitz  
via newmobility.com*

### They Think: 'I Can Get Away With It'

The other night I parked in the very last park-

ing space in the lot, so no one would park next to me. When I came out someone had parked in the driveway, blocking my clearly marked van doors. As I drive from my wheelchair, I had to find someone to move my van so I could access my lift. People just don't care, as they think, "I'm just going to be here a short time, so I can get away with it."

*Robert Wiese  
via newmobility.com*

### Accessible Vegas Condo

I have an accessible Las Vegas condo/van that I list on Srin's Accomable.com — a great website run by a smart, great guy! ["Making Peer-to-Peer Lodging Work for You," October 2016]. I've been lending my condo out to other folks with disabilities for almost 10 years now and like the feeling of setting a traveller up to have a fun, accessible vacation so they will want to come back again and again!

*Barry Lindemann  
via newmobility.com*

### Ervin's Gift

On the nose! Mike Ervin has mulled over, written and posted essays before I've had time to scrunch up my eyebrows in consternation about a topic ["Of Movie Scripts and Butt Wiping," October 2016]. I appreciate his prose. Insightful, educational, and just plain witty enlightenments bring me back time and again. I'll always recommend and read Mike's work.

*Mary Ellen Robee  
via newmobility.com*

### Wry Symphony

A fine piece by one of my favorite writers, Mike Ervin, who makes a symphony out of wry. See more at [smartasscripple.blogspot.com](http://smartasscripple.blogspot.com).

*Janine Bertram  
via newmobility.com*



## ARC YOUR TURNS. PUNCH THE SPEED.

AND KEEP YOUR CAR CHASE  
SOUND EFFECTS TO A MINIMUM.

LEARN MORE AT [RIDEQUICKIE.COM](http://RIDEQUICKIE.COM)

QUICKIE®

CUSTOM FIT.  
IDEAL HANDLING.  
[RIDEQUICKIE.COM](http://RIDEQUICKIE.COM)

## Paralyzed Monkeys Walk Again in Brain-Spine Interface Study

In a study published Nov. 9 in the journal *Nature*, scientists say they have successfully connected brain implants in the motor cortex to epidural stimulation electrode arrays in the lumbar spine of paralyzed monkeys via wireless technology. The brain-spine interface, when activated, enabled the monkeys to resume walking. Lead researcher Grégoire Courtine, who heads up an international team of scientists, claims this specific type of brain-spine interface is a first in spinal cord injury research.

Courtine, a neuroscientist at the Swiss Federal Institute of Technology, told NBC News, "This is the first time that neurotechnology (has restored) locomotion in primates. But there are many challenges ahead and it may take several years before all the components of this intervention can be tested in people."

Besides the complexity of designing and perfecting a brain-spine interface in humans, another reason for Courtine's muted optimism is the anatomical difference between monkeys and human subjects. In the study, two monkeys each had one hind limb paralyzed via a clean laboratory transection, leaving them with three working limbs for ambulation. Traumatic spinal cord injuries in humans, typically more complex and varied, usually affect both legs and result in complete or near-complete loss of walking ability. Also, restoring balance in upright humans is a much more sophisticated challenge than dealing with monkeys, whose balance is more easily assured with four limbs on the ground.

The study is noteworthy, however, since it could possibly point the way to further studies that move away from robotic control in an effort to restore volitional control by wirelessly linking the brain to

epidural stimulation technology. If successful, it could potentially result in restoring movement in spinal cord-injured humans, however imperfect, without the need to wear cumbersome computer-driven exoskeletons or other external prosthetics.

In a *New York Times* article, Courtine said that he hoped his team's new brain-spine interface system could be used "in the next 10 years" on humans in a rehabilitation setting to "improve recovery and quality of life."

## Ruling Ecuadorean Party Nominates Paraplegic for President

Lenín Moreno Garcés, who served as vice president of Ecuador from 2007 to 2013, may become his nation's next president. Moreno, who became paraplegic in 1998, has been selected by the nation's ruling party, Alianza País, as its next leader following the announcement that Ecuador's current

## People in the News: Tiffiny Carlson Honored

**N**EW MOBILITY's own SCI Life columnist and community partner, Tiffiny Carlson, was named the Morton Cure Paralysis Fund 2016 honoree at its annual dinner and fundraiser in September. The C5-6 quadriplegic was honored by the Minnesota-based charity for her extensive writing and work on behalf spinal cord injury research.

"I am more than delighted because it feels great to be looked at as a research advocate," says Carlson. "I am and always will be a proponent for a cure."

Carlson has been writing for NEW MOBILITY since 2003 and is the executive director of the nonprofit SPINALpedia.com, which posts daily articles, videos and blog posts on living adventurously with an SCI. She has also contributed numerous disability articles to publications such as the *Huffington Post*, *Penthouse* and *Nerve.com*.

In addition to her writing, Carlson has spent the last decade speaking publicly at a variety of events — from disability conferences to summits — on the latest cutting

edge stem cell research for a cure.

"I am particularly excited about the nerve transplant surgery Dr. Justin Brown is doing in quadriplegics, enabling them to open their hands again," says Carlson, who has been a research advocate since 2005, when she attended her first Unite 2 Fight Paralysis' Working 2 Walk symposium. "I'm also very excited about the epidural stimulation that Dr. Susan Harkema is doing. Who would've thought electricity [electrostimulation] may hold the secret to the cure? I think it's fabulous."

The Morton Cure Paralysis Fund was started more than two decades ago after Minnesota native Peter Morton became a quadriplegic in a bicycle accident in 1995. Since then, the MCPF has raised over \$4 million for spinal cord injury research, and it has expanded its fundraising beyond Minnesota to Wisconsin and Arizona.

— MAUREEN GAZDA

For more information on Tiffiny Carlson: [beautyability.com](http://beautyability.com). More information on Morton Cure for Paralysis: [mcpf.org](http://mcpf.org).



president, Rafael Correa, will not seek a third term in 2017.

A lawyer by profession, Moreno as vice president took Ecuador's people with disabilities from being barely regarded as citizens to people receiving housing and economic assistance, including guaranteed social security from their government.

Moreno's work earned him a nomination for the 2012 Nobel Peace Prize and an appointment as the United

Nations Special Envoy on Disability and Accessibility in 2013. "We have taken enormous steps in Ecuador, but much work remains," wrote Moreno for Americas Quarterly in 2012. "Our goal is for no disabled person to be denied comprehensive attention."

The 63-year-old can perhaps finish that work if he's elected with his running mate and successor, current vice-president Jorge Glas. Early polls suggest he is a strong candidate for president with

35 percent support against a splintered opposition. However, Ecuadorian voters are hungry for change as their country's oil-dependent economy currently finds itself in a recession.

Moreno is well aware of this, calling for unity at his party's leadership convention and emphasizing just how hard it will be for his party to be re-elected. "We need to be united brothers, because the path is tough, tough, tough," he said.

— AARON BROVERMAN

## CORRECTION

The following listing in the November Consumer Guide contained an error. Here is the corrected listing:



### SOFTECH CUSHION SYSTEM

SofTech is a completely automatic pressure ulcer treatment cushion that alternates up to 60 times per hour. Custom made, able to offload full time under an existing ulcer. Self-contained with all components located inside the cushion base. No separate controller. Any shape, any size, and no weight limit.

Available from Aquila Corporation, 866/782-9658 or [www.aquilacorp.com](http://www.aquilacorp.com)

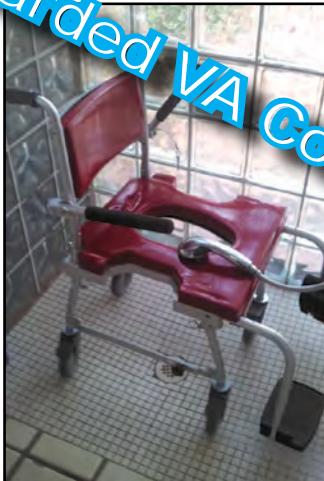
The Safe, Practical and Convenient way to travel wherever and whenever you want.

No more waiting for accessible facilities!

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

# Go! Mobility Solutions

## "GO-ANYWHERE" Chairs



30-Day  
Risk-Free  
Trial

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

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



## Forced to Pay Wheelchair Rental?

By Michael Collins

**Q.** *The electric wheelchair I've been using the last 10 years is beyond repair, and my vendor says replacement parts are unavailable. My need for the wheelchair is critical. I have multiple sclerosis, am partially paralyzed on one side of my body, can stand and walk short distances but no more than a few feet without assistance. Limited arm function on one side makes it impossible to push a manual wheelchair.*

*My previous wheelchair, apparently classified as complex rehab technology, provided tilt and recline functions and a joystick, so I stayed in the chair from morning until I went to bed at night, except for short periods. I could also transfer to my couch if I needed a major shift in position or rest.*

*Now I have learned that my level of disability does not allow me to have a chair with the same features. I have been "demoted" to a standard power wheelchair.*

*I am expected to rent this equipment and make payments on it for over a year before it is considered my property. If something happens to me and I am unable to make a payment, I worry that they would repossess the chair and leave me without a mobility device. With all of the changes in Medicare the past few years, I had hoped things would get better. The process of obtaining a replacement wheelchair has been extremely time consuming, frustrating and I still don't understand the reasoning behind it. Can someone explain what is happening to the process and why? Renting wheelchairs seems like a very cumbersome process that is more costly to administer than dealing with purchases one time. What is behind all of this?*

— Not walking, I need to roll

**C**ongress mandated changes to Medicare policies regarding durable medical equipment, which includes

your wheelchair, as part of a broader fraud prevention and cost saving measure. The Medicare insurance program has been the target for fraud and abuse for many years, especially involving three-wheeled scooters, which has resulted in billions of dollars of excess costs. Congress tasked the Centers for Medicare and Medicaid Services with new laws to devise programs for lowering costs and providing additional oversight. Those laws expanded and made permanent a cost-saving program (competitive bidding), which changed the amount Medicare will pay for certain DME, prosthetics, orthotics and supplies. Since CMS reported saving approximately \$2 billion in the most recent reporting year for this program, competitive bidding may remain in place even though it is unpopular among vendors and many end users.

You have several options if you are dissatisfied with what is happening in regard to your next wheelchair. The first step before ordering the chair requires a prescription from your physician, followed by a joint evaluation with an assistive technology professional and a qualified therapist. That team has fairly strict guidelines regarding eligibility, based solely on your capabilities and disability type. If you disagree with their findings, you can request a secondary evaluation in hopes of getting upgraded to a CRT wheelchair. This must be done prior to ordering.

Be sure that your request is extremely detailed. Additional correspondence from physicians familiar with your specific disability should be included if they agree that you need more complex equipment. Remember, Medicare still pays only for equipment meant to be used "in the home" (many advocates believe this is an arcane regulation that needs to be changed). Renting your manual or standard elec-

tric wheelchair is just one option. Your supplier should also give you the opportunity to purchase outright with a 20 percent copayment as in the past. After paying, you own the wheelchair and will be responsible for paying coinsurance for any maintenance on it. If you decide to rent to purchase, that down payment would be broken into 13 installments that would be paid monthly; the first three payments would be slightly higher than the last 10. During that time any repairs or maintenance of the equipment would be the responsibility of the supplier. You would own the wheelchair after 13 months.

Each individual has unique needs, so it is important to get specific answers before proceeding rather than relying solely on this general information. The Medicare website lists participating vendors in your region. You should follow up with them to discuss all options.

Fraud has been reduced and savings realized. But the complexity associated with additional paperwork requirements and scrutiny of each DME purchase has created a cumbersome and flawed system for end users. Congress is still considering additional items to include in competitive bidding, which will create even more paperwork for vendors at a time when their reimbursement rates have been reduced and large numbers of vendors have already been driven out of business.

It is important to contact your congressional representatives if you are concerned that this program is not working properly.

### Resources

- Medicare website, [www.medicare.gov](http://www.medicare.gov)
- "A Separate Medicare Complex Rehabilitation Technology Benefit Is Needed," United Spinal, [www.unitedspinal.org/separate-medicare-crt](http://www.unitedspinal.org/separate-medicare-crt)



# CARBON IS THE NEW BACK

## MADE TO MOVE YOU

With compression-molded, lightweight carbon fiber construction, AGILITY CARBON™ combines high-strength performance with a streamlined design. The result is a precision-crafted seating system that looks as good as it feels.

INTRODUCING  
THE AGILITY CARBON™ FROM ROHO®

VISIT ROHO.COM FOR MORE INFORMATION

THE FOLLOWING ARE TRADEMARKS AND REGISTERED TRADEMARKS OF ROHO, INC: AGILITY CARBON™ AND ROHO®.



By Tiffiny Carlson

**"I felt foreign in my own body, I had many moments of feeling as if I didn't belong in this superficial world anymore."**



### Perfecting Her Glide

If *Push Girls* were to cast another season, Steph Aiello, 26, from San Bernardino, California, would definitely be on the show. Injured at the C5 level in a car accident in 2010 while driving home from Las Vegas, she has figured out how to live her life like a boss. "My injury doesn't take a break from my life, so why am I going to stop living my life because of my injury?"

One of her biggest passions in life is beauty. "Glam was always in my soul. I was supposed to start cosmetology school after my accident," Aiello says. "Style has and always will be running through my veins. I'm now a licensed makeup artist and am more confident about my art than ever." But it wasn't an easy process getting here.

"When I was initially injured, I had no idea what challenges I was in for. I felt foreign in my own body, I had many moments of feeling as if I didn't belong in this superficial world anymore."

and hated the idea of being 'different.' It was Steph's identical twin sister, Tiff, who helped her see her life was still worth living. "My twin sister used to get so upset with me whenever I said, 'I want to be normal again.' It took me a good year until I woke up telling myself that I was alive and blessed."

Now a popular and fiercely independent beauty vlogger, she is unstoppable. Aiello is also the first quad to join The Walk and Roll Dance Team, a hip-hop wheelchair dance team. "I'm in love with my dance team! These girls inspire me so much and keep me motivated to try new things. I'll be forever grateful for the opportunity, the friendships and workouts I get from the dance team, and the weekly classes are amazing."

Follow her on YouTube:  
[www.youtube.com/user/  
 StephSCI](http://www.youtube.com/user/StephSCI)

### Significant Others Keeping It Real

For those who date people with spinal cord injuries, learning about our world has a learning curve and comes with its fair share of intimidating moments. But Sam, a 29-year-old RN, and Chelsea, a 27-year-old filmmaker, wanted to show the world that their relationships with men who are paraplegics aren't as different as the world might think.



They debuted their blog — Wheel Love (aka "Life, Love and Wheelies") — earlier this year, and it has been growing in popularity quickly. Many of their blog posts are on topics that prospective daters are curious about, like "Top 10 Wheelchair Date Ideas" and "Mom, Dad? My Boyfriend's a Paraplegic ..." They also touch on what they've learned like, "10 Things We Learned from Dating Someone in a Wheelchair" and "Your Wheelchair Makes Me Awesome."

Read the blog — [wheellove.ca](http://wheellove.ca).

### The Autopilot Wheelchair Cometh

Using a joystick is hard for Valery Spiridonov, a Russian engineer and wheelchair user. To solve this problem and help others, Spiridonov is developing "The Clever Chair," a wheelchair accessory that will learn your home environment and drive you to certain rooms with the touch of a button.

See for yourself at [cleverchair.com](http://cleverchair.com).



# VaPro Plus Pocket

Touch Free Hydrophilic Intermittent Catheter

We're for the woman who makes her dreams a reality.



## You can help her.

By recommending **VaPro Plus Pocket** hydrophilic intermittent catheters, you can help patients focus on what matters. The catheters are easy to teach, learn and handle. Plus, the touch free design of the protective tip and sleeve are designed to help reduce bacterial contamination. Simple, clean, independence in a discreet package.

Call 888.740.8999 or visit [hollister.com/vapro](http://hollister.com/vapro) to request a sample\*



**Continence Care**  
People First



## Healthy Holiday Snacks

The holiday season is upon us, and winter weather entices us to snuggle up and stay indoors while enjoying a nice cup of hot chocolate and indulging in a few too many holiday desserts. These festive treats get us in the holiday spirit but also tend to get us in trouble. Not only do high sugar foods add on extra pounds, they can also contribute to excess inflammation in the body, joint and muscle pain, blood sugar imbalance and constipation — issues that affect many individuals with mobility impairments.

To help prevent mindless snacking this holiday season, keep healthy high-fiber and protein goodies on hand that help keep blood sugar levels from spiking, support healthy digestion and make us feel full so we aren't tempted to reach for a sugar-filled treat. One way to do this is to swap out white, fiber-less flour for high protein/high fiber options like almond or coconut flour.

Almond flour is an excellent source of protein, fiber and calcium — which supports healthy bones. Coconut flour is also high in protein, fiber and healthy fats to help sustain energy. These flours not only transform baked goods from nutrient-void sugary snacks into nutritious nibbles, they also help keep the number one New Year's resolution — weight loss — off your list!

### Coconut Flour Chocolate Chunk Blondies

$\frac{1}{2}$  cup coconut flour  
 1 tbsp tapioca starch  
 $\frac{1}{2}$  tsp baking soda  
 $\frac{1}{2}$  tsp sea salt  
 2 medium ripe bananas  
 1 tbsp chia seeds + 3 tbsp water, set for 10 minutes  
 6 tbsp almond butter or seed butter  
 4 tbsp coconut sugar  
 $\frac{1}{4}$  cup coconut oil, melted  
 $\frac{1}{3}$  cup maple syrup  
 1 tsp vanilla extract  
 $\frac{1}{2}$  cup walnuts, chopped  
 $\frac{3}{4}$  cup dark chocolate, chopped in chunks

Preheat oven to 350 degrees; grease or line a square baking tin.

In small bowl, whisk together flours, baking soda, salt. Set aside.

In separate large bowl, peel and mash bananas until smooth. Stir in chia, almond butter, coconut oil, coconut sugar, and maple syrup until combined. Slowly add flour mixture to wet mixture, stirring until combined. Fold in walnuts and chocolate.

Pour batter onto baking pan. Smooth out the top. Bake for 23-25 minutes. Do not over-bake!

By Joanne Smith  
 and Kylie James, authors of  
*Eat Well Live Well with SCI and Other Neurological Conditions*,  
[eatwelllivewellwithsci.com](http://eatwelllivewellwithsci.com)

### Raw Gingerbread Cookies

1  $\frac{1}{4}$  cup pitted dates  
 $\frac{1}{4}$  cup almond flour/meal  
 $\frac{1}{4}$  cup buckwheat oats  
 $\frac{3}{4}$  cup rolled oats  
 1 tbsp cinnamon  
 1 tsp ginger  
 $\frac{1}{2}$  tsp nutmeg  
 $\frac{1}{4}$  tsp vanilla  
 $\frac{1}{4}$  tsp cloves  
 optional coconut sugar

Blend all ingredients, except dates, in high-speed blender or food processor until you get a fine consistency, like flour. Add in half of dates and process until well combined. Add remaining dates until you have a uniform dough. Scoop out about 1 tablespoon of dough, flatten with a rolling pin and use a cookie cutter to make desired shapes. Sprinkle coconut sugar on top of cookies.



Join the conversation. /quantumrehab

[quantumrehab.com](http://quantumrehab.com) • (US) 866-800-2002 • (Canada) 888-570-1113



• MOBILITY VENTURES •  
**MV-1**®

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

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.

Mobility Ventures LLC  
*an AM General Company*

**[Visit our website to find your local MV-1 dealer and learn more about this revolutionary vehicle.](#)**



• MOBILITY VENTURES •  
**MV-1**®

# My FIRST BABY!



## Tips and Tricks I Have Learned

BY STEPHANIE ARRACHE

(we varied the heights both to secure the wall and to ensure safety from curious hands trying to reach them from inside the crib). We found a solid wood, electronic crib, which has buttons that move the mattress up and down. This allows you to set the mattress at whatever height works for you. When at the uppermost height, I am able to slide right in under the bed frame while seated in my wheelchair. My knees clear the bottom perfectly.

**Playtime.** For the first several months, babies are easy. Sure they cry and eat a lot. But they also sleep. A lot. They don't move

around too much. Then they start getting more active and curious. And they want to play. A lot. My son loves to play with all the bright dangly toys on his play mat. I've come up with a system for getting him to and from the floor. He has a baby stander that I keep next to the sofa so I can put him into it. I then lower myself to the ground. Next, using the sofa to give an extra level of support for my back and core, I lift him out of his stander. I then put him on my lap and scoot the couple of feet to the play mat. To get him back up to the sofa, I just reverse the order.



This solid wood, electronic crib's mattress moves up with the touch of a button.

**H**aving a baby is nerve-wracking for any first-time parent. Add on the fact that one of the parents is in a wheelchair (me), and there is a whole new level of stress. While the year hasn't been exactly easy, it has been absolutely amazing. The following are some of the tips and tricks I have learned throughout the first year with my son.

## CRIB, PLAYTIME AND GETTING AROUND

**Modifying the crib.** There aren't a lot of options for parents with wheelchairs. Drop-side cribs were banned in the United States for fears of babies being able to fall out. And very few companies make cribs with walls that open in a "French door" style, which makes the price astronomical. My husband and I modified our own crib, and it has been perfect.

We installed hinges on the left side of one of the long walls and several barrel bolts at varying heights on the right side

Sometimes we have playtime in his crib because it's a little easier for me. I will bring the play mat to his room and place it on his crib. Or we play with other toys. The crib is also a great place for reading time. I place him on his crib and sit him at an angle in front of me, so we can both see the book and he can play with it while we are reading. This is another benefit of having modified our crib for easy wheelchair access.

**Crawling.** When my son was learning to crawl, it was difficult for me to give him the help he needed in learning to keep his body upright. The angles of being on the floor and helping him made it difficult. I tried putting him on my own bed, the height of which made it easier for me to support him and help him with his form. And he loved the soft landing when he inevitably toppled over.

Learning to crawl was another time that the modified crib was handy to have. I was able to put him into his crib and really help him with learning the form and ability. The downside to a crib is limited space. Once he got the movements down, the floor was clearly the best choice for all of his crawling. To get him to the floor I use the sofa-stander-floor transfer described earlier.

**Mommy and baby share a moment while they each use their walker.**



**Wraps and carriers.** Carrying the baby around the house is difficult in a manual wheelchair. It's hard to hold a precious little bundle and wheel yourself. The use of wraps and carriers allows me to do this and keep him safe. I personally liked the Moby wrap, which is basically one gigantic piece of fabric. Some people do not like it because it is so long, but I preferred it because I could fit it to myself and make sure my son was snug.

I used the Baby K'Tan, which was nice. But the large size was too big and the medium always felt a little too tight for him. Now that he is a big guy, we use the Baby Ergo 360 as it allows me to carry him in a frontward seated position on my lap. I find it pretty easy to get him in and out of the carrier, and he loves being able to watch where we are going. He also loves being in the carrier and zooming around stores or the park.

Now that he is able to sit on my lap, I don't use the carrier around the house as much. The carrier is now used for getting him outside to my car and in public. My son is so used to riding on my lap that he's learned to sit still while we are rolling. We are working on him not trying to put his hand on the wheels while we are rolling. Around the house, I will put him on my lap and hold him with one arm while using the other to push. Every few feet I will switch the arm holding him and the arm pushing.



**With a little forethought, most activities are possible with a baby — even shopping.**

as support while giving him a bath.

An inexpensive option is to use a large plastic tub on a table that is wheelchair accessible. An option for a person with no wheelchair accessible sink or tub would be to use an ice chest with the lid off (also known as a "cooler") in a shower. The benefits of using the ice chest is there is a plug on the bottom for easy draining.

**Outside time.** My son loves swinging. Most parks are composed of grass, sand and bark, substances not so easily traversed in a wheelchair. My FreeWheel has saved me in this area of motherhood. I am able to go off-roading and be nearby when he's playing. I use my FreeWheel so often that I can't recommend it fast enough to anyone and everyone. And as my son gets older and more active, I know that it will be used more and more often, not only in parks but on hikes and dirt roads when we go on awesome adventures together.

**Support system.** This one is huge. I am a very independent person. Stubbornly independent at times. I was worried that if I asked for help, people would think I was an unfit parent. But just the opposite is true: Asking for help is never a bad idea. Another fear was that my son would be so used to being carried by his nanny (I am a working attorney) that he

## INEXPENSIVE HOME MODIFICATIONS AND OUTSIDE TIME

**Bathtime.** Bathroom mods can be spandy, but not so much with babies. I was able to install a wheelchair accessible sink in my kitchen where I can bathe my son. My house is an open floor plan, so instead of tearing out the original cabinets and sinks, we simply added another sink and counter at an ADA height. The cabinet doors under the sink swing open so I can roll right under. We also put in six very deep drawers where I store all of his bath supplies. We set the sink back about 10 inches so there is a lip for me to rest my elbows and to use

wouldn't be OK being around me in my wheelchair. If anything, I think the opposite is true. He loves sitting on my lap while I roll him around the house.

**Getting stronger.** Since my baby was born, I've really focused on getting back to the gym and working on my upper body strength. It was quickly apparent to me that I would need to be in the best physical shape myself so I could hold him, carry him, play with him, chase him, etc. He was the motivation I needed to start strength training with a trainer at my amazing local gym. Those sofa-stander-floor transfers are easier now that I am getting stronger. The benefit of working out on a consistent five to six day a week basis has also helped with my energy levels.

**Finding solutions to things I think I can't do.** I refuse to accept that there are certain things that I won't be able to do with my son. For example, living in Southern California, my family often hangs out by the beach because my parents live right on the beach. My husband has taken the baby on the beach several

times, and I wasn't able to go along with them. It made me sad that I couldn't be a part of an experience that had shaped a major part of my life. So I did some research and found out that the local life-guard station has a beach chair to use free of charge on a first-come, first-served basis. There are also businesses which rent beach wheelchairs.

The first time my son went in the pool was a similar experience. We were at my aunt's house and there was no lift. While I'm sure I could have easily gotten in, I would have been more of a distraction in the pool, and I wanted to make sure that all eyes were on my son for his first pool time. This was very hard to accept. But trying to be a positive sort, I was happy to be there, and now we have 100 pictures of him being in the pool because I am the Picture Taker in Chief in my household. However, there is a public pool near my house that has a pool lift, so I can experience being in the pool with him. Sometimes you just need to channel the things you can't do and find ways to make them happen. **NM**

## RESOURCES AND PRODUCT LIST

- Infantino Go GaGa Deluxe Twist & Fold Gym: \$49.99 at Target
- Combi All-in-One Mobile Entertainer - Classic Car: \$88.99 at Target
- Baby K'tan: \$49.95 at Target
- Baby Ergo 360: \$159.99 at Target
- Dream On Me Electronic Crib: \$449.99 at Babies R Us
- Everbilt Barrel Bolt: \$2.97 at Home Depot
- FreeWheel: \$599.00 at [www.gofreewheel.com](http://www.gofreewheel.com)
- Gym Membership: \$30/month at Anytime Fitness Palm Desert
- Personal Trainer: \$50/hour session at Anytime Fitness Palm Desert



**WSPE  
BEST IN STATE  
Engineering  
Excellence  
Award 2015**

Call or visit our website for more information and to see a video of our cushion being pressure mapped.

Medicare Code E2609

**The most important component of a wheelchair is the cushion. It is your only protection against a pressure injury.**

**Choose the SofTech automatic cushion. Engineered to treat and prevent injuries by alternating up to 60 times per hour. Custom built for each client.**



**AQUILA CORPORATION**  
Seat Cushion Systems

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

# HOMOSASSA SPRINGS WILDLIFE STATE PARK

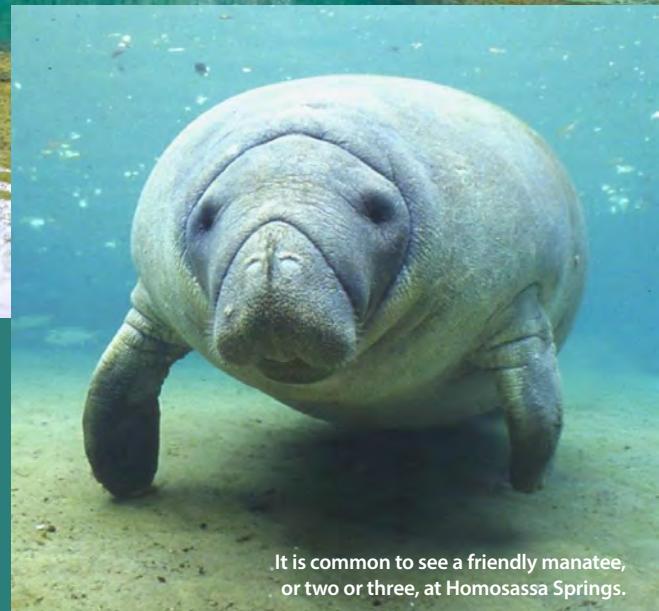
BY WILL SIERRA



This accessible floating platform is a great place to watch wildlife.

## *IN NEED OF INSPIRATION — I HEARD A LITTLE BIRD'S CALL TO SEE NEW AND INTERESTING GEOGRAPHY*

**M**any years after sustaining my C4-5 spinal cord injury, my wife and I decided to take time away from work for a vacation to a place where the landscape varied from that of our backyard in the Pacific Northwest. Having lived many years amongst green trees, beautiful lakes and mountains where the weather in March is frequently cool and wet, traveling to southerly Florida below latitude 30 north appeared to be a nice destination. Florida seemed interesting to us with the ocean nearby, and March weather being warmer, in the 70s to low 80s, and



It is common to see a friendly manatee, or two or three, at Homosassa Springs.

pleasant. I sought a place to relax and recharge, and trusted that the little bird would be right and the time well spent.

Our visit to Florida Gulf Coast's Homosassa Springs Wildlife State Park began with a pontoon boat tour along Pepper Creek, a calm canal-like waterway surrounded by vegetation and wildlife. I rolled onto the pontoon boat via a gently slop-

ing dock-ramp lowered upon the deck near the bow of the boat where there is plenty of flat deck for two power chairs, possibly three, or four manual wheelchairs.



Leaving the dock, the pontoon boat's electric motor makes little noise, and we move slowly along the waterway as the park guide points out various wildlife species coming into view. There is no noticeable wind, and the water surface reflects the green and golden colors of the shoreline-rooted trees. In places, the arching foliage covers the waterway, creating a green tunnel of vegetation. In other areas the open blue sky above shines into the water. It is

March and the air temperature is comfortably in the upper 70s. I appreciate all the green foliage, water, and reflected images as we glide forward.

The guide points out an American alligator lounging on the shore, warming its blood in the sun. This gator is about 8 to 10 feet long and a similar number of years old, as alligators grow about one foot per year until maturity. Mature male American alligators can exceed 12 feet, with very large gators exceeding 13 feet in length.

Further along, I see sunning turtles; these turtles are yellow-bellied sliders, the sunlight highlighting yellow stripes on the sides of their faces. The turtles are aligned upon trees that have fallen into the creek, creating perfect turtle perches. When the turtles are startled, they quickly slide off the trees into the water.

Later, the boat approaches a turtle swimming near the surface, its webbed feet visible as it paddles through the water. The turtle senses the boat and dives for deeper water near the side of the canal. I watch as the turtle vanishes into darker waters before the boat arrives. Not far away is a female anhinga, known as the snake bird, perched on a tree branch drying her wings in the sun; the bird has beautiful brown and shiny black feathers. The feathers of an anhinga are not waterproof, so they absorb water, making the bird less buoyant and a more capable diver and hunter of fish, which the anhinga spears with its beak. Later we see great blue heron and a large osprey nest.

## MESMERIZED BY FISH

The pontoon boat takes us 1.2 miles into the 210-acre park, where disembarking, we are near the west entrance. Arriving at the boathouse, I notice the boat-ramp appears a bit steep. However, after the foot passengers are off loaded, the boat weighs less, decreasing the boat's draft, and the ramp angle is a gentle slope.

The boat tour is wonderful and included with the park ticket price, \$13 for adults and \$5 for children. We take two boat



The Springs are home to many animals, such as these playful otters.

Photo by Heather Dickens

tours, the initial tour from the main entrance to the west entrance, and a second boat tour when leaving the park on the return trip to the main entrance. If for some reason the boat ride is not of interest, you can skip the boat tour and take a three-quarters mile path to the west entrance, or park your car in the parking lot off of West Fishbowl Drive near the west entrance.

At the west entrance we are close to the Homosassa Springs and the West Indian Manatee area. I take the rolling trail going

## IF YOU GO

Ellie Schiller Homosassa Springs Florida State Park is located at 4150 South Suncoast Blvd. in Homosassa along the Gulf Coast of Florida, next to US 19. The park is within 70 to 90 miles of Florida cities Tampa, Orlando, and Gainesville.

The park's enclosed habitats appear designed to be naturalistic. According to park signs, "Most of the birds and animals living at Homosassa Springs cannot survive in the wild." The park paths are paved and boardwalk, fairly flat, and easily navigated using a wheelchair. If you'd like to pack a lunch, there are park benches along the paths and picnic tables at the Garden of the Springs area. The park has food concessions near the west entrance.

Visitors should consider the time of year, weather, and using sunscreen and a hat when planning a visit, as Florida can be UV intense, hot, and humid, especially during summer months. If bird watching is of interest, Florida is home to the 2,000-mile-long Great Florida Birding Trail, and a short 11-mile drive north from the wildlife park takes you to the Crystal River Archaeological State Park, a location with 2,500-year-old Native American mounds that is also a bird habitat site on the Great Florida Birding Trail.



The author found his trip to Homosassa Springs to be restful and rejuvenating.



Photo by Jansing Scroggins

That splash you hear could be a wood duck or a yellow slider.

upon the circling fish and into the spring vent and deepening shades of blue water. There are paved paths around the spring pool with many vantage points for looking at the beautiful spring waters and watching the fish. In addition to fish near the

to the left that leads to Homosassa Springs, which is a first-magnitude springs producing millions of gallons per hour, at times more than 100 cubic feet of water per second. The natural spring pool waters are clear, with varied shades of green, blue, and turquoise. I notice fish swimming all around the spring pool, with concentrated schools of hundreds of crevalle jack, snook, and mullet circling the spring vent.

Near the spring vent is a floating platform, an "observatory" that is wheelchair accessible and provides a great view of the spring pool. From the floating platform I look down

spring vent, many fish are close to shore resting in the shallows, or slowly swimming in the clear waters. Here a person could sit at waters edge for hours, mesmerized while watching the fish and having a nice conversation.

## SEA COWS AND OTHER EXOTIC SPECIES

Next we head to the West Indian Manatee area, where there is a spring-water-fed park pool. There we see the large, roundish, blue/grey herbivores swimming. Through the crowd, I see three manatees in the pool floating near the water's surface, munching on lettuce provided by the park guide as the guide shares information about the lives of manatees, and the people closest to the rail look down upon the manatees in the pool. From the pool rail you can get within ten feet of the gentle mammals with a close view of whiskers, backs, flippers, and flukes. Manatees swim into the park pool from the springs-fed Homosassa River, using a park controlled gate. At times during park presentations, sight lines are obscured by the crowd near the manatee pool. However, after the presentation, there is plenty of opportunity to see the manatees up close. After the crowd fades, we take our time and enjoy watching the manatees from the rail.

Depending on weather conditions you may see manatees near the spring vent as well. Manatees are about 10 to 12 feet in length and can weigh over 1,300 pounds. Manatees feed on sea grass, mostly in shallow water, and are sometimes referred

## 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)

## 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

Sincerely,  
Joe Paladino

**FREE Delivery**

**Call Today**

Local/Fax: 860-224-9017

Toll Free: 855-332-0285

**New Britain  
Medical Supplies**  
*Specializing in Urology*

74 VINE STREET • NEW BRITAIN, CT 06052  
[WWW.NEWBRITAINMEDICALSUPPLIES.COM](http://WWW.NEWBRITAINMEDICALSUPPLIES.COM)

22 NEW MOBILITY

to as sea cows. During our Florida visit, I frequently sighted manatees in the waterways as they surfaced for air, or as a slow moving brown or gray shape below the water surface, or upon first hearing their exhalation and then sighting a manatee face at the water's surface.

Even when not surfacing, manatee flukes can cause subtle surface waves that can be seen in calmer waters. During periods when water temperatures drop, the manatees are attracted to the springs and the flowing, warmer 72-degree fresh water. When water temperatures drop below 68 degrees, manatees are susceptible to what is called "cold stress," which can be fatal. Although a manatee's shape may cause one to think the mammals carry considerable fat that could insulate them from cold temperatures, manatees actually do not have much fat, and their shape is defined by their bone structure. Thus, manatees are quite vulnerable to boat impacts, which frequently cause significant damage. Throughout Florida one notices signs cautioning boaters on speed, and to watch for manatees.

In recent years, surprisingly, the Florida manatee population has increased to approximately 6,300. In addition to seeing manatees at Homosassa Springs, we also spotted manatees about seven miles north in the waters of Crystal River near Kings Bay.

There are many other species to see at the wildlife park. Birds at the park include white-feathered egrets, pink-feathered roseate spoonbills, whooping cranes, and reddish-pinkish-orangish feathered flamingos. There are also river otter, Florida panther, cougar, bobcat, black bear, red wolves, and snakes in the reptile house. We thoroughly enjoyed the relaxing afternoon watching



This swan and her cygnets are one of many bird species that call the Springs their home.

the wildlife. The highlights were seeing the beautiful clear blue water at the springs with the hundreds of circling fish, the manatees, and the scenic pontoon boat tour.

Our visit to Homosassa Springs, along with other beautiful places on our trip, confirmed the little bird's wisdom. I felt relaxed, reenergized, and ready to accomplish new goals. ■■■

## RESOURCES

Homosassa Florida, [www.homosassaflorida.com](http://www.homosassaflorida.com)  
Florida State Parks Homosassa Springs,  
[www.floridastateparks.org/park/Homosassa-Springs](http://www.floridastateparks.org/park/Homosassa-Springs)

### MULTICHAIR Slider Systems

**ALL NEW!** MULTICHAIR 6000RS



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

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

#### Features Include:

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

Tub, Toilet and Shower Access Systems

 **nuprodx inc**

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

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



Photo courtesy of OIS/IOC



Photo by Thomas Lovelock

To be an athlete at the Paralympic Games is a strange thing. You are there to compete in a sport; to do a task that you have spent countless hours practicing. I play wheelchair rugby. I have been in my rugby chair — perfecting the same push stroke, performing the same cuts, spins, and picks, passing and catching the same ball — upwards of 2,000 times over the past 10 years. I have arrived here in Rio de Janeiro, along with another 95 wheelchair rugby athletes, and roughly 4,300 other athletes, ready to do something that is as familiar as anything in this world. All the Hickory

feel like a spoiled athlete. There are separate rooms where athletes are outfitted by Nike, Ralph Lauren, and Omega. You have personal assistants, custom tailors, men with Germanic accents who explain the machinations of luxury watches. At the Nike station, the mirror in your dressing room is electronically embossed with your name. It is all very surreal. At the end of the day you leave processing with loads of very nice, very expensive gear. You are made to feel like this is all normal, that you deserve it because you are an athlete representing the United States of America.

that this actually is normal.

Like our kit, everything about the Paralympics is larger and shinier — on several orders of magnitude — than anything we otherwise experience. Take the village. Rather than booking a block of rooms at a team hotel, we've been given a city. A cluster of 18-story high-rises, 31 of them in all, defines one border of the village. The other is the dining hall (the largest tent that most-anyone has ever seen), the welcome center, and the transport mall. A road loops 1.6 miles around the complex, and a walking path wends its way through the middle of a communal park that bisects the village. There are stores, gardens, swimming pools, indoor and outdoor gyms, a recreation center, a post office, a salon, a dry cleaners,

## You are made to feel like all of this is normal, that you deserve it because you are an athlete representing the United States of America.

High clichés apply: The rugby court is still 94 feet long, there are still four players on the other team, and there are still four, eight-minute quarters, two penalty boxes, two referees, and one soft-touch rugby ball made by the Molten corporation of Hiroshima, Japan. In all quantifiable respects, I will be playing the exact same game that I have spent the bulk of my disabled life playing.

Yet this is the Paralympics.

As much as the actual game is the same, everything surrounding the game could not be more different. It starts before you even get to Rio. We go to processing in Houston, where we are outfitted with the kind of kit that makes you

For anyone who has been involved in para-sport at any level, this is not at all normal. I'm used to playing in national championship games where the only spectators are the athletes who've already been eliminated. I'm used to being on a team, ranked number one in the world, where the only kit our budget allowed was two game jerseys and a T-shirt that one of our staff screen-printed in his spare time. Now we have a team of smart, well-paid professionals devoting significant mental and monetary resources to ensuring that we project the proper image of the United States (one of largesse, professionalism, and style) to the world. We smile, say thank you, and pretend

THE EXTRAORDINARY ORDINARY

Photo by Loren Worthington

ORDINARY

# LIFE AT THE PARALYMPICS

BY SETH MCBRIDE

a wheelchair and prosthetic repair center, and one free and very busy McDonald's.

The village itself looks much like you might imagine: functional, purposeful, if a bit sterile. There are 159 nations represented in the Paralympics, only 48 less than in the Olympics. In terms of housing, egalitarianism reigns. Each building appears identical,

as with each floor, and each apartment within those floors. It looks rather like communist-bloc housing, if the USSR had survived until white tile floors, and glass balcony railings became a thing. The only areas for international envy within the village are the relative locations of the dining hall, and McDonald's, respectively, to your building. We are a bit of a trek from the dining hall, and about as close as you

can get to the McDonald's. This is either coincidence, or the Brazilians' idea of a joke.

The village itself offers some of the finest people-watching in the world. If this is your first Paralympics, the sheer cornucopia of disabilities is a bit overwhelming. You see things that you have never seen before. Little people riding little bicycles. A statuesque Polish woman with a unilateral below-the-knee amputation pushing



As the United States defeats France in this exciting game in Carioca Stadium, Seth McBride does his part by keeping the ball away from the opposing team. The United States won the silver medal, and the gold went to Australia.



Photo by Al Tielemans

a heavy-set Polish man with paraplegia over a ramp. An Italian with a motorized scooter wheel attached to the front of his wheelchair towing three more wheelchair-using Italians, all clad in Armani, through a throng of people. An 8-foot, 2-inch Iranian folded into a hospital chair, carrying a tray of rice and meat on his lap. The blind leading the blind.

This all comes as a bit of a shock at first. Even if you have been living for decades, or all your life, with a disability, you've never seen this many gimps in one place at one time. The strangeness of it makes you feel very normal. Strolling from point A to point B reveals that having a disability does not make me morally superior to the nondisabled person at the grocery store who stares at me as I reach for a carton of eggs. In the village I catch myself staring at people with disabilities all the time. I also catch myself thinking, "Oh man, I'm glad I don't have what that guy has." I'm quite sure that guy was thinking the same thing about me.

It takes some getting used to, this being disabled around so many other disabled people. As a wheelchair user, I'm used to people getting out of my way when I'm rolling down a busy sidewalk. If I'm rolling toward someone who can see me, they step sideways out of my way, I keep rolling straight, and we go on our respective ways. Here, I have to actually

think about moving myself out of the way.

I'm glad that quad rugby isn't at the beginning of the games. We have seven days before we start competition, plenty of time for the shock and awe to subside, and a sense of normalcy to set in.

## FANTASTIC, WITH A FEW MINOR INCONVENIENCES

In the lead-up to the games, most of the news regarding Rio had been negative: there's no money, they haven't sold any tickets, Zika!, etc. I read it all with a skeptical eye. The media tends to focus on the negative because it gets people talking, it makes people click a link. "They're working really hard to do the best they can, and everything is probably going to be fine" isn't much of a headline, but is much more accurate than the ones that had been popping up on my Facebook feed before we left. Zika turned out to be mostly a non-issue during the games. There were some serious issues with the Paralympic budget. Fortunately, last minute negotiations between the Rio organizing committee and the International Paralympic Committee had freed up enough funds to get all the teams to Rio, and the lights and the air conditioning running in the village.

For an athlete from the United States, the Paralympic experience has so far felt

very similar to that of London (2012) and Beijing (2008). There have only been two noticeable differences. For one, there hasn't been much variety of food in the dining hall. There's a lot of it, and it's been tasty, but it's mostly the same thing day after day. After a week and a half, this gets pretty old. Second, as in the rest of South America, you have to put your toilet paper in the trash can instead of flushing it. Maybe headlines should have read: "Rio: overall fantastic, but with a few minor inconveniences!"

My biggest concern is with ticket sales. As of August, only some 15 percent of the available tickets to Paralympic events had been sold. We were going to be playing in a 13,000 seat arena — the largest that has ever hosted a wheelchair rugby match. I played in front of packed stadiums in London and Beijing. It's a singular sporting experience that only happens at the Paralympics. It makes you feel like an athlete and a bit of a rock star. It also makes you feel like you're part of something much bigger than yourself. Seven of the 12 players on our team have never been to a Paralympics before. It just wouldn't be right, to make it all the way to the Paralympics, and not get to experience playing in front of a sold-out stadium.

Fortunately, once the Olympics ended, ticket sales picked up sharply. The day before we flew to Rio they broke a record for single day ticket sales, and our second

Photo by Bob Martin





The American cheering section enthusiastically roots for their Paralympic athletes.

day in country they broke it again. All of a sudden there is talk that certain events are selling out.

A few days into our stay, we want to get a feel for what the crowds and the venue are going to be like. One day, we take a bus down the road to the Olympic park — a cluster of venues not far from the village, hosting everything from wheelchair rugby, to wheelchair basketball, fencing, judo, goalball and boccia. The U.S. women's basketball team is taking on China in a pool play game hosted at Carioca 1, the same arena at which we'll be playing. We file off the bus, down the ramp, and into the back entrance to the venue. We don't have tickets to the match, but we do have accreditation cards. We move like we're supposed to be there, and volunteers escort us through the back halls of the arena, through a curtain, and suddenly we're floor level next to the court. The arena is enormous. Stands rise level upon level. A giant screen hovers above the court displaying the game stats. The seats aren't completely full, but there's a large crowd for a random pool play game featuring two countries not named Brazil. We wheel to athlete seating, a low riser just off one edge of the court, and settle down to watch the game. It's already into the second quarter and the U.S. is holding a 10-point lead.

The crowd is into the game, cheering

scores and letting out collective sighs when a ball rims out, not quite falling in. During a quick break in play, the wave starts and is maintained for a full four or five revolutions. The atmosphere feels like we're courtside at a professional basketball game. I look to the game and see fellow U.S. Paralympian Desiree Miller throwing an outlet pass to teammate Rose Hollerman. There are wheelchair athletes sprinting down that court. That's the same court we'll be playing on in just a few days. The thought sends a chill down my back. I look up to the crowd, the lights above the

fun. We smile, high-five, and take more pictures than we can count. When the game ends, there are so many fans who want pictures that it takes us 20 minutes to get off the court. All that worry about interest and ticket sales, and the Brazilians are embracing these games with a passion you'd be hard pressed to match anywhere in the world.

## THE BIG WAIT BEFORE SHOWTIME

Days at the Paralympics revolve around eating and training. We are only allotted one two-hour training block each day. Compared to a typical, three-a-day training camp, the schedule is downright luxurious. The hardest part about Paralympics isn't the fine-tuning of strategy or reaching peak fitness and mental preparation. We've spent the last four years working on all of that. At this point, most everything associated with the game is almost automatic. As athletes, it's what we do.

The hard part is filling up your newfound excess of free time without going crazy. I sleep 10 hours a night, trying to make up for a long summer of exhaustion. I sit for long periods of time in the dining hall, sipping coffee in the morning and watching the world go by. Chuck Aoki and I play a game: Most unlikely country you've seen to field a Paralympic team. The Seychelles and Lesotho take a firm lead. We decide that

As we sit watching the game, people keep trickling down from the stands, bending over the rail and asking us to take selfies with them.

court, the television cameras, and take in the moment. I know that when we're playing here, I'll be too focused to really revel in the surroundings.

As we sit watching the game, people keep trickling down from the stands, bending over the rail and asking us to take selfies with them. Kids, adults, it doesn't matter; everybody wants in on the

the only way to top those would be a Nauru or Tuvalu sighting.

In the apartment we spend hours sitting in a circle playing catch, bouncing a ball off one wall, or a wall and a ceiling. We call out names, and if the thrower misfires or the recipient can't make the catch, one or the other is eliminated from the game. We have quadriplegia. The

games don't last very long.

You find ways to entertain yourself because if you're not keeping yourself busy, you find yourself thinking constantly about the upcoming competition. You want to be prepared, but over-thinking is a surefire way to ruin your performance. One of my flat-mates is of Polish descent. His distraction is to venture down to the recreation center to find other athletes to beat at chess. Most nights he seems almost disappointed at the ease with which he's won.

I read, write, and Facetime with my wife at home. This all goes well for the first week or so. But at some point all this sitting around being cooped up in the village and barely practicing, rolling to the dining hall and back again, starts to get to you. People get irritable. People get snippy. Guys who normally hang out in big groups start to need some alone time. You feel like your nerves have a static charge. All you want to do is go strap into your rugby chair and beat the hell out of somebody, but you can't even do that because you need to save this restless energy. As annoying as it is, this cooped up craziness you feel inside of you is a

necessary part of your preparation. And just when you start to feel like you can't stand it anymore, one morning you wake up and it's time to start playing.

I sit up in bed and yell across to my roommate, "Lee, you know what day it is?"

"It's game day, baby!" he yells back.

Four years of preparation and it's finally time to do what we do.

## CODA: HEARTBREAK

The tournament went exactly as we could have hoped, right up until the final game. We took care of business against France and Sweden: started hot in both games, had some struggles we were able to work through, then closed both teams out without overworking any one player. We had a nail biter in our last pool play game — Japan came to win and they pushed us to the limit. We pulled out a 1-point win in overtime. It was intense, pressure-packed, and everyone rose to the occasion. It was the kind of game that makes a team better, stronger. In the semifinal we defeated Canada. We were the better team and we played like it.

Suddenly it was showtime, the gold medal game, United States vs. Australia.

It was the kind of game that makes sports special: back and forth, intense, 13,000 screaming fans, and two teams showing why they're the best in the world. Through four quarters, and then an overtime, we could not be separated — the lead changed hands again and again. Then, with 3.3 seconds left in the second overtime, we turned the ball over. It was over.

It's difficult to explain to someone that you're disappointed with a silver medal. People look at you like you're an ungrateful brat. *Do you know what people would give to have any medal? To even go to the Paralympics?* I do know. I understand with all the logical parts of my brain. Indeed, there are six other wheelchair rugby teams who would trade places with us in a heartbeat. But directly after the gold medal final, all I feel is shattered.

To win a silver medal you have to lose a heartbreak game. It was a game we had every opportunity to win, and Australia still took it. Am I proud to have won a silver medal? I sure am. I'm proud of my team, and everything about the process of getting there. But for the rest of my life I'll think about what else we could have done to get that gold.

American Josh Brewer lies on his back clinging to the ball. Despite giving its all, the American team was not able to defeat Australia in the gold medal match in mixed wheelchair rugby.



Photo by Bob Martin



U.S. men's wheelchair basketball player Brian Bell topples to the floor in the match between the U.S. and Iran. His team went on to win the gold after defeating Spain. Photo by Thomas Lovelock.



Concerns that severe budget cuts and dismal early ticket sales would dampen enthusiasm for the games proved unfounded, as sales picked up in the days before the games. Many events sold out and, as shown, the opening ceremonies were attended by an enthusiastic audience. Photo by Bob Martin.



U.S. extreme wheelchair athlete Aaron Fotheringham flies down a megaramp and bursts through a giant ring during the opening ceremonies to Rio's 2016 Paralympic Games. Photo by Al Tielemans.

# PARALYMPIC MOMENTS

The Rio 2016 games were the most successful for Team USA in 20 years. Taking place Sept. 7-18 in Rio De Janeiro, Brazil, the American Paralympians brought home 115 medals — the most won by the team since the 1996 games held in Atlanta. This time around, the women stole the show, winning more than half the team's medals — 70 total, including 24 gold, 24 silver and 21 bronze — and sweeping the podium twice in track and field events.

All photos courtesy of OIS/IOC

The U.S. sailing team took home a silver medal in the three-person keel boat event. This is the first time these three sailors have won a Paralympic medal. Photo by Loren Worthington.



The stars of this year's Paralympic Games are these three women who swept the podium twice: silver medalist Chelsea McClammer, gold medalist Tatyana McFadden and bronze medalist Amanda McGrory. Tatyana McFadden (above) won four gold and two silver, the most medals won by a Paralympian in track and field. Photos by Bob Martin.

The U.S. men's wheelchair basketball team celebrates winning its gold medal match against Spain. This is an historic eighth gold medal for the team, and its first gold since the Seoul games in 1988. It is the first year both the men and women brought home the gold since 1988, and the first time since 1996 that both teams medalled.

Photo by Simon Bruty.





The U.S. mens goalball team took home the silver, emerging from what commentators called "the group of death," beating both Germany and Brazil to play in the final match against Lithuania. These blind athletes use eyeshades to ensure no player has an advantage in catching a ball with bells embedded in it.

(Above) Gail Gaeng cheers as the women's wheelchair basketball team wins its third gold out of the last four Paralympic Games.

(Left) Mike Tagliapietra competes in men's air pistol.



If women's tennis player Kaitlyn Verfuerth looks familiar, it is probably because she and her partner Greg were featured on the February 2014 cover of NEW MOBILITY. She competed in both singles and doubles in Rio, marking her third Paralympics appearance.

All photos this page by Loren Worthington.

# THE (*Lasting?*) LEGACY OF RIO 2016

BY EMILY ROSE YATES



Emily Rose Yates, shown wearing glasses, wonders if Rio's accessibility changes will benefit residents.

**S**uadades. The Portuguese word beautifully epitomizes the vibrancy and emotion that every single native of Rio de Janeiro — every *Carioca* — has for their home. Suadades does not have a direct English translation, but it's an expression of total longing and nostalgia for something you once had or felt.

A longing comes easily for the sheer beauty of Rio and its people. However, even on the heels of all of the investments and improvements that led up to Rio hosting the 2016 Olympics and Paralympics, I doubt Rio's disabled locals will ever praise their city for its accessibility. Indeed, the longing or nostalgia of suadades may only apply to those who were fortunate enough to see the inclusion present at the Paralympic competitions as well as their desperation to see this materialize elsewhere in Rio.

Barra da Tijuca, where most of the 2016 games took place, is Rio's newest, most commercial area, and a great (if

somewhat sanitized) example of the city at its best in terms of inclusion. Bililingual signs were at every turn during both the Olympics and Paralympics, as was a military presence and some flipping fit athletes with rucksacks, white canes and wheelchairs. It was, without doubt, an impressive example of accessibility deserving of commendation: Buses were ramped for the first time (a legacy that will undoubtedly last), and staff in restaurants and shops were pleasantly aware of additional needs (a skill that cannot be unlearned). On the other hand, it must be emphasized that the Olympic Park was not "real Rio." The pastels weren't as juicy, nor the caipirinhas as sweet, and, most importantly, there was little to liken the area to one that a disabled Brazilian would encounter on a daily basis — an area that, let's be honest, wouldn't have "inclusion" as its middle name. However much it tried, Olympic Park was not the authentic, loud, vibrant, dangerous Rio.

Attractions are open and welcoming to disabled visitors, hotels ensure that accessible vehicles are available and tour operators now realize they'll get more business if they have an awareness of additional needs.

Access in Rio has improved drastically since I first visited to consult on the accessibility of the metro system in 2013. Attractions are open and welcoming to disabled visitors, hotels ensure that accessible vehicles are available and tour operators now realize they'll get more business if they have an awareness of additional needs. The city is finally starting to appreciate that accessibility is profitable as well as the ethical thing to do — hugely important at a time when Rio is finding financial footing again after economic downturn.

While volunteering at the 2016 Paralympics, I was blown away with the accessibility, even with my two-hour journey from Copacabana at 5:30 every morning (due to the Park residing in its own accessible "bubble" outside of the city rather than a lack of quick and easy options for me). Once in the sports arena, I was able to access everything my colleagues could, and was just as impassioned to cut out the

biscuits when I saw medals being won.

But once I left that hyper access-conscious environment, when I was at dinner with my friends in another area of the city, my “disabled” status returned when the restaurant where we were dining

more than they are about the issue at hand. I totally understand it, though: I’m fortunate to live in a place where the access is so good for the most part, and that those with disabilities are genuinely being seen as people demanding of respect.

ability equated with education, interest and greatness continues to bring me great joy, and the Paralympic Games helps push this concept on. But not all Brazilian locals, disabled or not, will agree with this sentiment. It’s worrying that I could



The beaches in Rio, including the Copacabana, have become much more disability-friendly.



Rio's buses were ramped for the first time in preparation for the Paralympic Games.

didn't have an accessible bathroom, and the security guards had no choice but to help me down 30 steps.

Having been to Rio five times, I can see the city from the eyes of what feels like a semi-local, and this is where the legacy of the games gets more important than ever. For the city to be fully inclusive, not just for our amazing Paralympians, accessibility must continue to flourish as something that is a desired result, rather than a time-pressured “tick-box” exercise. And it's not there yet.

Rio's inhabitants are some of the most helpful I have ever met. It is rare that I have waited more than 20 seconds when struggling to get up onto the pavement or off a bus. In fact, dare I say it, the willingness to help, combined with a lack of political correctness and fear of “getting it wrong,” is refreshing for me, a British girl who is more often than not surrounded by reserved helpers who are concerned about being offensive and patronizing

Still, at home I don't need much help with curb cuts or getting on public transit. In Rio I always do.

It isn't all doom and gloom as some incredible events have been born, with Paralympic and government funding in tow, that I hope will continue as markers of legacy. One funded example is the city's first “Wheelchair Festival,” which saw cool and quirky models dotted all over the Port Area, banishing the idea that disability and fashion must be mutually exclusive. Furthermore, I had never considered the beach an accessible place for me to go, especially alone. Now, the Copacabana sand is done up weekly, with smoothed walkways and accessible bathrooms, whilst excited surfers can be taken down to the sea in an adapted wheelchair with a reclined back and large floating wheels. Once in the water, it's surf, paddle or body board — all particularly Brazilian and all the choice of the individual.

As a disabled person, watching dis-

watch Ellie Simmonds win a gold, then switch over the channel with a flick of a button and sit in front of a program that focuses on a disabled person fighting for their benefits with 99 pennies to last them for the month. The two extremes exist, but “normalized” representation of those with disabilities still seems to be pretty far behind, and it's concerning that real understanding and acceptance of disability is unlikely to happen without it, in Rio or elsewhere. We can all cheer for our country winning medals and get on our soapbox when judges don't vote in our favor, but not all of us can get onto that field, dive off that board or give our all on the basketball court, and that should be OK, too.

Let's hope that it's not just the “super-human” of us that experience an accessible Rio in the future.

*Emily Rose Yates recently authored the Lonely Planet guide Accessible Rio de Janeiro.*

# WE LOVE TAKING RISKS. YOU SHOULD TOO.



With fall reaching its end, we're squeezing out the last bit of fun for the season.

We've seen some beautiful views and reached unbelievable heights with WHILL Model M.



For more information, contact us at [info@whill.us](mailto:info@whill.us) or [\(844\) 699-4455](tel:(844)699-4455)

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

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

08/16 740-01451-MKT-08



# SPOTLIGHT: ROCHESTER, NY

BY SUE SHEPARD

## MY TAKE

Rochester has a lot to offer for those living with a disability. Winter weather aside, there are many aspects of this region that helped me get the most out of life's adventures, including raising a daughter as a single parent. Our regional spinal cord injury and rehabilitation center offers immediate access to help during a crisis and the inevitable follow-ups. Local universities focus on cutting edge research and provide student-based therapy to those who have limited insurance coverage. Competent specialists offer assistance and education for primary care physicians regarding spinal cord disabilities.

My work with Rochester Accessible Adventures allows me to participate in and develop adaptive sports clinics so that our disabled community and their families can participate together in outrigger canoeing, fencing, biking, sled hockey, rugby, water skiing, sailing, golf and more.

## PLACES TO GO

Spring, summer and fall offer the best opportunities to enjoy Rochester's rich cultural and scenic atmosphere. Music connoisseurs revel in the week-long International Jazz Festival. Fall is prime time for a Finger Lakes wine tour dotted with dozens of craft breweries and wineries tucked into rolling hills flush with spectacular fall foliage. For more physically active folks, beautiful, historic trails follow the Erie Canal, allowing wheelers the same access that everyone else has.

Accessible indoor adventures include the nationally known Strong Museum of Play, the Rochester Museum and Science Center and the Memorial Art Gallery. Entertainment seekers will enjoy the Rochester Broadway Theater League, GEVA Theater or one of the many world-class acts that frequent the beautifully decorated Eastman Theater.

## ACCESSIBLE LIVING

Transitioning from the hospital to the community can be frustrating and scary. Slowly over the last few years there has been an increase in numbers of accessible

## SKINNY ON THE CITY

Located in upstate New York, Rochester is surrounded by accessible lakes, scenic wine trails, historic architecture and beautiful parklands. Regardless of the season, there is a multitude of indoor and outdoor activities to fill your schedule. Families enjoy rich cultural experiences at nationally known museums, art galleries and the world-renowned Eastman Theater. Weekends are loaded with festivals showcasing the best of film, food, music and crafts.



Biking is more fun with Rochester Accessible Adventures.

housing units. Fortunately, Rochester does have a good supply of affordable houses and a number of contractors with experience in home modifications. Many nonprofit organizations work directly with social workers in our health care system to secure living arrangements that are a good fit.

## GETTING AROUND

There are great options in Rochester for those able to afford their own vehicle. As

with any city, finding accessible parking is a challenge, depending on the place and time of day. Other transportation options include Regional Transit Service — our local municipal bus company offers four types of paratransit eligibility — and multiple wheelchair van companies provide accessible taxi services. All public-based options operate with geographic constraints that can be frustrating for time sensitive schedules. Some will accept Medicaid payment with prior approval.

## MUST SEE, MUST DO

Food lovers can delight in their choice of elegant restaurants, but don't forget fun, "lip smacking" options like the Dinosaur BBQ, Sticky Lips BBQ (featured on "Man vs. Food") and for those brave enough, a "garbage plate" from Nick Tahou's.

Also, sports fans have accessible options for every season. Adaptive sports are available for all ages via the WNY Wreckers quad rugby, Rochester Wheels adult basketball and the Rochester Rookies youth activities.

Learn about the Rochester Chapter on next page

## MEDICAL FACILITIES

An exciting development in Rochester will be the University of Rochester Neurorestoration Institute, which will be directed by Dr. Bradford C. Berk, who stepped down as CEO of the UR Medical Center to devote himself to the URNI. With an incomplete C3-C5 SCI, Dr. Berk's knowledge, passion, and determination will create a destination facility. The URNI will offer comprehensive clinical services and research trials; focus research on pain, stem cells, complementary and integrative health; and provide devices for restoration of sensory and motor deficits.

## Rochester: Perseverance, Inspiration, Teamwork

The Rochester Spinal Association, a chapter of the United Spinal Association, is truly a portrait in perseverance. Founding members Cathy Flanagan, Sue Shepard and Amy Scaramuzzino were on hand 25 years ago to cheer on Dave Resseguie and Bruce Holiday as they wheeled from Albany to Rochester to promote ADA awareness for people with disabilities.

In October of this year RSA celebrated its anniversary by holding the first annual Variety Live fundraiser. This one-of-a-kind event brought together influential members of the Rochester community and wheelchair users to champion the cause of RSA. Variety Live was the largest fundraiser in the history of RSA, raising more than \$70,000 toward the chapter's mission of enhancing the lives of people living with spinal cord injuries.

This success would not have been possible without the energy and vision of John Casey, the current board chairman. Casey suffered a traumatic spinal cord injury three years ago. Facing life as a paraplegic created daunting new challenges for him and his family. Fortunately, he began attending an SCI social support group that opened his eyes to resources in the community and most importantly the lack of adequate resources for families touched by spinal cord injury. Through his vision and determination, RSA set out with the goal of becoming a comprehensive resource for anyone living with SCI/D.

Team work was the key. Pulling from the healthcare, business, philanthropic and nonprofit entities in the Rochester community allowed RSA to develop a well-rounded board of directors. The first few meetings focused on developing the chapter's goals, mission and vision. This process took some serious blood, sweat and tears, but the board persevered, knowing it was critical to the chapter's future growth.

The founders quickly realized that good intentions meant very little if they didn't have an accurate grasp on their membership. Updating mailing lists and researching ways to maximize community outreach became a continuous priority. Email, Facebook, social media and a dedicated website fuel marketing efforts.

The board meets monthly to access opportunities to be seen, heard and recognized. In Rochester alone there are, on average, 75



RSA is excited to collaborate with Dr. Bradford C. Berk on developing the Neurorestoration Institute.

new cases of SCI per year and thousands of people in upstate New York living with SCI. The financial challenge for these families is overwhelming, with more than 25 percent of those with SCI living below the poverty line.

Discussions at the monthly social support groups cover the many issues facing the chapter's members, including equipment, transportation, home modification, lack of insurance coverage, lack of healthcare services and access to resources. Partnering with United Spinal Association has helped grow the chapter's peer mentoring and employment mentoring services. It has also opened the board's eyes to the national scene and the importance of understanding and building on common strengths from community to community. United Spinal Association facilitates this sharing and engages on the common cause.

RSA's local efforts include close relationships with organizations focused on maximizing the functional independence of those with SCI/D. RSA is excited about collaborating with Dr. Bradford C. Berk on the development of the University of Rochester Neurorestoration Institute. Berk previously worked as CEO of the UR Medical Center and brings a unique perspective, as he is a

C3-5 incomplete quadriplegic as the result of a 2009 bicycle accident. The URNI will offer a comprehensive and integrated set of clinical services for the people it serves, focusing on post-acute and chronic care by offering state-of-the-art therapies that facilitate the restoration of nervous system function. The URNI will build robust clinical research programs utilizing the University's existing strengths in neurology and neurosurgery (top 10 rated in *U.S. News and World Report*), and neuroscience (ranked seventh in NIH funding last year). Specific research areas will include pain, stem cells, complementary and integrative health, and devices for restoration of sensory and motor deficits.

The chapter believes that nothing is more inspiring than being part of a social support group that brings together people who have been in chairs for many years and people who are newly injured. The meeting can take on a "life of its own" as the more experienced listen and advise those faced with an endless list of challenges. One quickly realizes that there are no "perfect" answers. Each individual needs to find answers that work for him or her. What's important is that RSA provide the exposure to potential resources and solutions for its members.

## VetsFirst: Friends to Help with Your Benefits

**D**ealing with the VA and making sure you get the benefits and services you need can be tricky. Luckily you have a friend at VetsFirst.

Lynn Kelly had been married to her husband, Gerard, for 42 years and was no stranger to navigating the world of his veteran's benefits, but when he passed earlier this year she was overwhelmed. "I'd never been through anything like this before," she says, "There were so many decisions, and I had so much else going on." To help her figure things out, she called Christine Golden, the national service director for VetsFirst and her husband's case worker since 2006. Golden got Kelly her Dependency Indemnity Compensation and burial benefits and helped her understand issues around veteran's mortgage insurance. Kelly had watched other friends wait upwards of a year to get benefits and was surprised how quickly Golden resolved all of her issues. "Christine has been a godsend," says Kelly. "She really has been here for me. She has gone above and beyond, constantly calling me and making sure I got everything I needed and deserved."

Kelly's experience is not unique for VetsFirst clients. The VetsFirst staff prides itself on going above and beyond to ensure everyone who submits a problem via "Ask VetsFirst" or calls the offices, gets their issues fully resolved. "All of my clients are friends of mine," says Johnny Parker, VetsFirst's veterans service officer. "I genuinely care about all of them."

Jerry Ridgley, a Marine veteran from the Vietnam era, is one of those friends. Ridgely, who lives in Philadelphia, came to VetsFirst early this year with no disability rating and a growing number of serious medical issues. On top of that the city was threatening to foreclose on his home. Parker remembers Ridgely's first visit to the VetsFirst office vividly. "He was totally distraught," says Parker. "He wasn't getting the answers or the help he needed from the VA or the VA Medical

Center." Parker didn't waste any time. "I saw that he was in desperate need of attention, so I called the VA Medical Center and I told them I was sending him back there and someone needed to see him today and that I was putting in a claim for some disabilities."

Parker's review netted him a 100 percent disability rating and paved the way for much needed medical attention. "I've been in and out of the hospital with no billing to me whatsoever," says Ridgely. "I'm talking hundreds of thousands of dollars because I had a triple bypass and then I got a major heart attack."

Parker also helped resolve the outstanding issues with the city and got him a Veterans Temporary Assistance loan to help Ridgely catch up on mortgage payments. Parker talks with Ridgely almost every week now. "We got him on even keel and stable, and we're just rocking out from there," he says.

That level of personal attention even applies to clients who find VetsFirst through the internet and the "Ask VetsFirst" portal. Yvonne Snyder is one of the thousands of clients whose road to help started by clicking on Ask VetsFirst.

Snyder's husband, who served in the Navy, passed Aug. 23

and she didn't know what she was eligible for. She is thankful she overcame her initial skepticism of VetsFirst. "I didn't know if VetsFirst was a real organization," she says. "Then once I started talking with Christine I realized it was legitimate. Everything went so fast and so smooth. I really thought things were going to take months, but she had all the info I needed and everything went so fast. Now I'm all set."

Now, Snyder has Golden's phone number saved in her contacts. "If anything happens with any of my friends, this is the number they're going to get," she says.

For more information about VetsFirst, or to start getting the answers you need via Ask VetsFirst, visit the website at [www.vetsfirst.org](http://www.vetsfirst.org).



VetsFirst helped Marine vet Jerry Ridgley save his house and his health.

## 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)

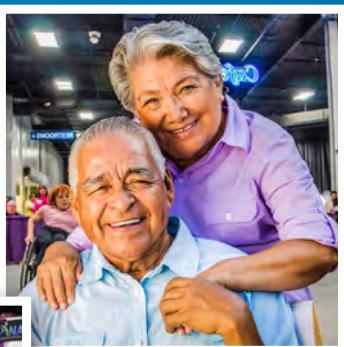
### CONGRESSIONAL LIAISON OFFICE

*Disability Policy Advocacy*

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



# 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

Toronto  
January 20-22, 2017

Los Angeles  
March 24-26, 2017

New York Metro  
May 5-7, 2017

Chicago  
June 23-25, 2017

Houston  
August 4-6, 2017

Boston  
September 8-10, 2017

Bay Area  
October 27-29, 2017

DC Metro  
December 1-3, 2017

# THE RIPPLE EFFECT:

## *Siblings and Adaptation*

BY CINDY HALL RANII



From left to right are shown Laury, Debby, Cindy, Stevey, Mikey and Bobby when they were very young. And below, they are shown all grown up.

These six are a tight-knit clan, always there for each other, each in their own way.



**B**irth order has always intrigued me. Born the fourth child of six, I might have been a “lost-in-the-shuffle middle child” who couldn’t find a baby picture of herself. But I was the first girl after three boys, the last of whom my mother threatened to “throw out the window” because she wanted a girl, not another G.D. boy!

That privileged position of being the only girl changed when two more daughters were born, completing the half dozen. We were the Hall kids: Bobby, Mikey, Stevey, Cindy, Debby, and Laury, six kids born within eight years. It was the 1950s, and I grew up reflecting the stereotype of an oldest daughter: responsible, organized, self-disciplined, take-charge, strong and a bit anxious. When our mother died in 1957, I became all the more “oldest daughter-ish” (or bossy, as some characterized it). I can still hear my younger sisters admonishing me, “You are not our mother!”

The six of us bickered and quibbled and fought — a “Lord of the Flies” type of single-parent household, but no set of siblings could be more supportive and loving of each other either. So it was a shaking family event when 11 years ago I was

stricken almost overnight with transverse myelitis, a rare neuro-immunologic disorder. When it paralyzed me from the T3 level and below, the invulnerable oldest sister all of a sudden couldn’t walk, let alone wiggle a toe, turn over, pee without a catheter, poop without a major process, or move independently from a bed to a chair.

“What? That can’t happen to Cindy!”

“How could she be paralyzed if there was no trauma, no accident?”

“When will she be better? I read that a third of people with TM recover fully. That will be Cindy. She’s so strong.”

But we all soon realized that being a strong, competent older sister had no effect on my damaged dendrites and the myelin sheath that fell down on its job of protecting my spinal cord. Strong had everything to do with the degree to which I would adjust to my paralysis, but it was not going to change the basic fact that “nobody was home” below T3, and there was no reset button.

### **Now What?**

When I realized my paralysis would be permanent, for some reason it didn’t strike me as a calamity. As a git-r-done oldest daughter type, I was eager to get started in the gym and to learn the new skills that I would need to adjust to life as an active wheelchair user. One by one, my siblings made the trek from southern to northern California to see me in rehab.

When younger sisters Debby and Laury came to visit, I was delighted to have their comforting company. We sat out on the sunny patio and laughed at the dark humor my partner Shelly and I had already started to voice to help us cope. We would act out the wheelchair scene from the classic 1962 movie, *What Ever Happened to Baby Jane* — “But you are in that chair, Blanche, you are in that chair!”

Brothers Bob and Steve came to see me, too, and I began to reflect, “This must be more serious than I thought.” Then there was my brother Mike, who does not like to travel. When he came to visit with his wife and three kids, I was concerned: “Wow, I must be screwed!” And when his daughter Danielle hugged me and said that everyone was praying for me, I got worried. Our family is not known for church-going or prayer. “Was I going to die and nobody told me?”

To Shelly and me it was obvious that our lives were changed forever. But out of ignorance, denial, strength, grace or a combination, I never really worried that my life was somehow going to be diminished. I had Shelly, my brothers and sisters, extended family, a solid career, sick leave benefits, good insurance, a little bit of money in the bank, excellent rehab care; it would be OK. I wasn’t dying. I just couldn’t move or feel below the

chest, pee or poop! Together we would figure this out.

So we all soldiered on ... the whole family adjusting to Cindy being in a wheelchair. I sometimes wondered how my new normal affected my siblings, but I had never really asked them. As kids of the 1950s, avoiding talking about something life-changing was the family norm. It took us some 55 years to talk about our mother's death, so talking about my paralysis only 11 years post-injury seemed to be great progress. I wondered about the ripple effect on my brothers and sisters. Had my paralysis changed my role in the family? Did they think differently of me?

What I did find was that my paraplegia hadn't really changed their view of me or my role, but that my paralysis was a dramatic reminder of how life can turn on a dime. It strengthened their "seize the day" approach to living, and it gave them renewed appreciation for the ease with which they can do everyday things: turning over in bed at night, taking a walk, hopping out of bed to run to the bathroom, taking a quick shower, popping in and out of the car, reaching something on a top shelf, running errands, pulling on pants. It has also increased their appreciation for the level of complexity that being a wheelchair user brings to everyday life.

## ***Realizations, Complications and Adaptations***

Several years ago my oldest brother, Bob, and I were sitting at a Starbucks. I had fallen out of my wheelchair an hour earlier, and I thought my leg might be a little swollen. He helped me to get a

Cindy and her partner, Shelly, appreciate the support they receive from Cindy's siblings.

baggy full of ice and to prop my right leg up on a chair. Half way through our coffee we realized that "a little swollen" might be an understatement. Bob raised his eyebrows and calmly said, "Maybe you should get that checked out." We finished our conversation, and then, out of an abundance of caution, Shelly and I went to the hospital. We laughed in the ER, because Shelly had seen the X-rays and determined that there was no sign of any fracture. The radiologist begged to differ. I had broken my tibia and fibula. No pain ... but two breaks!

Like my other siblings, my brother Mike was saddened by my situation but confident Shelly and I were handling everything as well as any couple could. He realized, however, that many simple things in my life would no longer be so simple, and that certain mundane pleasures were gone. He told me that one night not long after visiting me in rehab, he turned over in bed and started crying. He realized that for me it would no longer be an automatic, perhaps pleasurable thing to turn over at night with ease. He, too, was reminded how fragile life can be: "And that's scary," he said. Our shared vulnerability is basic to our human condition, but who wants to come face to face with it?

Steve reminded me that when he first heard that I was in the hospital, the doctors thought I would be OK and back to normal within a month or two. But within four days, news of a "limp foot" and a "minor stroke" gave way to transverse myelitis and T3 complete paralysis. Steve's reaction? "What the F?"

After the initial shock and sadness, Steve took solace in the fact that I had such a loving partner in Shelly and that we seemed to be getting down to the reality of adjusting to our new reality. "No one could take away the paralysis, but everyone was doing the best they could. How you and Shelly handled your new situation, helped me to handle it. Your paralysis has not changed how I see you. I see you living the life you want. Finishing your career, continuing to educate others, being competitive in sports, being active with the grandkids." Any questions for me? I asked. "I have wondered how you actually can go to the bathroom."

Besides Shelly, my sister Debby has had perhaps the closest look at what it



Since you can never have enough brothers and sisters, Cindy has extended siblinghood to Sebastian and Todd.

means to live with paraplegia. For several years she worked with me on a weekly basis, before Shelly retired. Debby, and her partner Sam, helped with housework, errands, chores, exercising, and personal care. But most importantly Debby helped me to process my new normal through dozens of conversations while we folded laundry or packed and unpacked through a variety of moves. She and Sam helped me to stay actively engaged with life, including preparing me for the 2010 U.S. Open Wheelchair Tennis Championships, although some days it was more than 100 degrees on the court. She even humorously narrated the YouTube videos we made to help "newbies" see how even a senior citizen wheelchair user could be energetic, productive, independent and athletic.

Debby tells people how I now compete in international table tennis events, often traveling by myself, and how Shelly and I take different combinations of our 12 grandchildren on elaborate adventures. She says it never surprises her that with Shelly's support, I was never on the sidelines. "You made an effort to not disconnect. You take on more than most nondisabled people."

My sister Laury came to realize the complications of paraplegia when she traveled with me to New York to attend the funeral of our daughter-in-law's mother. She learned first hand that traveling with me was sort of like traveling with a baby. ... Diapers? Check. Wipes? Check. Skin ointment? Check. Emergency change of clothes? Check. Bed pad? Check. Emergency food and water? Check.



Sometimes when Laury is out with me she wants to let strangers know that I am not unable but extremely competent. She wants to say, "This is my big sister. She is OK. She is an active grandma, traveler, and athlete. You have no idea what she can do."

## We Are All Siblings

In exploring the theme of ripple effect, I also spoke with Beth Ann, my sister-in-law. She had flown from Utah to California to stay with us for a couple of weeks when I was first out of rehab, helping me with every detail of transitioning home and providing Shelly some emotional support and the chance to get back to work. Like my brothers and sisters, Beth Ann at first was shocked and saddened by what I had lost. She, like all of us, had the freshened realization that we can be knocked flat out of the blue. That life comes at you full force sometimes.

She feels she is more compassionate now, and more respectful of the effort that it takes for people with mobility challenges to go through their days.

"Now when I see a person in a wheelchair, I wonder about their stories. Were they injured? Did they get sick? Can they walk? Do they need any help? Do they want any help?"

Beth also shared that the ripple effect for her included learning a lot about the hidden challenges that come with paralysis: transferring, using catheters, scheduling bowel programs, avoiding pressure sores, contending with fatigue, trying to adjust to temperature changes. "Why is it that you get cold easily, but if I put an ice cube on your leg you wouldn't feel it?" "How can you feel the pain of a kidney stone when you have no feeling below T3?"

In talking to my siblings I began to realize that the "ripple effect" that I had expected to uncover was actually the wrong image. The conversations revealed to me that what they had seen as my strength in dealing with my paralysis was actually a reflection of the strength that flowed to me from the love and support of Shelly, my siblings and others. The correct image was not of waves rippling out from me. Rather, it was an image of love and energy coming in to me, strengthening the older sister and

giving her confidence to make the adjustments to life as an active wheeler.

This afternoon a new friend, whom I will call Todd, is coming over to the house to play some ping-pong. He is 30 years old, a quad, two years post-injury. Until a few months ago he was living as a virtual shut-in with his grandparents, who had been keeping him sedated and inactive. He has no loving partner, no robust circle of helpful friends or colleagues, and no siblings to support his full and active recovery. But recently he has managed to break through toward a life of self-reliance and independence.

He has his own apartment now and is gaining strength every day as he pushes around town with a mutual friend, Sebastian. Sebastian is also a quad and has taken on helping Todd as if he were a younger brother. Todd's new engagement in life has come, in large part, to his adopted "older brother" who gives him the love, support and vision that life as a wheelchair user can be engaging and full.

Which takes me back to the sibling effect. Seems to me that Todd could use an older sister. I'll try not to mother him. ■■■

**KEMPF**

Enjoy driving with both hands on the wheel!

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

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

NATIONAL MOBILITY EQUIPMENT CHALLENGE ASSOCIATION GAP

## The Banff Sulfur Mountain Gondola



By Kary Wright

t's not very often that we quads get to the top of a mountain, but here I go. "Are you going up alone?" asks my wife, a little concerned.

"Looks like it," I reply. There's no turning back now.

The door closes to the cable car. I look at the attendant with a smile and can feel the swing of being suspended in the air. Cool. Then they hit a button or two and zoom ... I take off, high above the mountainside. What a rush, I love it!

I look up through the glass ceiling and see the beautiful blue sky. There are pine trees and rocks below, and off to the right a picturesque mountain town. What a blast to be sitting in this small capsule and zooming up the mountain by myself on the Banff Sulfur Mountain Gondola.

We are camping in the area with some friends, Jim and Sheila. You may remember Jim from a previous story when he and his brother successfully thwarted Murphy (and his law) after I got my chair soaking wet and it quit in Ketchikan, Alaska. He is definitely a handy guy to have around, and he adds a huge element of safety to these adventures (I may even have to step up my "breaking-stuff" game).

The four of us decided to take a ride on the gondola to experience a new view of the area, check the wheelchair-accessibility of the facility, and just have some good old fun. We had assumed that I would be loaded on board first and then the others would jump in with me, but this isn't the case.

The attendant sees me coming and grabs a wooden ramp they use to load wheelchairs into the cars. They do advertise that the gondola has four-person cabins. But apparently when you have a fairly large (or so I have heard) person



The amazing 360-degree views from the top of the mountain and in the cable car (left) were as good as Kary Wright imagined they would be.

sitting in a wheelchair that is similar in size to a 1974 Buick, putting four people inside the cable car is a bit optimistic. I have no trouble driving up the ramp as it is only about 6 or 8 inches high, but once inside it is quite cramped, and I'm sitting sideways. None of us really like that set-up as the power chair may be able to accidentally open the doors, which could be quite counterproductive at 100 feet above the ground. So the workers flip the benches up at the front and

back, then I fiddle my chair back and forth until I am facing frontwards. It then becomes evident that with no place else to sit, I will be riding by myself.

"I'll leave my chair shut off with brakes locked until the top. Should be no problem," I say to my wife and friends.

"See you at the top, Kary!" Jim laughs.

And then I'm off. Since the help loading me was fantastic, I have no apprehensions about going alone as I am sure the workers at the top will be as attentive.

I am soon zooming up the mountain, enjoying every second. What a fantastic experience. All too quickly the eight-minute journey is over, and I'm slowing down to enter the upper terminal at about 7,500 feet. Offloading goes very smoothly. After my car stops, a ramp is quickly placed up to the door and two people grab ahold to stabilize it. Then the doors open, I anti-fiddle-about and drive out. By the time the others arrive in the next gondola, I am down the hall waiting.

Although there are attractions inside, what we really want to see are the amazing 360-degree views from the top of the mountain outside. It is as good as I imagined. To the northeast is a spectacular view of the town of Banff. To the west a highway follows a meandering mountain river towards the scenic Lake Louise. To the south, the valley leads to the area we are camped in. It is so amazing to see it all from this vantage point. The view is of particular interest to me as I regularly fly this area on a glider simulator that has photorealistic scenery — it all seems so familiar.

As a wheelchair user I am confined to the terminal area, but there is so much to see from so many angles that I never get bored, and the walkway circles the facility. The girls hike to nearby Sanson's Peak, named after a man who walked there every week for over 30 years to check the

## Frequently Asked Questions

### **Is it wheelchair accessible?**

Absolutely. The new facility is just being finished and is designed to be completely wheelchair accessible.

### **Is it scary?**

Not at all, just exciting to zoom up the mountain.

### **Where is it located?**

In the Rocky Mountains near Banff, Alberta.

### **Is it expensive?**

It cost \$49 Canadian (about \$37 in U.S. dollars).

### **Where can I find information on it?**

At [www.brewster.ca/activities-in-the-rockies/brewster-attractions/banff-gondola/](http://www.brewster.ca/activities-in-the-rockies/brewster-attractions/banff-gondola/).

weather. Jim and I stay put and take in the sights of the stunning mountain valleys and photograph everything multiple times. We watch the gondola cars arrive and leave the terminal, enjoy the small mountain creatures scurrying around, solve all of the world's problems twice, and just generally enjoy being at the top of a mountain.

Too soon it is time to go. I get loaded into a car just as smoothly as on the way up. It is exhilarating as it moves forward

quickly and then drops to start the long descent to the lower terminal. This time I have my video camera mounted to my wheelchair for the ride down and I film the whole thing. What a blast — and now I can enjoy it over and over.

While up there we noticed several other people in wheelchairs enjoying the trip. I would definitely recommend this to anybody who wants to experience being on top of a mountain, whether in a wheelchair or not.

# 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.

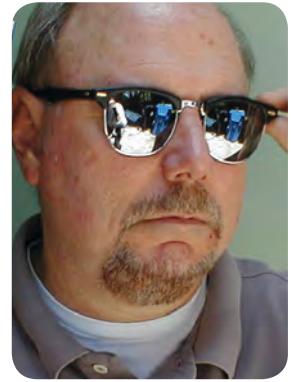


[www.conceptsinconfidence.com](http://www.conceptsinconfidence.com)

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

\*one time discount per customer

Nothing can ruin a holiday affair faster than when the guy in the chair, slurring his words, falls over backwards into the onion dip.



By Allen Rucker

## Holiday Party Do's and Don'ts

It's that time again, Wheelchair Nation, to head off to your annual office or neighborhood holiday party and try to have fun, though you can't stand eggnog and are bored by most of the people who'll be there. Be that as it may, you will be going — it's a sacred end-of-year obligation — so I thought I'd weigh in with a few tips about proper party etiquette to avoid potential embarrassment, humiliation, or outright banishment from all parties going forward.

**What to Wear.** You're in a wheelchair. You can wear anything! Bathrobe, prison jump suit, Bermuda shorts, you name it. But in this setting you should try to dress for success — or at least safety. Many of us like to stand out with some oversized elf ears or a bow-tie that lights up every time we shake hands. That's fun stuff, for sure, but on a more practical side, wear something that will help you maneuver through a dimly-lit party setting. A miner's hat with a light is always a safe choice, and if you can afford it, get a backing-up alarm beeper like those little service trucks at Home Depot. See if you can find one that plays "Jingle Bells" or Adam Sandler's "The Hanukkah Song." Pretty soon you will be the campfire around which everyone gathers for a sing-a-long.

**Mingling.** Circulating at a holiday party in a chair is damn near impossible. Your host or hostess will feel much

better if he or she can plant you in a corner and forget about you, knowing no one will trip over you or vice-versa. You need to prepare for this by surveying the room the moment you arrive and choosing your own spot. If you like to chat with total strangers, park next to the restroom. "Hey, how did it go in there?" is always a winning ice-breaker. If you just want to gorge on the roast beef and cream puffs and not make stupid chit-chat, park at the far end of the catering table, an arm's length from seconds and thirds. The food servers are always happy to oblige, out of guilt or just to stick it to the boss man.

In either situation, unfortunately, you will probably be confronted by someone obsessed with chronic disease and death who blithely assumes you are an expert in both fields. Feign food poisoning and rush to the restroom, cupping your mouth. They rarely follow.

**Inebriation.** Of course the main reason, maybe the only reason, to go to these parties is the free drinks, but chair users should be careful. Again, your host will feel sorry for you and compensate by plying you with Two Buck Chuck. Resist the temptation of asking for your own bottle. Nothing can ruin a holiday affair faster than when the guy in the chair, slurring his words, falls over backwards into the onion dip or slides under the coffee

table and can't get out.

**Watch Your Language.** In the course of the evening, people will invariably call you handicapped, "confined" to your chair, their personal hero, even though you just met, and "you poor dear." Resist the impulse to correct them with a lesson in proper dis lingo. They are at a party, for goodness sake, not an HR training seminar, and they don't want to be called out by some surly crippled guy. Cool it, kemo-sabe, with the finger wagging.

**Physical Contact.** There's always a lot of kissing and hugging at these parties. In your sit-down position, kind and often beautiful women will approach you to give you a hug for no apparent reason. They are forced to bend over, often adjoining their bosom to your face. Depending on your dating preferences, this can be an annoyance or a gift from God. If the latter, don't follow them around for the rest of the evening.

Finally, as it gets late and people get desperate, a drunken attendee you've been eying all evening might drop into your lap and start nibbling your ear. How to respond? First, check their driver's license for age of consent. Then have them sign a waiver that they landed in your arms of their own free will. If the light is green, begin softly singing "Strangers in the Night."

See, this could turn out to be the best holiday party ever!

## 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)



For shipping instructions call 844-754-3305 or e-mail: advancedtechandrepair@gmail.com



**JOHNSON  
HAND CONTROLS**

**717-449-0089**

### Manufacturers of:

Crossover Signal Controls

Signal Arm Extensions

Gear Shift Extensions

Driving Accessories



dealer inquires welcome

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



Helping you regain your Independence



NMEDA

## 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)



**QUANTUM**  
Q100 Bathchair

**NEW SEATING!**



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

**ChallengeCircuit**  
multi-purpose weight training machine  
**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

**SPORTAID**  
Wheelchairs & Stuff

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

SG-A601 \$102      AZ-1 \$279

Z4 \$288      Portable Hand Controls & Spinner Knobs

Get your **FREE** catalog today!  
[www.sportaid.com](http://www.sportaid.com)  
**1-800-743-7203**

## Ferti Care® Personal & introducing the new 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 women 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)

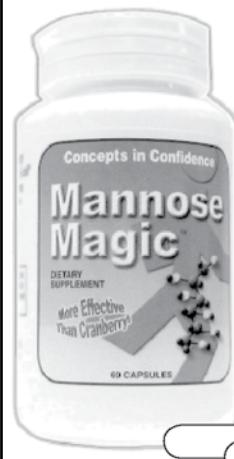
Fax. 714-594-4038

[info@medicalvibrator.com](mailto: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

## 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.

The screenshot shows the 'Sharing The Journey' website's 'Affiliate Service Providers' page. The page features a sidebar with categories like 'Sharing The Journey', 'Medical Equipment', 'Therapeutic Equipment', 'Bathroom Equipment', 'Urological Supplies', 'Scooters', 'Wheelchairs', 'Ramps', 'Assistive Devices', and 'Other'. A search bar at the bottom allows users to search by location or provider name.

**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

**Nationwide Wheelchair Van Rentals.** For the next time you want to get out, vacation, doctors appointment, or try before you buy. Learn more at [www.BLVD.com](http://www.BLVD.com)

**Over 1500 wheelchair Accessible Vehicles** for sale at one website. A complete selection of New, Used and Pre-Owned wheelchair vehicles from dealers and private parties nationwide. Check it out today. [www.blvd.com](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)

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

Would you like to work from home/anywhere, whenever you want, and say goodbye to money worries? Then click on this link: [http://track.mobetrack.com/aff\\_c?offer\\_id=1651&aff\\_id=1523649](http://track.mobetrack.com/aff_c?offer_id=1651&aff_id=1523649) Or reach out to me at: superquad702@gmail.com to learn how to create your own economy in 2017!!

## WANTED

Wanted, used Quickie II --- the older the better. [litolark@yahoo.com](mailto:litolark@yahoo.com)

**Mayo Clinic** is seeking volunteers who have a spinal cord injury to participate in research. Research opportunities exist for people of various ages, mobility and type of spinal cord injury. If you or your loved one is interested in learning more about spinal cord injury research opportunities at Mayo, please do the following: leave a phone message at 507-284-2491 or send an email to [SCIRehabResearch@mayo.edu](mailto:SCIRehabResearch@mayo.edu)

## ISO

Lonely gentleman looking for nice single woman for companionship age is not important, kindness is. Write to Gary Cooper, 3504 SW Kerr Avenue, Topeka, KS 66611.

## 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

New Zealand disability vehicles, hand control cars, left foot accelerator cars for hire. Explore New Zealand – we make it easy! We are happy to pass on our former clients' recommendations of accessible activities and accommodation. See [www.freedommobility.co.nz](http://www.freedommobility.co.nz)

### On The Beach Los Cabos, Mexico

Ultimate accessible vacation. Get out of the cold! On the beach, totally seamless and barrier free. All the toys, power beach chair, accommodations, pool, and boats are completely wheelchair accessible. Designed and constructed by a C-6/7 quad. Visit [www.vrbo.com/669234](http://www.vrbo.com/669234) <http://www.vrbo.com/910690> [http://www.bajaenterprises.net/Ocean-front-condo,\\_wheelchair\\_friendly,\\_sleeps\\_six,\\_pool,\\_boardwalk\\_to\\_beach.\\_Rents\\_dail](http://www.bajaenterprises.net/Ocean-front-condo,_wheelchair_friendly,_sleeps_six,_pool,_boardwalk_to_beach._Rents_dail) weekly, monthly. St. Simons Is., GA. [bmmk4@frontier.com](mailto:bmmk4@frontier.com) 419-569-6114.

**Las Vegas!** 2 Bedroom accessible condo & adapted van available for rent in fabulous Las Vegas! Guard Gated, Close to the Strip, Sleeps 4 [www.BarrysVegasCondo.com](http://www.BarrysVegasCondo.com)

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

**Wellspect HealthCare: CIC is often a lifelong therapy.** With 3,600 or more insertions and withdrawals per year, choosing the right catheter is important. For FREE samples of LoFric catheters, contact 855/456-3742 or [www.wellspect.us](http://www.wellspect.us)

Silver

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

**KD Smart Chair**

**EZ Lite Cruiser**

**Girards Law Firm**

**Michigan Auto Law**

**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.*



## BOY WITH CEREBRAL PALSY EJECTED FROM TRUMP RALLY, MEETS PRESIDENT OBAMA

On the Saturday before the election, J.J. Holmes, 12, begged his mother to drive him to Trump's Tampa, Florida, rally so he could protest the future president's treatment of people with disabilities. As he did with all protesters, Trump ordered him out of the rally, prompting his supporters to chant, "USA! USA," while pushing the teen's wheelchair.

The very next day, President Obama invited J.J. to a Clinton rally in Kissimmee, where the teen shook his hand and posed for a photo that lit up the internet.

## POWER PINNING

This was our most pinned pin on Pinterest the week of the election. See more pins and follow NEW MOBILITY at [www.pinterest.com/newmobility](http://www.pinterest.com/newmobility)



## TO POST? OR NOT TO POST? THE WEIRD WORLD OF ONLINE DATING FOR A WOMAN IN A WHEELCHAIR

*In her Nov. 6 Pushliving.com blog entry, 22-year-old Alexandra Stoffel shares how she struggled with whether she should post photos showing her wheelchair to online dating sites or stick with waist-high ones:*

I eventually chose a balance of both, two with the chair, two without. The response was interesting. I saw a lot of messages from guys who told me I was pretty with that ever delightful follow-up of, "It's a shame you're in a wheelchair" because apparently, the two are mutually exclusive. I got many similar responses that implied my wheelchair cannot add to beauty or simply be beautiful in itself.

And then, of course, I got some straight up odd responses, my personal favorite being, "So are you actually in a wheelchair or are you just about that wheelchair life?" (I wish I was making this stuff up.) Once I had pictures of me in my chair on my profile, the odd and pity-expressing messages piled in, which made me feel like taking those photos down. . . .

Fortunately, I had a friend who urged me to keep the pictures on my profile. He encouraged me to lean into the discomfort and self-doubt I was feeling, to revel in it and to address it head on. Why couldn't I see myself as beautiful when in a chair?

*Read the whole post at [pushliving.com/to-post-or-not-to-post-the-weird-world-of-online-dating-for-a-woman-in-a-wheelchair](http://pushliving.com/to-post-or-not-to-post-the-weird-world-of-online-dating-for-a-woman-in-a-wheelchair)*



DO YOU HAVE A RELIABLE SOLUTION TO YOUR BOWEL PROGRAM?

# CEO-TWO®

## Laxative Suppositories



Use CEO-TWO® Laxative Suppositories as part of your bowel program. These unique 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® Pharmaceuticals, LLC. CCA 469 1114

# permobil

| FOR THE RIDE OF LIFE



For each person and every moment Permobil is determined to develop industry leading solutions empowering you to experience, explore, and enjoy everything that life has to offer.