

Controlling Body Temp Roll on Capitol Hill Sunny Slovenia



life beyond wheels



Outdoor Recreation Programs for All

TO
SUBSCRIBE,
CLICK HERE



United Spinal
Association

newmobility.com

JUN 2017 \$4

küschall[®]
designed for life



STAND OUT even when you're
SITTING DOWN

küschall[®] Champion[™]

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



küschall[®]
designed for life

©2017 Invacare Corporation. All rights reserved. Trademarks are identified by the symbols [™] and [®]. All trademarks are owned by or licensed to Invacare Corporation unless otherwise noted.
Form No. 17-005 Rev. 05/17 170105

Onli

Ready to Use Hydrophilic Intermittent Catheter

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

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

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

Ready. Simple.

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



Continence Care
People First



TAKE IT FOR A SPIN!

WIN A YEAR OF VMI VAN PAYMENTS

VMI invites you to take one of our wheelchair accessible vans for a spin, and enter to win a year of VMI van payments valued at \$12,000.*

**on the purchase of a new wheelchair accessible vehicle.*



Get 1-on-1 Assistance

Call our Customer Advocate Center at 1-855-VMI-VANS to get all your questions answered.



Visit a VMI Dealership

Visit your local mobility van dealer to experience the VMI difference firsthand.



We'll Come to YOU.

Can't make it into a dealership? We're happy to pick you up or bring a VMI van right to your doorstep.

HURRY! LAST CHANCE TO ENTER IS JULY 2ND!

ENTER ONLINE:

VMIVANS.COM

ENTER BY PHONE:

855-VMI-VANS
(864-8267)

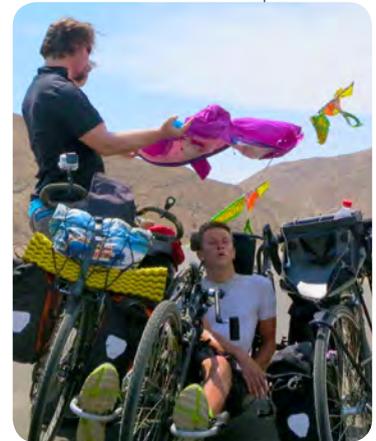
FEATURES

19 CENTRAL EUROPE'S ACCESSIBLE GEM You never knew you wanted to go to Slovenia, but after reading LILLY LONGSHORE's article, you may want to add it to your bucket list.

25 SIX YEARS, ROLLING STRONG As United Spinal hosts the 6th Annual Roll on Capitol Hill, IAN RUDER looks back at the event's origins and how it has shaped the organization.

37 TEMPERATURE TANTRUMS Finding and maintaining the ideal body heat can be a wheeler's worst nightmare. SETH MCBRIDE reports on ways to tame your temperature.

39 MAKING A DIFFERENCE A resilient nature and a passion for helping others have shaped Sebastian DeFrancesco's life as a veteran, Paralympian, advocate and father. BY CINDY RANII



COVER STORY **OUTDOOR RECREATION FOR EVERYBODY** 28



Summer is finally here, and we've got great recreation ideas for everyone. Whether you're looking to break a sweat, get back to nature, or simply chill and catch some rays, BOB VOGEL has you covered with kayaking, sailing, hiking, camping, handcycling and more.

Cover Photo by Derek Nunner/Telluride Adaptive Sports

DEPARTMENTS

- | | |
|----------------------|------------------------|
| 4 BULLY PULPIT | 15 EAT WELL, LIVE WELL |
| 5 CONTRIBUTORS | 16 HOW WE ROLL |
| 6 LETTERS | 46 MOTORVATION |
| 8 NEWS | 50 RAISING A RUCKUS |
| 12 EVERYDAY ADVOCACY | 55 CLASSIFIEDS |
| 14 SCI LIFE | 56 CRIP BUZZ |



JUNE 2017

NEW MOBILITY IS THE
MONTHLY MAGAZINE OF



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

EDITORIAL

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

CUSTOMER SERVICE

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

ADVERTISING SALES

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

PRODUCTION

PRODUCTION MANAGER: DEANNA FIKE

CIRCULATION

CIRCULATION MANAGER:
BEVERLY SMITH
CIRCULATION COORDINATOR:
MARIA KURTZ

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

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

New Mobility (ISSN 1086-4741), Volume 28, Issue 285, is
published monthly by United Spinal Association, 120-34 Queens
Blvd, #320, Kew Gardens NY 11415.

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

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

www.newmobility.com

(BULLY PULPIT)



My 15 Minutes of Fame as a Whoopee Cushion

Playing the part of a Whoopee cushion is not something you wake up one day and just decide to do. It takes years of hard work, conditioning and discipline before you are ready to make that kind of commitment. OK, you might do it impulsively for a Halloween party or in a bar on a drunken dare, but never for a church event, on stage, right?

It all started when I decided to become a competitor in an annual night of humiliation, chutzpah and all-out craziness called Fall Untalent Night, put on by my church. In my first Untalent Night performance, more than 20 years ago, I played a ventriloquist. My 7-year-old daughter was my dummy — decked out in a fluffy dress, face made up with large freckles and a square wooden jaw. She sat on my knee and flapped her jaw when I squeezed the back of her neck with my hand. What came out of her mouth was, of course, my voice. It was the perfect setup to make jokes about the church bigwigs. Visually, I wasn't the one doing the skewering. It was my 7-year-old dummy-daughter. But she got the last laugh by producing a pie tin filled with whipping cream and smashing it in my face.

On another Untalent Night, I parodied the then-current stage sensation, Riverdance. Since the winner of the Untalent Night contest is always the act with the least talent, my dance troupe consisted of teenage girls with barely passable dance skills wearing clunky, oversized rubber boots. "Rubberdance" didn't win that year — we were just a wee bit too talented. Perhaps because I donned an Irish green bathing cap and sat on stage in my wheelchair with the clomping girls and pounded out the typical Irish stepping beat

on my head with loud slapping sounds. Sadly, I never missed a beat, so we lost by a hair.

There were other Untalent Nights, like the time I disappeared inside a giant chicken costume, wheeled on stage and sang "Some Enchanted Evening" in my most ludicrous

Dressed in drag and lip-synching badly, we were "Diana Gross and the Testosterones." Again, no trophy, but the brave pastor got plenty of flack.

chicken voice. No trophy that time, either. Or the time I conned the pastor and associate pastor into joining me in a send-up of the iconic singing group, The Supremes. Dressed in drag and lip-synching badly, we were "Diana Gross and the Testosterones." Again, no trophy, but the brave pastor got plenty of flack.

As strange as these gigs were, they were just a warm-up to my Whoopee cushion performance. The target of my skewering this time was the fall election campaign media onslaught with its seemingly neverending negative ads, empty promises, and bombast. I rolled on stage in my Whoopee cushion costume and in my most serious voice proclaimed that I was there to comment on the current election. After a dramatic pause, I took a deep breath, then very loudly (and amazingly on-key) began mouth-farting the grandiose finale of "Stars and Stripes Forever."

I finally went home that night with the grand prize: a gold-painted, 3-foot-long zucchini.

— TIM GILMER

(CONTRIBUTORS)



JUNE 2017

CONTRIBUTING EDITORS

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

COMMUNITY PARTNERS

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



One of the original NM freelancers, Michael Collins, injured in 1988 at C5-7, wrote his first article for *NEW MOBILITY* (then called *SPINAL NETWORK EXTRA*) in 1991. Since then he has distinguished himself as executive director of both the California State Independent Living Council and the National Council on Disability. His championing of disability rights and independent living have been a constant for nearly 30 years. He is also the only NM freelancer who pens two columns — *Everyday Advocacy* and *Motorvation* (as "Uncle Mike"). He lives in the state of Washington.

Besides being a *NEW MOBILITY* contributor, Cindy Hall Ranii is a lifelong athlete, retired superintendent of public schools and grandmother of 12. She was paralyzed at the T3 level from an onset of transverse myelitis 11 years ago and subsequently took up table tennis. She will be competing in November in the Para PanAmerican Championships in Brazil. Active in expanding the sport for everyone, she was recently honored by the City of Santa Cruz as a Volunteer of the Year for her efforts. To celebrate her 70th birthday in May, she played 70 games of ping-pong on the same day.

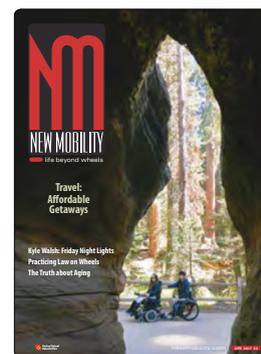


Allen Rucker has been a contributing editor and columnist with *NEW MOBILITY* since 2008. He is the author or co-author of 13 books, including a memoir of paralysis, *The Best Seat In The House: How I Woke Up One Tuesday and Was Paralyzed For Life*. Rucker and his wife, Ann-Marie, are featured in *Option B*, by Facebook COO and best-selling author Sheryl Sandberg, and the *Optionb.org* website. He is chair of the Writers Guild of America Writers with Disabilities Committee and lectures widely on disability issues. He lives in Los Angeles.

Sheri Denkensohn-Trott, a C4 quadriplegic from a diving accident at 16, is an attorney, disability advocate, writer, speaker and *NEW MOBILITY* blogger. Throughout her 25-year tenure as a lawyer for the federal government, Sheri advocated for individuals with disabilities in the workplace, the community, and as a board member at her local CIL. She and her husband, Tony (who also has a disability), own Happy on Wheels, a company whose mission is to inspire people — with and without disabilities — to live happier lives. Sheri resides in Arlington, Virginia. You can learn more at www.happyonwheels.com.



I constantly recommend Washington, D.C., as the most accessible city.



Washington, D.C. – Super Accessible

Mount Rushmore has been on my bucket list for years, so I'm happy to see that it's accessible ["Great American Getaways," April 2017]. Also, I constantly recommend Washington, D.C., as the most accessible city in America — and maybe the whole world. One other attraction I'd recommend to visit in D.C. is the U.S. Bureau of Engraving and Printing. You get to actually see how money is made. It's pretty overwhelming to see so much money, and they offer a completely accessible tour.

*Cory Lee (CurbFreeWithCoryLee.com)
via newmobility.com*

Aging Sucks

I would say at age 60, aging with a disability can really suck. ["The Truth About Aging," April 2017]. My breathing is getting worse, my bones ache, and I can't sit up as long as I once did. One shoulder is shot and bad pain is part of my daily life. I do not have a spouse, but I pray frequently and rely heavily on my two dogs to give me unconditional love and support that dogs do so well. No, I haven't learned to navigate the rough waters. Some days the waters are more placid, while other days are like riding rapids. And for me, one day the question will become quantity versus quality. I will never go to a nursing home. I decided that long ago.

*Ines Gaudet
via newmobility.com*

Support All-Important

I notice that a common thread is a good loving spouse ["The Truth About Aging"]. This is hugely important. I am 40 years post-injury, C5 complete, 56 years old. I have been happily married for over 32 years. I still drive myself with no assistance, I am fairly healthy (just the expected development of osteoporosis and deterioration of

spine). I do what I can, as I have no other caregiver other than my loving wife, but no longer take as many risks.

*Andy ET Smith (from South Africa)
via newmobility.com*

Coach Kyle

He was the best football coach I ever had the opportunity of knowing and learning from ["Rolling Under the Friday Night Lights," April 2017].

*Jess Farnsworth
via newmobility.com*

Role Model

Coach Kyle Walsh was the first coach we met when we moved to College Station, Texas, and from that point on, I knew I wanted my boys to play for him and this team. This great article confirmed what I already knew: Coach Walsh is a great role model and inspiration.

*Christine Wixson
via newmobility.com*

Respect? Not My Experience

HA! Been there, done that ... on a local accessibility campaign for about six or so years — emailing, calling or talking to a manager ["Restricted Access to Tables," Everyday Advocacy, April 2017]. My concerns get paid lip service or I get an occasional gift card to keep me happy, but no long-term results. Restaurant personnel seem genuinely surprised to know about the ADA and tables. I've had to sit as far away as a foot from a table before — pretty hard to eat that way. I've learned some ways to be better accommodated, but it sure would be nice if more places were accessible. Frankly, the most accommodating establishments are fast food restaurants.

*Michele Linn Ash
via newmobility.com*

Finally, Respect

My late wife and I wanted to have dinner at a new place, but they wouldn't let us make a reservation. When we got there, they seated us in an elevated area ["Restricted Access to Tables"]. Halfway through the meal my wife needed to use the restroom, so we carried her down stairs to the bathroom. I complained to the manager, and he comped everything we ate or drank and asked if we could come back in the morning. It seemed odd (coming back before it opened) but it turned out to be a staff training session. The manager laid down the law to employees that disabled patrons can absolutely reserve an accessible table, no questions, just cooperation. That was the one and only time that anyone had treated us with so much respect.

*Andre E. Senay
via newmobility.com*

CBD Pot Works

I have been using Fentanyl patches and Baclofen for years, and I worry about being addicted to the patch ["More Neuropathic Pain Meds," April 2017]. However, about six months ago I started using topical and edible CBD [marijuana] products and found that they are great — with no side effects. I also have used CBD transdermal patches and they work as well. The cost is a little high, but well worth it. CBD and hemp oil products are available from numerous companies, such as Miracle Smoke and Healthy Hemp. I also have phantom pain from a left below-the-knee amputation since 2013, as well as diabetic neuropathy in my right leg/foot. Topical CBD cream from Miracle Smoke works best for me, as it relieves all of my breakthrough pain issues quickly.

*Tom Alsup
via newmobility.com*



CONFIDENCE



INDEPENDENCE



WORK



REACH

• • **QUANTUM®**
iLevel®
 power chairs
NOW WITH
12 INCHES
OF LIFT
AT 3.5 MPH
ON THE Q6 EDGE® 2.0
AND THE Q6 EDGE® Z
FEATURING STANDARD
LED FENDER LIGHTS



SHOPPING



COOKING



GROOMING



COMMUNICATION

The iLevel® Difference: #1 for Safety and Performance

Newly Passed AHCA Dangerous to People with Disabilities

On May 4, House Republicans passed a revised version of the American Healthcare Act by a 217-213 party-line vote. The revised bill, voted on before it could be scored by the Congressional Budget Office, now moves to the Senate, where it is expected to undergo major changes.

The revised bill keeps most of the core tenets of the previously failed House bill, e.g., replacing income-based subsidies with fixed tax credits based on age, distributing federal Medicaid funding based on a per-capita rather than cost-based system, and no longer requiring Medicaid to provide a minimum of “essential health benefits.” For a summary of how the base provisions of the AHCA affect people with disabilities, see NM’s March News.

Under current law, insurers are required to accept people with pre-existing conditions without charging them higher premiums. Under a revision to the AHCA, states would be able to obtain a waiver to this requirement but would be required to set up “high-risk pools” for those with pre-existing conditions. Insurers would have no upper limit on premium charges for the high-risk pools. A last minute amendment added \$8 billion dollars in funding to the Patient and State Stability Fund, which is partly aimed at defraying costs within the high-risk pools, but as *The Atlantic* noted in its analysis of the policy revision, this “is likely a drop in the bucket.”

Revisions would also allow states to define what “essential health benefits” insurance plans are required to cover. States could allow insurers to offer bare-bones coverage policies to help keep costs down, which could in turn affect employer plans that use individual plans as benchmarks for the coverage they provide.

The American Medical Association and

AARP issued statements denouncing the bill soon after it was passed. United Spinal Association issued a news release on May 8 condemning the AHCA, arguing that the revisions would allow states to cut people with disabilities from the general insurance marketplace.

“The AHCA will hurt people with disabilities through higher health care costs, less coverage, and a greater risk of institutionalization,” said James Weisman, president and CEO of United Spinal. “Critical services such as personal care, mental health treatment, prescription drugs and rehabilitation services should also not be cut to save money.”

Epidural Stimulation Trial Enables Movement and Stepping

On April 3, the Mayo Clinic published the results of a new trial that further validates the effectiveness of epidural stimulation for functional improvement in spinal cord injury subjects. In this trial, a 26-year-old man, three years out from a motor-complete SCI at T6, regained volitional motor function below his injury level while using an implanted epidural stimulation device. The study sought to replicate results of a previous epidural stimulation trial conducted at the University of Louisville.

The Mayo Clinic trial began with the subject, Jered Chinnock, undergoing 22 weeks of three times per week locomotor and task-specific strength training. Following the initial period of motor training, surgeons implanted an epidural stimulation device made by Medtronic and FDA-approved for pain (with off-label approval for functional rehabilitation purposes) and connected it to an electrode array positioned on the dorsal epidural surface of the lumbosacral spine. After three weeks of post-surgical recovery, the team began epidural stimulation — with



Jered Chinnock, who has a T6 motor-complete spinal cord injury, has regained some function.

Chinnock attempting volitional leg movements while researchers tuned the settings of the stimulation device.

In the first two weeks of epidural stimulation, with the device turned on, Chinnock was able to:

- Control his muscles while lying on his side, resulting in leg movements
- Make step-like motions while lying on his side and standing with partial support
- Stand independently using his arms on support bars for balance

Previous trials had produced standing and some volitional movement of lower limbs while reclining, but only after 17 weeks of stimulation and motor rehabilitation. The Mayo Clinic trial marks the first time a subject has been able to voluntarily make step-like movements while standing with partial support.

“We’re really excited, because our results went beyond our expectations,” says neurosurgeon Kendall Lee, M.D., Ph.D., principal investigator and director of Mayo Clinic’s Neural Engineering Laboratory. The preliminary results show functional return only while the epidural stimulation device is turned on. Previous studies have shown that after prolonged therapy, some volitional control of previously paralyzed muscles remains even when the stimulator is turned off.

NYC Subway System Sued for Disabled Access

New York City has the least wheelchair accessible subway system in the nation, according to a pair of class action lawsuits filed against the Metropolitan Transit Authority on April 25. The complaints were filed in both federal and state courts in Manhattan by Disability Rights Advocates on behalf of a coalition of disability groups and three individuals. They allege that only 112 of the city's 472 subway stations are wheelchair accessible, and that MTA discriminates against those with disabilities by failing to maintain the many elevators and electric lifts across the city's aging subway system.

The state suit challenges a chronic problem: Over 350 New York City subway stations are unusable to people who cannot navigate stairs, "a flagrant violation of the New York City human rights law." The plaintiffs say the state lawsuit is the first to contest system-wide inaccessibility.

"Around 6 million people who use wheelchairs, and others who can't traverse stairs, are essentially blocked from its use because there are not enough elevators. And those that do exist break down too frequently," says Michelle Caiola, director of litigation for Disability Rights Advocates. "This is a major violation of the right to equal access. As everyone in NYC knows, the subway is crucial to everyday life and provides the most efficient, economical mode of transportation in town."

The federal lawsuit alleges that failure to maintain operable elevators and lifts violates the Americans with Disabilities Act. "The lack of elevators doubles my commute time, at best, says plaintiff Sasha Blair-Goldensohn. "And if just one elevator is out of service, I'm stuck. I never know when I'll have to ask strangers to carry me up the stairs in my wheelchair. It's nerve-wracking, dangerous and degrading."

The MTA will not comment on the lawsuits, but Beth DeFalco, an agency spokeswoman, said in a statement that it was "committed to serving the needs of disabled customers."

Keep your essentials on hand while on the go with this great backpack!

- Works with most chair styles
- Easy-open zippers
- Ample storage
- Mesh pockets great for water bottles or other often-used items
- Durable construction
- Helps spread United Spinal Association's active lifestyle message



United Spinal Association

800.404.2898, ext. 7203
www.unitedspinalstore.org/united-spinal-wheelchair-backpack/



Just \$19.95!

permobil

ADDED STABILITY WITH UNIQUE SUSPENSION GEOMETRY AND LINEAR SPRING DESIGN

PATENT PENDING FLEXLINK™ SUSPENSION FOR ADVANCED VIBRATION REDUCTION

FEEL THE DIFFERENCE.

M3 FEATURING **FLEXLINK™**

FOR MORE INFORMATION VISIT WWW.PERMIBILUS.COM



Helping Families be Families. MV-1 is the only mobility vehicle built from the ground up for accessibility, comfort and safety. Unlike conversion minivans, the MV-1 has successfully completed a battery of specific FMVSS crash tests, making it the only mobility vehicle recognized by the National Automotive Dealers Association (NADA). Contact your local dealer to see why more families are switching to MV-1.



www.mv-1.us • (877) 681-3678
© Mobility Ventures LLC



CHAPTER NEWS

Virginia Chapter: Changing the Face of Rehab in the Mid-Atlantic Region

When two of the largest health systems in Virginia announced they are collaborating to build a state-of-the-art, 114-bed, \$119 million rehabilitation hospital just outside Richmond, there were smiles all around the room, but perhaps no one had a bigger smile than Sharon Drennan, the executive director of the Virginia Chapter of United Spinal Association.

That's because Drennan knew that in addition to dramatically upgrading the rehab options for the region, the new facility would revolutionize her chapter's ability to connect with and help the local SCI/D community. Simply having a state-of-the-art facility in the chapter's backyard would have helped some, but Drennan and other chapter leaders had been working with VCU Health and Sheltering Arms, the two health systems, for months to plan the new project, and one of the CEOs had personally told her they were planning to have a space for her organization in the new facility.

"I was just thrilled," recalls Drennan. "Now we're going to be connected to the [people with] new injuries at the time they really need us — we'll be right there."

The chapter already offers peer mentoring and support groups for people with injuries and their families, but Drennan worries that many people fall through the cracks in the transition from the hospital.

"We hear a lot of people say, 'I wish I would have known about you when I was in rehab. Where were you then?' If we're connecting to families earlier in the process, we might be able to alleviate a lot of headaches and questions," she says.

The chapter played a vital role in establishing the need for the facility and shaping its offerings. Drennan and members Richard Bagby and Cole Sydnor attended multiple envisioning meetings and repeatedly testified about their own personal experiences.

"VCU and Sheltering Arms started talking about it and came to us because they wanted to hear the stories about why we were going out of state when somebody was newly injured," says Drennan, whose son, Rob, did his rehab at Kennedy Krieger Hospital in Baltimore. "What was happening was people with new injuries would be at VCU for the trauma piece, then they'd leave the state for inpatient rehab and then come back and do their outpatient rehab at Sheltering Arms. The medical community was looking at that and asking 'why?'"

"The idea behind this collaboration is that folks in the mid-



An artist's rendition illustrates plans for a state-of-the-art rehab hospital near Richmond, Virginia.

Atlantic region — not just Virginia — will have a place to go, so we don't have to go to Atlanta or Colorado."

The hospital is expected to open in 2020.

For more information about the chapter, visit www.unitedspinalva.org.

Louisiana Chapter: 10 Years of Conference Growth

The Brain Injury Association of Louisiana hosted its 10th annual conference March 10-11 in Kenner, Louisiana, for a record turnout of 220 professionals, caregivers and SCI survivors. This year, for the first time, the organizers split the conference into two tracks, one for SCI and one for brain injury, reflecting the chapter's dual-natured clientele.

"I think it was a very positive way to wrap up our first 10 years and make it bigger and better going forward," says Kimberly Hill, the chapter's director of outreach and resources.

This was Hill's first time coordinating the conference, and the second conference since BIALA became the official Louisiana chapter of United Spinal. "I think the partnership has been great," says Hill. "I appreciate that whenever I call anyone, they call back right away. It's really refreshing and helpful."

With the conference complete, Hill and the chapter can turn their focus to growing their program offerings. This July, the chapter is hosting a peer mentor training session, and staff is working on partnerships with established recreation programs in the area. "Rather than reinventing the wheel with our own recreational program, we decided to reach out and partner up with groups who were already working," says Hill.



By Michael Collins

The Real Fear of Flying

Q. *My niece is getting married on the opposite side of the country and I use a power wheelchair. Despite flying in the past, I now question my ability to do so safely. We hear reports about flights that were canceled, delayed extensively, or people being removed from departing flights for no apparent reason. I cannot imagine what it would be like to be forcibly removed once I had gone through the arduous process of preparing for the trip and being transferred into a seat on the plane.*

Friends have shared incidents of extensive damage and temporary loss of use of their mobility devices due to all kinds of mistakes. I really need my wheelchair to be in operating condition upon arrival and when returning home, as I do not have a spare. My main concern is what needs to happen before and during the flight so my travel experience does not turn into a disaster. I could use some helpful advice.

— *Grounded, at least temporarily*

Many incidents can be prevented with better advance planning and knowledge of the Air Carrier Access Act's regulations that govern passengers with disabilities. Also, remember that you will be dealing with airline and contracted employees who might have limited knowledge of the rules but feel they have authority to make decisions that may or may not be in compliance. So you need to know the law and be prepared. The Federal Aviation Administration, a branch of the Department of Transportation, administers and enforces the ACAA. Fortunately, before booking, you can review its free booklet, *New Horizons: Information for the Air Traveler with a Disability*. Also, United Spinal recently re-released its *Accessible Air Travel* booklet (see resources).

Travelers using power devices espe-

cially need to take extra precautions. Know how your mobility device operates and where the different switches and connections are located. Make sure it is powered by non-spillable or "gel cell" batteries. That will eliminate the need to remove and repackage the batteries before flight and help minimize damage. Obtain a note from the wheelchair vendor, on letterhead, stating that non-spillable batteries are in use. The battery needs to be disconnected from operating controls during travel, which can also prevent damage.

Label everything with your name, especially if removable, and know that whole mobility devices have been lost. If an armrest or leg support can be removed, it is susceptible to loss or damage. Know how to disassemble and reassemble your wheelchair. Insist that you or a trained assistant must be present to supervise both of these processes. Travel with a roll of duct tape or tie-down straps to secure any loose items on the seat base — after stowing your seat cushion in the overhead bin. Remember, baggage compartments are usually full, and any flat surface will be used for stacking; do not leave anything protruding from your chair or it may be broken, removed or lost.

Also, prepare instructions on a sheet of colorful paper detailing how to set and release your wheelchair brakes; attach it where it is very visible. The brakes will have to be released to roll it and load it into the plane, and then locked again as it travels up the baggage belt and into the cargo hold. It also helps to label switches and controls.

Some types of equipment require notification to the airline at least 48 hours in advance. It is also a good idea to advise the carrier that you will be traveling with a mobility device powered by non-spill-

able batteries. Request a seat with a movable armrest to make it easier to transfer. Arrive at the airport early, as it can take an extra hour if a power wheelchair is involved. Signing up for the TSA Precheck program in advance will minimize delays for security screenings. Do not transfer out of your wheelchair until you arrive at the door of the plane, and pre-board whenever possible.

Remember, things can and do go wrong. Be prepared for weather delays, mechanical malfunctions or crew shortages; carry extra medication and urological supplies. All carriers must have a complaint resolution officer available to take complaints from passengers with disabilities about virtually anything that can go wrong. Point out immediately if equipment is damaged and follow up to resolve the situation. If you are removed from a flight, you must be provided with a written reason for that removal in order to be able to file a complaint.

The recent negative publicity about passengers being removed from aircraft has had one positive side effect: In the event that a flight is overbooked, some airlines have now raised the limit on the amount of money that passengers can be paid for voluntarily giving up their seats to about \$10,000.

Resources

- *Accessible Air Travel* booklet, www.unitedspinal.org/accessible-air-travel-2
- Air Carrier Access Act, www.transportation.gov/airconsumer/passengers-disabilities
- *New Horizons: Information for the Air Traveler with a Disability*, www.transportation.gov/airconsumer/new-horizons-information-air-traveler-disability

Introducing a new soft, easy-to-use coudé catheter for men



Hygienic

The soft-squeeze grip makes it easy to guide the tip into the urethra safely without touching it. The dry sleeve means the catheter can be inserted without having to touch the tube itself.

Flexible

The flexible tip enables easy guidance through the curves and bends of the urethra while the soft catheter ensures easy handling and gentle passage.

Discreet

For tidy, discreet and hygienic handling and disposal, SpeediCath Flex Coudé is reclosable and features non-medical, practical packaging.

Every detail makes it easy

The newest member of the award-winning range of SpeediCath® catheters, SpeediCath® Flex Coudé, is a standard length catheter in a compact package, designed to make every step of catheterization easy. With SpeediCath Flex Coudé, Coloplast continues to set the standard for quality catheter design and performance.

Request your free sample today!

www.coloplast.us/try-flex

SpeediCath® Flex Coudé is prescribed for use by catheter users who require bladder drainage due to chronic urine retention or post void residual volume (PVR). Before use, carefully read all of the instructions. Call your doctor if you think you have a UTI or can't pass the catheter into the bladder. For more information regarding risks, potential complications and product support, call Coloplast Corp. at 1-866-226-6362 and/or consult the company website at www.coloplast.us.



SpeediCath®



By Tiffany Carlson

“Surround yourself with positive people and be open to trying new things.”



Once a Dancer, Always a Dancer

Always the girl with a smile on her face, Kim Ocampo, a 24-year-old dancer living in Oakland, California, never let her smile wane. In 2015, she was hit by a car while riding her bicycle to the dance studio where she taught salsa, ballroom and tango, and competed. “I had the green light to cross the street, but a car ran the red light and struck me on my right side.”

She wound up with a T8 injury but has had a very positive outlook, which she credits to her family. “I believe a strong support system is important, as well as how I was raised by my mom. I was always a happy baby.” Ocampo has bounced back from her injury, fiercely wanting to learn as much as she can about her new life. “Don’t change who you are, but become a better ‘you’ by overcoming challenges and conquering your fears,” she says. “Surround yourself with positive people and be open to

trying new things.”

She practiced what she preached a few months ago when she flew to Oakland to take part in a seven-month apprenticeship for the Axis Dance Company, one of the most prestigious wheelchair/mixed-ability dance companies in the world. “I’m learning how to dance with my new body, as well as teach adults and kids how to dance.”

For a dancer who in her previous life danced in a Pitbull video, her post-injury transition has been surprisingly fluid. Her positive outlook has even garnered the attention of a film director who is currently working on a documentary about her life. Called *The Kimberly Ocampo Story*, the film will show how her positivity has touched many lives. It will be out in a couple of years. Watch the trailer here: www.youtube.com/watch?v=Nkadk2fhgSg. Follow her online at kimocampo.com.

A Cool Mobile Lift

When you’re looking for robotic-like help in the transferring department, there is a new, compact option on the market. Made in Greece, the easyGo is small and light and has sturdy wheels, so it can be taken out into the world. With only seven parts — which can be disassembled in minutes and fit in the back seat or trunk — the easyGo can also be used anywhere you can think of: with furniture, the bathtub, movie theater, traveling and beyond. It even makes it easy to be transferred into a car, sparing caregivers a backbreaking transfer. The easyGo does require an attendant. Hydraulic or electric versions are available. Price and import charges are available upon request at easygo-disabled.com.



Blog to Follow: Quadcapable

Charlie Merritt, a C3 quadriplegic, former Marine and strongman competitor, has started his own blog — Quadcapable. His goal is to create awareness, from sharing posts on using FES to strengthen his arms so he will be able to lift again, to a video on how he does a quad cough-assist. Check it out at quadcapable.com.

EAT WELL, LIVE WELL

Give Peas a Chance

A highly nutritious food we rarely hear about anymore is the green pea, but this wasn't always the case. About 10,000 years ago, the green pea (a legume, not a vegetable) was one of the first cultivated crops by agricultural societies. Five thousand years later our Egyptian ancestors worshipped this valuable food source so much that they buried peas with pharaohs so they could take them into the afterlife.

Rome's first cookbook celebrates these green gems with nine elaborate recipes. The English children's rhyme — *Peas porridge hot, peas porridge cold, peas porridge in the pot nine days old* — is a tribute to peas, as they helped sustain the masses during the 16th century famine. And for almost 200 years, a single pea has been the focus of one of the most famous children stories of all time — Hans Christian Andersen's *The Princess and the Pea*.

With such a rich history and so much nutritional value, it surprises me that we don't hear more about the powerful pea. It has a lot of essential nutrients and health benefits for people with SCI. Peas are ...

- a healthy source of protein to help maintain skin integrity,



- complex carbohydrates that help sustain blood sugar levels for energy,
- low in fats and cholesterol to help maintain healthy lipid levels,
- low in calories to help maintain ideal weight,
- high in fiber to help support bowel function/routines,
- high vitamin C content to help boost immune system,
- rich in calcium and magnesium that help support bone health,
- less likely to cause gas than other legumes,
- inexpensive compared to other nutrient-dense foods.

The culinary potential of the pea is endless. They can liven up any of your favorite stew, soup, casserole, salad or curry dishes. And their versatility goes beyond consumption — you can put a bag of frozen peas on sore or injured limbs to help reduce inflammation.

So please, give peas a chance.

Spring Pea Dip

- 1-1 ½ lbs. fresh pea pods
(or 2 cups frozen peas)
- 1/3 cup ricotta cheese
- ¼ cup fresh mint
- 2 tbsp. Parmesan cheese
- Salt and pepper to taste

Shell fresh pea pods (or use frozen). Boil three to four minutes until they are bright green. Strain peas and place in blender with mint. Blend until mushy. Transfer into bowl, add salt and pepper. Fold in cheeses.

Garnish with a few raw peas.

Tips to easily shell peas: press thumb against fullest part of outside seam at bottom of pod, then split open pod. Slide peas out. Or tear stem end and pull string down along the pod (like a pull tab). Pod opens easily and you free the peas with a run of the thumb. For optimal results, tear stem backwards and pull down along indented side. This removes the sturdiest bit of string and unzips the pod.



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

HOW WE ROLL

NURSING STUDENT **Andrea Dalzell**



Nurses always had United Spinal member Andrea Dalzell's back since she started dealing with transverse myelitis at age 5. Now 29, the former Ms. Wheelchair New York is eager to repay the favor when she graduates from nursing school this year.



Ignoring Doubters

As a wheelchair user striving to become a nurse, Andrea Dalzell has been surrounded by doubt from day one. Nursing school administrators questioned her ability to complete the program. Hospital administrators told her insurance wouldn't cover her. Faculty doubted her ability to safely administer the duties of the job.

Dalzell, 29, learned to tune them out. "I detach from whatever situation is actually happening and just take a moment to remember why I'm doing it," she says. "Part of that is to say that I'm out there in the world doing something that someone told me that I couldn't do. And that's something that we've all been told at one point or another, that we can't do something. That's my fuel for the fire. Tell me I can't, so that I can show you how well I can."

Whether it was passing finals with the highest grades, receiving exemplary feedback from patients' families or simply figuring out a way to accomplish her daily responsibilities from her chair, Dalzell has done more than just show she can be a nurse; she has proven she can

be an excellent one. Later this year she will graduate from the College of Staten Island with her bachelor's in nursing and take her boards. Then she will finally be a nurse.

Back when Dalzell started her quest, all she had to hang onto was her belief in herself and a sole YouTube video. The video showed another woman who had attended nursing school in a wheelchair. That was all Dalzell needed — if someone else had done it, so could she. Still, every day presented new challenges.

"My peers all had someone to look to, other nurses that they could ask how to do things. I couldn't ask someone who is standing up how they did something because I have to adapt that to me," she says. "I deal with it every day when I'm in clinical. A professional will ask, how do you expect to do this? And I have to show them that I can do it."

How *does* she do it? "By thinking 20 steps ahead of everyone else all the time," she says. Even with constant vigilance, Dalzell says accomplishing what she has would have been near impossible without the support



BUCKET-LIST CHECKMARK: The craziest thing I've done is probably when my sister and I went skydiving in New Jersey. We decided to meet death on our terms. It was the most freeing experience.

FAVORITE FANTASY PRODUCT:

If I could invent one technology that would make my life easier, it would be a flying wheelchair. That would make life super easy.





Later this year Andrea Dalzell plans to add a nursing degree to the bachelors of biology/ biological sciences she earned in 2012.

of her family, friends and fellow students. "All of them are like, 'Oh, no, we've got you. Don't worry about it. Whatever you need, just ask us.'"

As if merely proving the doubters wrong was not enough, she received the ultimate reinforcement of her decision while working with a person who recently had a stroke. The partially paralyzed woman had been posing problems for Dalzell's coworkers and refused to get out of bed. Oozing positivity, Dalzell rolled into the room as a favor to a colleague. She began to worry when the woman instantly started crying hysterically. As Dalzell tried to calm her, the woman explained her reaction. "I've never seen a nurse in a chair. I thought my life was over." Seeing Dalzell had given her hope.

"In that moment her whole life changed," recalls Dalzell. "She went from this patient who was giving everyone a hard time, had given up on life and was probably headed to a nursing home, to now — an hour later, after getting cleaned up and in her chair — she was ready to go to therapy."

ADVICE TO MY YOUNGER SELF: If I could go back and tell myself one thing before I used a wheelchair, I wouldn't say a thing. In order to be the strong person I am today, I needed to go through everything I have.



CAN'T LIVE WITHOUT iWatch

If Dalzell's face looks familiar, it may be from her central role in Apple's new ad campaign for the iWatch, which focuses on its accessible features.



“ I was blown away by the whole process of filming. It wasn't staged, what you see is literally my life — what I do every day. Everyone wants to be fit, but when it comes to wheelchair users and having to track what we do, it's a whole different ballgame. Before, there was nothing out on the market that differentiates between steps and pushes. I use the iWatch to track calories when I'm cycling, boxing or just working out. I love being able to see the difference in burning calories between pushing and walking. But more than a fitness tracker or a watch, the iWatch has become a lifesaver. I deal with autonomic dysreflexia and it helps me monitor my heartbeat, so whenever it gets too high, I can do something before it gets outrageous. ”



WHY I JOINED UNITED SPINAL: Being a member makes you part of a community; it gives you a home base — people who understand what you are going through, or are at least able to support or help you get you through whatever it is. That's incredibly important when you have a disability.



Right from the start

Intermittent catheterization for men and children.
Easy for beginners. Great for long-term use.



Peel-open tab

Adhesive tab on back for reliable hanging

Instant activation – all it takes is a gentle squeeze to activate with the pure salt solution

Adjustable Insertion Grip for better grip and control with no need to touch the catheter tube

Hydrophilic catheter with Urotonic™ Surface Technology for minimal friction during insertion and withdrawal

Not manufactured with PVC, phthalates and natural rubber latex

Smooth eyelets for maximum comfort

Also available in coude tip!



coude tip

Contact us for
FREE SAMPLES

1.855.456.3742
www.wellspect.us



Foldable into handy discreet pocket size

NOW
available in
straight tip

Connect with us online at LoFric US:   

Wellspect HealthCare, 880 Apollo Street, Suite 200, El Segundo, CA 90245
Contact us at: 1.877.456.3742, info-lofric-usa@wellspect.com or www.wellspect.us





SLOVENIA: THE SUNNY SIDE OF THE ALPS

BY LILLY LONGSHORE

Slovenia, a central-European country slightly smaller than the state of New Jersey, is tucked between Austria and Croatia north to south, and Hungary and Italy east to west. The Eastern Alps cover much of the northern part of the country, melting into rolling hills and green plains until reaching the west coast at the Adriatic Sea. Slovenia was the first nation to secede from Yugoslavia in 1991, claiming its independence and establishing a democratic government that continues today.

Tourism became a focus for newly re-formed Slovenia. Much has been done over the past decades to welcome visitors of all abilities. A wheelchair-friendly certification program with many accessibility standards similar to our ADA recognizes communities that have gone the extra mile to make themselves wheelchair accessible. Curb cuts, ramps, accessible restrooms and other accommodations have been provided where feasible — even at historic sites — making this small, friendly nation surprisingly accommodating.

Miriam Zweizig, who is a T7-8 paraplegic and uses both a manual chair and canes for mobility, has visited three times. “I really like Slovenia a lot,” she says. “For such a small country, it has so many different environments — Alpine mountains, the Adriatic Sea by the border with Italy. And the capital city of Ljubljana is a very nice-sized city.” Zweizig is a translator and her husband teaches Slovenian at the University of Washington. “Visiting Slovenia comes with the package,” she laughs.

In addition to the unique environments Zweizig mentioned, Slovenia has significant limestone caves, caverns and underground rivers in the Karst region. The geologic term “Karst topography” derived its origin from this very place.

LJUBLJANA: THE ACCESSIBLE CAPITAL

Ljubljana, the capital, is not only worth seeing, it is a good place to stay. Bike paths, curb cuts and accessible buses make it easy to navigate here. There are even green-space parks, complete with wheelchair accessible swings. The “Old Town” district has beautiful architecture in a variety of styles, echoing Slovenia’s history of occupations and reconstructions over centuries, from



Miriam Zweizig sits in the entryway to the walled hill town Smartno.

Medieval days starting as an outpost during Roman occupation, then adding Gothic arches, then Baroque-style buildings, followed by Venetian and Vienna Secession styles.

Ljubljana Castle, an example of Romanesque-turned-Gothic and Renaissance architectures, is now a magnificent history museum. Sitting atop a high hill, it overlooks the beautiful, rolling green foothills of the Alps. The exhibits display centuries of rich history, beginning with prehistoric through Roman times, continuing to the Middle and Early Modern Ages, then World War I, World War II, the Yugoslavian era, ending with independent Slovenia. “I found access good for places like museums,” Zweizig says, “even in smaller towns.”

Kelly Narowski, a professional speaker, military spouse and avid traveler, visited Ljubljana in September 2016. “I judge accessibility on if I can do it by myself, and I think with good planning, I could have in Ljubljana,” says Narowski, who traveled with her husband.

Both Zweizig and Narowski toured Ljubljana Castle.

“I went to everything — the puppet museum, the chapel. All of the grounds were accessible except the tower,” says Narowski, who sustained a T6 complete spinal cord injury from a car crash in 1998. She often uses her “cobblestone chair” when traveling — a manual chair modified with oversized casters and wheels.

“I asked if the castle tour was wheelchair accessible, and the tour guide just took a little different route so I could get around,” she says. “It was my biggest accessibility surprise by far in Slovenia.”

Narowski praised those who modified Ljubljana Castle. “They were so cognizant of accessibility. Ramps were built within the grounds and they blended in ... they even added accessible bathrooms. How many castles have accessible bathrooms? I wasn’t expecting that.”

Another worthwhile stop in Ljubljana is the Slovenian Ethnographic Museum. “I particularly liked this cultural museum,” says Zweizig. The completely accessible facility is “for the people, about the people” and compares traditions and cultures of the Slovenians with that of peoples who influenced their nation.

Slovenians have a reputation for being both well-read and multilingual, often speaking five languages. The Ethnographic Museum documents the varied cultures within their region, which took planning and effort. It is now preserved in the Ethnographic Museum.



Which of these vehicles is **safely adapted** for a person with a disability?

The **QAP** difference may not be visible, but it can be life saving.



know more

What you don't know **can** hurt you.

Quality Assurance Program™ accreditation means putting safety first—for persons with disabilities everywhere. Say no more to unregulated vehicle modifications and know more about adaptive driving options.



Find a QAP dealer near you at nmeda.com/NM or call **844-232-1884**.





Miriam particularly liked the Slovenian Ethnographical Museum, which she said was, "for the people, about the people."

LJUBLJANA AND SCI RESEARCH

With its ancient history and architecture, Slovenia may seem like a destination to be avoided by wheelchair users. But even prior to seceding from Yugoslavia in 1991, this nation's capital city, Ljubljana, had a reputation for its independent ways and ties to the western world — in particular, paraplegics.

Ljubljana played an important role in the development of functional electrical stimulation, forerunner of today's most exciting spinal cord injury research protocol — epidural stimulation [see this issue's News, page 8]. In 1971, I made plans to visit the city, while traveling in Europe, with the purpose of meeting researchers at the University of Ljubljana. At 26, just six years post-injury, I was interested in possibly participating in their experimental research, which had enabled a complete paraplegic to stand without braces for the first time.

A friend and I traveled by train, across the Alps, from Munich to Ljubljana. Our specific destination was a then-modern lab dedicated to the emerging field of biomedical research. I was to meet with Lojze Vodovnik, the lead researcher, but on the day I arrived, he was busy at a conference. I met instead with an American researcher, part of the project's international team.

In the lab I scrutinized the "state-of-the-art" setup — an old-style oscilloscope, a mainframe computer, wires with electrode patches. The only essential research element that was the same then as it is today was the subject — a paralyzed person with hopes of one day standing and walking.

As it turned out, I had to return to the United States due to a serious family illness. Now, 46 years later and 72 years old, I am still waiting for my turn — but not holding my breath.

— TIM GILMER

ACCESSING THE ALPS

The centralized location of Ljubljana and its many truly wheelchair-friendly hotels make it a great location from which to explore the country.

"Slovenia is so small, it is only a four-hour drive from one side to the other," says Vesna Susic Palmisano, a native Slovenian who uses a power chair for mobility due to spinal muscular atrophy. "We say 'you can go skiing in the morning and have dinner by the sea in the evening.' It's great, really."

Several ski resorts are in the Triglav National Park region in the Julian Alps by the Slovenian-Austrian border. Skipass Hotel in Kranjska Gorda is an hour's drive northwest of Ljubljana. Professional skiers are available and eager to help anyone who brings a mono-ski and is keen on skiing the Alps.

Triglav National Park, established in 1924, is one of Europe's

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

No more worry about having accessible facilities!

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



Mobility Solutions

"GO-ANYWHERE" Chairs



30-Day Risk-Free Trial

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

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



Accessibility is refreshingly common.

around Lake Bled is almost completely wheelchair accessible except for a short length of gravel.” Bled Castle, one of the oldest in Europe, overlooks the lake and is wheelchair-friendly. The history of Bled, dating back to 1011, is housed and exhibited here.

Lake Bled harbors Bled Island, the only natural island in Slovenia. Pilgrimage Church of the Assumption of Maria is built on the island. Tourists arrive via paddle boats. “They aren’t accessible, but a man, without even discussing it, helped my husband pick me up into the boat,” Narowski says.

Zweizig stayed in the town of Bled instead of going to the island. “I thought it was really pretty. The town of Bled is certainly a beautiful place.” Neither Narowski nor Zweizig was able to ascend the 55 steps to enter the church.

THERMAL SPAS SLOVENIAN-STYLE

Palmisano describes over a dozen natural hot spring spas sprinkled throughout the country, some in the Alps on the north and northeast sides of the country, and others in the seaside towns. “Slovenia is known for its thermal spas,” Palmisano says, “and most are wheelchair accessible.”

In the Panonic region near the mountain town of Maribor — one of the award recipients of Slovenia’s wheelchair-friendly certification program — the thermal spa of Terme 3000 Moravske Toplice resides. It provides more than 10 wheelchair accessible rooms in its three-hotel resort, and 14 pools, the largest of which is accessible by lift. Additional family fun includes

oldest national parks. It is highly protected and remains largely unspoiled. Four hundred mountains over 6,500 feet in elevation lie within Triglav, Slovenia’s only national park. At 9,396 feet, Mount Triglav is the highest peak. The valley town of Trenta in the park region is a nicely accessible community along the Soca River. The Trenta Lodge is wheelchair-friendly, as is the Trenta Museum with exhibits on folklore, culture, heritage and mountaineering.

Also in the Triglav region is famous Lake Bled, which has served as the venue for the World Rowing Championship multiple times. This 358-acre glacial lake is truly picturesque. “It’s like something out of a fairy tale,” says Narowski. “The 10-mile path



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.

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



Medicare Code E2609

AQUILA CORPORATION
Seat Cushion Systems

AquilaCorp.com



866-782-9658

a golf course, walking trails and excellent cuisine.

In Maribor, the Regional Museum Maribor is wheelchair-friendly, including restrooms. Part of the museum is housed in Maribor Castle, completed in 1483 by Holy Roman Emperor Frederick III. The museum exhibits focus on the regional history, as this region was occupied by Rome, Germany, Austria and Slovenia over the centuries. Archeology, ethnology, and the comprehensive cultural heritage of this area is also preserved here.

Along the 28-mile coast of the Adriatic Sea, a series of small villages are linked by a wheelchair-accessible bike trail. Palmisano describes a spa and beach operated by the Slovenian Muscular Dystrophy Association. “There is a spa in Izola that has great access to the sea and a heated swimming pool with sea water. Bathing attendants can help you in and out of the water. Also there are accessible showers and toilet. You can book a room, have PT and, if needed, personal care — it’s very nice when traveling and not so expensive.”

Tourists are welcomed to book a room, just like in a regular hotel. A similar center, also in Izola, run by the Slovenian Paraplegic Association, has a nice pool but no beach access.

GREAT WINE AND CAVES AND THE KARST REGION

Spanning the vine-covered hills one-hour’s drive north of Izola is the town of Goriska Brda. “It’s wine country,” Zweizig says. “It has all these little castle towns. It’s really pretty and even has accessible bed-and-breakfasts.”



For over 425 years the Lipica Stud Farm has bred Lipizzan horses, famous for their beauty.

Photo by Karolina Wenger

The green hills are dotted with wineries and tasting rooms, many wheelchair-friendly. Zweizig, Narowski and Palmisano all compare the wine produced in this region to that of Tuscany, Italy. “I didn’t know they had wine in Slovenia,” says Narowski. “It was really good. I bought four or five bottles of it.”

“You can visit all year round or come for the Cherry Festival or in the grape picking season,” adds Palmisano. Some of the most famous wine cellars in the region that are wheelchair-friendly include Klet Dobrovo and Movia.

Near Goriska Brda is the Karst region, a 166-square-mile plateau between the Vipava Valley and the Adriatic Sea. Among worthwhile sites in this area is the most visited cave in Europe, Postonja Cave, a network of nearly 15 miles of passages, caverns

JAY®

**BREAKTHROUGH
IN COMFORT**

HV

JAY J3 HV Back

- Breakthrough heating and ventilation technology
- Redefining comfort
- Engineered to optimize airflow



800.333.4000

www.SunriseMedical.com

JAY®

and chambers, which is served by a train. Visitors with mobility needs can view the wealth of calcite formations, stalactites and stalagmites from the train since the cave itself is difficult to navigate.

Another must-see in the Karst region is the Lipizzan Stud Farm in Lipica. “The farm is completely wheelchair accessible,” Palmisano confirms. “You can take a tour and see a performance of the classic riding school.” Austrian royalty began breeding white Lipizzan horses for agility, intelligence and sturdiness over 430 years ago. The official horse of the Spanish Riding School of Vienna, these intelligent and graceful horses are used exclusively for teaching classical horsemanship in its purest form. The 768-acre estate includes a wheelchair accessible tour of the Manor house, Cernigoj Art Gallery, Lipizzaner Museum, Carriage Museum, Chapel, and three miles of accessible nature trails.

A GRACIOUS PEOPLE

“If you come to Slovenia, it’s impossible to get lost because everybody speaks English, even in small villages,” says Palmisano. That certainly provides added comfort, as Slovenian is not the easiest of languages to learn. “Here, when we go to school, we have English, Italian and then we can choose French or German — a third language besides Slovenian.” This ups the odds of good communication in a country building its tourist trade. The foresight of Slovenia to provide wheelchair access nationwide puts them ahead of many countries vying for tourist dollars.

The friendliness of the Slovenian people is a strong asset, as well. “There’s never been a situation that we couldn’t find help,” says Zweizig. “It’s been very easy to make friends there. It’s not uncommon for them just to say ‘Hey, we have this cottage up in the mountains. If you want to go visit it, you’re welcome to.’” Zweizig and her husband plan to make more frequent trips to Slovenia and enjoy the company of their new friends.

“We loved it,” says Narowski. “We wished we had a couple more days there. I would totally go back.” NM

RESOURCES

Ljubljana, www.visitljubljana.com/en/visitors/

Thermal Spas, www.slovenia.info/en/Thermal-spas.htm?term_kopalsce=0&lng=2

Spa of Slovenian MDA, www.dom2topola.si/#

Slovenian Paraplegic Association, zveza-paraplegikov.si/eng/

Spa of Slovenian Paraplegic Association, www.domparaplegikov.si/

Bled, www.bled.si/en/about-bled

Triglav National Park, www.tnp.si/national_park/

Wine Country of Goriska Brda, www.brda.si/eng/

Lipica Stud Farm, www.lipica.org/en/discover-lipica

Accessible Wineries:

Klet Dobrovo, klet-brda.si/en/

Movia, www.movia.si/en/hisa-movia

MULTICHAIR Slider Systems

ALL NEW! MULTICHAIR 6000RS



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

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

Features Include:

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



www.nuprodx.com (855) 220-5171

Tub, Toilet and Shower Access Systems

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

STARTING THE ROLL:

A Look Back at the Roll on Capitol Hill

BY IAN RUDER

This June 11-14 well over 100 United Spinal members and fellow advocates will descend on our nation's capital to advocate for the SCI/D community at the 6th Annual Roll on Capitol Hill. Here's a look back at the event's origins and how it has evolved in its first five years.

THE TASK AT HAND

Imagine you wanted to plan a first-of-its-kind advocacy event in Washington, D.C. No sweat, right? Organizations do it all the time.

Well, what if you add in the fact that the majority of your attendees use wheelchairs or other mobility devices. Don't forget that many will need accessible hotel rooms, and that many will be traveling with attendants. The hotel will also need to have accessible meeting rooms and yeah, you'll probably need to provide some medical equipment for traveling attendees who can't bring their own. Still good? Excellent.

Next up, transportation. How are you going to get 80-plus wheelchair users from the hotel to the Capitol and back? And because you want a challenge, let's say that the event is going to be the first gathering of your organization since it merged with another organization and everybody is still feeling each other out.

A SENSE OF POSSIBILITY

Those were but a few of the logistical obstacles facing Alex Bennewith and the United Spinal policy team back in 2012 as they planned the first ever Roll on Capitol Hill for that summer. Bennewith, now United Spinal's vice presi-



dent for government relations, had just been hired as United's director of public policy six months earlier. She remembers the phone call where she learned that she would be part of the team responsible for putting the event together. As a policy person working in D.C., she had helped with similar conferences many times, but the logistics of the Roll on Capitol Hill were unique. "Making sure everyone was accommodated and doing it for the first time here definitely added another layer of complexity," she says.

As United's longtime legal counsel, James Weisman had been in on discussions about holding an advocacy event for decades. "We always wanted to do it, but we never got it together," says Weisman. "It takes so much from the staff to pull something like this off, and we never felt like we really had the ability." That changed in 2011 when United Spinal merged with the National Spinal Cord Injury Association. In addition to adding staff and resources, the merger brought NSCIA's members and chapters



Above: Stephanie Woodward, Alex Wegman and Scott Porter get ready to roll in 2012.

Left: Smiles abound in 2016, even after a long day on Capitol Hill.

in — many of whom were unfamiliar with United Spinal. “We had to have a face for the chapters so they could know who we were, and the Roll on Capitol Hill seemed like a good way to help them figure it out,” adds Weisman.

The first Roll on Capitol Hill kicked off at the historic Mayflower Hotel on a typically hot and humid June weekend in 2012. “There was a sense of possibility in the air,” says Abby Ross, now United Spinal’s COO. “Everything was exciting and

new, and having everyone finally together was so much fun.” There weren’t as many attendees as subsequent Rolls on Capitol Hill, and staff only scheduled about half as many visits to representatives as later Rolls would have, but the event showed what was possible and got rave reviews from attendees in the final day’s wrap-up session. “I was overwhelmingly buoyed by the spirit and enthusiasm the first year,” adds Weisman.

With one in the bag, the stage was set



After traveling via shuttles the first few years, advocates now take the D.C. metro to make their way to and from Capitol Hill. Shown here (L-R): Erin Gildner and Jen Goodwin from Arkansas, and Mark Krider and Mark Race from New Hampshire.

for future Rolls on Capitol Hill. “Once we knew that we could actually pull the Roll off, there was a big sense of confidence,” says Ross. For the next two years, the Roll on Capitol Hill moved northwest to two hotels in Woodley Park. The hotels offered more space and accessible accommodations, but a longer, more difficult commute to Capitol Hill. Each year the event grew, adding attendees, sponsors and advocacy priorities. Both Weisman and Bennewith saw a change in the way the Roll was perceived in year three.

“As much as we shaped the Roll on Capitol Hill, it has shaped us. It has changed who we are, and it has put us on the map as a disability rights organization.”

“I think the magnitude of the Roll kind of hit everyone in the third year,” says Bennewith. “People realized this was the real thing and it wasn’t going away.” Weisman was excited to see the impact grow beyond just the individuals who attended and the people they met with. “The people who came were caught up in the spirit and the enthusiasm, but it took a couple of years for the enthusiasm to translate to the chapters and the community. That’s when they started to see it as an important thing to do.”

What had started as a slightly awkward gathering of a newly mixed family had become a full-on family reunion. “When we started, I think chapters and members were somewhat isolated in their regions,” says Bennewith. “Now it’s a community. People can connect with

abbvie

SOLVING THE WORLD’S TOUGHEST HEALTH CHALLENGES TAKES ALL OF US.

AbbVie starts with research and innovation to develop and deliver new treatments to manage some of the world’s most difficult diseases.

Our global biopharmaceutical company builds our pipeline to provide solutions in therapeutic areas served by our proven expertise.

To make new solutions available to patients, we team with our scientific peers, physicians, governments, and advocacy groups.

When we work together, the result is a remarkable impact on patients’ lives and the healthcare systems which serve them.

Learn more at abbvie.com

PEOPLE. PASSION. POSSIBILITIES.



folks and not feel isolated and alone dealing with their issues.”

To save on the prohibitive cost of renting accessible transportation for 80 wheelchairs and to be closer to the action, the Roll moved back downtown for years four and five. The new location made it easier to use D.C.’s famed metro to actually roll to Capitol Hill. By year four the event had begun to take on a life of its own. Everyone from staff to returning attendees was more confident, there were less unexpected hiccups, and everyone was better able to focus on the most important thing – making the voice of the community heard on Capitol Hill.

“It’s been a pleasure to see people who have come multiple times and see how they are now prepared for it and excited for it,” says Ross. “They’re passing the information to the new people.”

MAKING AN IMPACT

The Roll on Capitol Hill’s impact has also changed United Spinal. “As much as we shaped the Roll on Capitol Hill, it has shaped us,” says Weisman. “It has changed who we are, and it has put us on the map as a disability rights organization. There is nothing more grassroots-y than bringing people to Washington. Because we come to Washington and bring our members, we put our money where our mouth is and we can take controversial positions ... Other disability groups in D.C. see us that way, and they want our support.”

“Now, whenever I go back to the Hill or have meetings around D.C., people say, ‘Oh yeah, I remember Roll on Capitol Hill,’” says Bennewith. She has a long list of representatives and aides who have told her the ROCH visits opened their eyes, not only to policy issues, but to the realities of living in an often-inaccessible world. “I remember one staffer telling me how one of the visits made them realize their office wasn’t accessible. That makes me feel good because that’s what it’s all about, helping people realize things about accessibility that they didn’t before.”

With over 100 wheelchair users already confirmed at the time of publication, not including fellow advocates and

other partners, the 2017 Roll on Capitol Hill is poised to be the biggest and most successful one yet. After the event’s intense four-day duration, United Spinal staff will take a few days off and then continue planning the 7th annual Roll. In fact, planning for 2018 started as early as the end of 2016. “10 is not very far down the road from six,” points out Bennewith.

Weisman makes it clear why it is so important that attendees keep making the arduous trip every summer. “I find

that with every disability rights issue, there is usually no logical other side,” he says. “So, if you keep making the argument, then eventually people will hear and do what you want. That’s why continued vigilance is so important, because if you don’t make the argument over and over again, it won’t get done. But if you do, then it becomes everybody else’s argument and they start to think they made it up. Discrimination won’t go away if you don’t highlight it.” M

Do you Believe in Magic?

Bowel & Bladder Basics are our Business!

Urological Supplements

Cran Magic +™
bladder, kidney & urinary health.

Mannose Magic™
maintain a healthy urinary tract- flush away E.coli.

Suppositories

The Magic Bullet™
safe & sure! Faster acting, water soluble suppositories.

Bowel Supplements

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

Enzyme Magic™
better digestion= better elimination.



www.conceptsinconfidence.com

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

*one time discount per customer

SUMMER OUTDOOR PROGRAMS FOR ALL

"I really love kayaking," says Luticha Doucette, 33, of Rochester, New York. "Being so close to the water and gliding along with each paddle stroke is soothing and calming." Doucette, a C5-8 incomplete quad with TBI, kayaks with Rochester Accessible Adventures.



BY BOB VOGEL

Adaptive recreation programs offer a great opportunity to re-connect with an adaptive version of an activity you loved prior to your disability, or to try out an activity for the first time, and there has never been a better time than now. Innovation in adaptive recreation equipment has expanded exponentially — a Google search of adaptive recreation in your state is



likely to pull up multiple hits. The benefits? Recreation puts us in the Zen state of being in the moment (usually in a healthy outdoor space), changes our perspective for the better, and allows us to share our experiences with other program participants to forge strong bonds and new friendships.

Here is a look at some adaptive recreation options — most of which are accessible to those with limited or no arm movement — along with some of the many programs that offer them.

KAYAKING

“Kayaking is fantastic, like gliding on water. It’s silent and an easy way to explore places I never thought possible,” says Betty Merten, 60, of Madison, Wisconsin. “It’s also a great workout.” Merten, who has spina bifida, kayaks with Madison SCI — a United Spinal chapter with a unique program that provides use of adaptive kayaks and handcycles through county, state, and municipal parks around the Madison area. The chapter is working on expanding the program state-wide. Madison SCI also has a trailer for people that want to tow a kayak to one of the countless bodies of water in central Wisconsin.

“I’ve kayaked with Madison SCI five times. It gives me independence, being able to paddle where I want, when I want, and it’s a great way to interact with wildlife on the water,” says Tina McFadden, 52, of Cottage Grove, Wisconsin. In her 27th year as a T12 para, she says, “I’d never kayaked before my injury and I really enjoy it.” McFadden’s first event was a Madison SCI group outing to the Wisconsin Dells — an area known for lakes and rivers that meander through scenic, glacially-formed sandstone formations. Kevin Karr, from the adaptive kayak equipment company Creating Ability, brought a wide variety of adaptive kayak gear, including seating adaptations, grips for people with no hand movement, levers to assist with limited hand movement, and double and triple-place kayaks for people with no movement at all.

“I loved kayaking before my MS pro-



Photo by Missy Rosenberry

Kerrie Giesen uses a Hoyer lift to get into a kayak.

gressed,” says Kerrie Giesen, 46, of Webster, New York. Giesen was re-introduced to kayaking through Rochester Accessible Adventures, a multi-sport program located in Rochester, New York. “What I love about kayaking at Accessible Adventures is they have a Hoyer lift, which takes away all of the hassles of needing to round up a bunch of people and teach them how to transfer me. The lift makes the transfer from my chair to the kayak seamless and easy. Also, with MS, I get numbness with my hands and it becomes difficult to hold the paddle, but they have a device that holds the paddle in the middle — holds it up — so I don’t have to worry about shoulder or arm fatigue.”

HANDCYCLING

Learning to ride a bike is one of life’s milestones, one that feels akin to flying and represents freedom. Handcycling offers a chance to get re-acquainted with that feeling or experience it for the first time. It is also a great family sport or activity to share with nondisabled friends.

“Cycling was another activity I used to really enjoy quite often, until my MS progressed to the point where I could no longer do it. I never thought I’d be on a bike again,” says Giesen, who hadn’t ridden in seven years. “I went handcycling on an upright handcycle (where seat height and rider position is similar to a wheelchair),

also with Rochester Accessible Adventures. Being on the handcycle was amazing, especially cycling on the Erie Canal path.” Giesen says the Accessible Adventure bike set-up — they have partnered with the Erie Canal Boat Company — is perfect because although she loves riding, she doesn’t want to spend the money for a handcycle and can rent one from Erie Canal whenever she feels like riding.

Lindsay Elegado, 39, from Charleston, South Carolina, found handcycling surprisingly enjoyable. “I had never cycled, and when I tried it, it was beautiful, I loved it,” says Elegado, who has a congenital neurological disease. She tried handcycling with Adaptive Expeditions, a multi-sport program located in Charleston. “I look forward to trying it again this summer. Plus, taking part in these programs is great because I meet new people with different disabilities, and it’s great to compare stories and laugh about situations that we get into.”

Another enthusiastic Adaptive Expeditions handcyclist is Maria Saxon, 37, from Hanahan, South Carolina. “Of all the adaptive sports I’ve tried, handcycling is my favorite,” she says. “I’d cycled since I was a kid, and it was great to be riding again.” Saxon, in her 23rd year as a T12 complete para, was introduced to the sport at an Adaptive Expeditions Handcycle Day where the organization provides a variety of bikes for people to try. In addition to new riders, quite a few wheelchair users who have their own handcycles turn out for the ride and festivities. “Handcycling makes me feel free, and at the same time it is the best workout I’ve found,” says Saxon. “I use muscles that I haven’t used in years, and it really gets my heart and lungs working. Plus it’s a lot of fun riding with other wheelchair users, getting to know them, and forming new friendships.”

Like many participants in multi-sport organizations, Saxon has also tried other adaptive sports through Adaptive Expeditions, including kayaking, sailing and surfing. “I never really did sports when



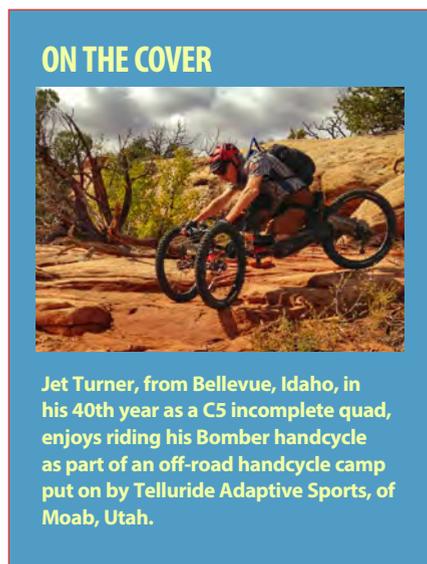
Maria Saxon tries adaptive handcycling with Joe Moore, executive director of Adaptive Expeditions.

I was younger,” says Saxon. “I’m a school teacher and found out about Adaptive Expeditions through an archery clinic. I took the clinic and had a great time, and it led me to try all of these new sports in the past few years.”

OFF-ROAD CYCLING

For getting out into the wilderness under your own power, nothing beats an off-road handcycle. The combination of rear-wheel drive and multiple gears enables a rider with the skills and muscle power to go almost anywhere nondisabled mountain-bike riders ride.

“I was a mountain biker before my injury, and it felt great to be back in the woods, on the trail, mountain biking again,” says Paula McNeill, 51, from Rutland, Vermont. McNeill, in her seventh year as a T8 com-



Jet Turner, from Bellevue, Idaho, in his 40th year as a C5 incomplete quad, enjoys riding his Bomber handcycle as part of an off-road handcycle camp put on by Telluride Adaptive Sports, of Moab, Utah.

plete para, was re-introduced to the sport at Vermont Adaptive Ski and Sports, a multi-sport program located in Killington, Vermont. She tried two different off-road handcycles, both manufactured by Reactive Adaptations. First McNeill tried the Bomber, a rear-wheel drive, rear-suspension model ridden in a prone position with legs tucked underneath the rider. Steering is accomplished with handlebars when gliding downhill and by shifting your weight on a chest-support while pedaling. Next she

tried the Nuke, a recumbent, rear-wheel drive, rear-suspension handcycle, where you sit upright with your legs suspended in front of you.

“I liked the Nuke best, it was more comfortable for me, plus I’m more interested in riding dirt roads and rough trails than single-track trails,” says McNeill. “It was fun and a great workout, working hard to pedal to the top of the mountain, and even more fun enjoying a fast downhill run through the woods. It’s a sport I will be back into for sure. I also kayaked before my injury and started kayaking with Vermont Adaptive as well.”

The Bomber was the handcycle of choice for Greg Durso, 32, of Stony Brook, New York, who also got re-acquainted with the sport through Vermont Adaptive. “I was really into mountain biking before I became a T4 complete paraplegic,” says Durso.

“As soon as I started off on the trails, I was blown away, thinking ‘I’m back, I’m mountain biking!’ I can’t believe this thing actually exists. Here I am eight years after my injury and I’m mountain biking! One of my first thoughts was I want one immediately, but how am I going to come up with the \$7,500 to buy it? Last summer I rode three different days, and I’m planning on coming out and riding a lot more this summer.”

Before being paralyzed at the C5-6 level in 2009, Kirk Williams, of Boulder, Colorado, was a semi-professional mountain bike racer. He got back into trail riding doing downhill mountain chairs at



Kirk Williams is shown on his own custom Nuke handcycle with BionX power assist. A former semi-pro mountain biker, Williams was injured at the C5-6 level while racing. He started downhill mountain-chairing at the National Center for the Disabled in Winter Park, Colorado.

the National Sports Center for the Disabled in Winter Park, Colorado. At Winter Park, Williams met Jake O'Connor, owner, designer and manufacturer of Reactive Adaptations. O'Connor said he was working on a recumbent mountain bike and wanted it to be usable for quads. Williams gave his input as O'Connor spent years developing what would evolve into the Nuke, a recumbent upright handcycle that could be ridden by anybody and easily adapted for quads.

"Jake worked with me and designed a version of the Nuke that I can ride by adding a power unit, the BionX," says Williams. The system consists of a lithium-ion battery and a power hub on the drive wheel. The rider can dial in the amount of power assist they want from zero (straight pedaling) to a 250 percent power assist. This is a great asset for handcyclists with aging shoulders, riders who are working on getting in shape but want to keep up with other cyclists from day one, and riders with limited arm movement and grip.

For Williams, O'Connor adapted a quad grip with a twist throttle to control the BionX motor, and another quad grip twist enables him to apply the brake.

O'Connor designed it so the quad grips can easily be put on and taken off, so programs can switch them out for a para or quad. "It's great!" says Williams. "I can ride it and climb up serious mountain bike terrain. You can set the amount of power assist you want, from no assist, to minimal assist, to full power where you aren't working at all. I'm so stoked on this bike, I can't describe it. Mountain biking is my passion again, thanks to the Nuke."

Williams raised the money to buy his Nuke partly on his own, but also got grants from the Challenged Athletes Foundation and the Kelly Brush Foundation [See resources].

ADVENTURE TRAVEL AND CAMPING

Nothing refreshes the soul and re-adjusts one's attitude like being outside, except perhaps adventure travel. When you combine the two, it creates a paradigm-lifting, positive energy-enhancing experience.

For Thea Rosa, 49, of Citrus Heights, California, in her 13th year as a T12 para, an adventure camping experience in 2011 inspired her to launch her handcycle rac-

ing career. Shortly after she bought a used handcycle, she heard about Rock 'n Roll Yosemite adaptive cycling camp, held each year in early May and hosted by the City of Sacramento Department of Parks and Recreation, Access Leisure section, through its Paralympic Sport Sacramento club program.

"Before my injury I was really into camping, and I found the program to be a perfect balance. The tent cabins give you the outdoor feel of camping but have ADA-height accessible beds, and there are public bathrooms and showers complete with shower chairs. I had a bike, I was back into camping, got to try adaptive rock climbing, and I was amazed at how accessible Yosemite is. It was a great re-introduction to camping, and even better was hanging out with other wheelchair users and others with disabilities, sharing stories and tips and laughing about disability-related things that can be frustrating in day-to-day life."

Another great option for adventure travel and sleeping under the stars is Wilderness Inquiry, a Minneapolis, Minnesota-based program that offers adventure trips — from exploring national parks to adventure travel in far-off corners of the world. The trips are based on universal design and incorporate nondisabled clients with people with disabilities. Wilderness Inquiry works with each person to see if they need assistance, adaptations or help with daily activities around camp, and will provide a personal care attendant if needed. "Because every trip and every client is unique, our attitude is 'if we can make it happen, let's make it happen,'" says Jeff Kemnitz, the program's outreach director.

Mark Smith, 43, of Brooklyn Park, Minnesota, estimates he has done about 30 trips with Wilderness Inquiry. "One of my favorites was kayaking and camping for six days in Prince William Sound, Alaska," says Smith, a para who also has a TBI and is vision impaired. "On the Alaska trip we saw glaciers calving and had to navigate through fields of ice." His favorite local adventure is doing canoe paddle trips and camping in the islands of the Boundary Waters of Lake Superior.

“Wilderness Inquiry trips are a mix of family and friends, as well as other people who are nondisabled. On most trips I don’t know other people until I get on the trip, and it’s always a great way to meet new people and form new friendships — that’s the best part of these adventures, meeting new people and getting to know them.”

Kory Macy, 40, from Madison, Wisconsin, has also been on many Wilderness Inquiry adventures. “I like their trips so much I got my husband John, who is 39 and had never done any kind of adventure trips before he met me, to try one, and now he joins me all the time,” says Macy. “They are great at thinking out

of the box to make things accessible. My initial experience with this was on a Wilderness Inquiry trip to Kenya in 2009 when my condition, spinocerebellar ataxia, had progressed to where I was using a wheelchair full time.” The trip was a safari, complete with lions, tigers, elephants, monkeys, giraffes, and hippos in the wild, and meeting local tribes-people, and camping out in their village. “To be able to join on hikes during the safari, the Wilderness Inquiry folks fashioned rickshaw-type poles that attached to each side of my wheelchair so it could be easily pulled and keep up with the group.”

Other Wilderness Inquiry trips Macy has been on include Yellowstone National Park and a three-day canoe trip on the St. Croix River, camping out each night. “I love being outdoors, camping and sleeping in a tent or under the stars if it’s a nice evening. Wilderness Inquiry is thinking about accessibility from before you register, starting with an extensive questionnaire and following up about a week before your trip with a phone interview to make sure they have accessibility



Kory and John Macy pose in front of geyser in Yellowstone National Park, during a Wilderness Inquiry trip.

issues covered. I’ve turned other people on to them, and they have also had positive experiences.”

SAILING

Sailing combines love of the water with harnessing the power of the wind, a unique synergy that a lot of people get hooked on.

“One of the things I love about sailing is it is a great equalizer,” says Kathi Pugh, 58, from Berkeley, California. “It doesn’t matter if you are competitive or recreational. A high level quadriplegic can do it just as well as a paraplegic or nondisabled sailor. It’s about who is the best sailor, not who has more muscle control.” Pugh, in her 38th year as a C5-6 quad, grew up sailing every chance she got with her dad. After her injury, she focused on her studies, passed the bar and was working as a lawyer for the largest law firm in the state. “My office window overlooked San Francisco Bay. On a beautiful day I’d look out and see all these boats sailing and think, ‘Oh my gosh, I’ve got a great job but all I do is work, work, work. I’ve

got to figure something fun to do because I’m miserable.” So she signed up to try sailing with the Bay Area Association of Disabled Sailors — BAADS — with its docks in San Francisco Bay, arguably the world’s most versatile sailing area.

The first time Pugh went out with BAADS she thought it would be on a dinghy riding puffs of breeze around the little harbor. Instead she was secured to a gimbaled seat on a 27-foot sailboat and sailed across the bay around Angel Island. “It was choppy and blowing like stink, and I loved every second of it — my life was forever changed,” she recalls. “I was back in the sport I never thought I’d see again — jumped in with both feet. I took sailing lessons and got certified through the Ameri-

can Sailing Association and ended up becoming vice commodore, then commodore of BAADS.”

These days BAADS has a 30-foot sailboat with a gimbaled seat, and the helm can be controlled by wheel or joystick, as well as a fleet of 25 single and double-person dinghies that can be operated by tiller or joystick. Moving the joystick left and right moves the rudder to port (left) and starboard (right); moving it forward lets the sails out; pulling the joystick back tightens the sails; and a switch enables independent operation of the jib and mainsail. “It’s a great sport to participate in with friends, family and kids, as recreation or competition,” says Pugh.

Another San Francisco attorney, Cristina Rubke, 38, has been sailing with BAADS for nine years. Rubke, who has arthrogryposis multiplex congenita (her nerves in her arms and legs no longer function), found out about BAADS during a chance meeting at a café. “A group of ‘old salty guys’ told me, ‘You should come sailing with us,’” she says. Sizing up her power chair and chin control setup,

MAKING THE MOST OF THE OUTDOORS IN MADISON

Riveting recreation doesn't have to involve strenuous exercise. No one understands that better than Monica Kamal, the founder of United Spinal's Wisconsin chapter, Madison SCI, and Access Ability Wisconsin, another Madison-based organization dedicated to providing outdoor mobility to enable wheelchair users to enjoy the state's beautiful public lands.

One of Access Ability Wisconsin's signature programs accomplishes this by offering four Action Trackchairs — battery powered, all-terrain chairs mounted on tank-style treads — that can be checked out for free. Included is a trailer to tow the Trackchair, which can be used for anything from hiking, fishing, hunting or camping to bird watching. Kamal, in her 16th year as a T4 complete para, says AAW's goal is to continue growing the fleet of Trackchairs and expand the number of places in the state where they are offered. The Trackchairs allow users to get out and explore without some of the limitations of traditional chairs.

"I've used the Trackchair for camping, and there is nothing like it for getting out in the woods," says Gary Stott, 62, from Oregon, Wisconsin, a C3-4 incomplete quad for seven years. "It is really quiet and a great way to get around the campsite, over trails and out in the bush."

For those looking to take their explorations to the next level, Kamal has put together a birdwatching program. The goal is to locate and identify and observe different types of birds, which is especially rewarding when you find a rare or unusual — for your area — species. It can be in a social group or a way to be alone in nature.

Kamal's advice for starting birdwatching is to contact your local Audubon Society and local Ornithological Society for information and advice. It turns out the best birdwatching times are at sunrise and sunset, something that doesn't always fit into body-management schedules for wheelchair users. "Because of this, I worked with the chapter president of the Ornithological Society in this area," says Kamal. "He came to a Madison SCI meeting and did a presentation on birdwatching and offered to lead a group in the later afternoon rather than evening," says Kamal. Turk even provided binoculars on a late afternoon birdwatching outing. "It was a success," says

Kamal. "We had wheelers, and one member came with her family and kids. We did it in September when there was a lot of migration going on and you could spot some rare species. We plan to do more of this."

Madison SCI member Tina McFadden is also an avid bird-watcher. "I live in a wooded area and we have many bird feeders in our yard," she says. "My kitchen looks over the backyard bird feeders. The challenge is identifying different species and trying to find new species to add to your list. So far I've seen three different types of orioles, indigo buntings, rose-breasted grosbeaks, and woodpeckers — both northern flickers and downy woodpeckers — as well as various kinds of hummingbirds. I have a bird book and I try and identify what I can. This is where it would be great to go out with the



Photo by Steve Spaenti

United Spinal members Mike Mohr, Tina McFadden and Monica Kamal go birdwatching in Madison, Wisconsin.

Trackchair and a trained bird guide so you could point out and positively identify each type of bird."

Even without a Trackchair, Madison has plenty to offer outdoor enthusiasts.

"The Madison area also has great hiking," says Madison-resident Betty Merten. "I go on walks (wheels) on the many walking paths and bike paths around the city. They are beautiful. It's a great way to get exercise, and see nature's many moods — from emerald green grass and white and pink flower blooms in the spring to late summer evening fireflies, and the riot of color performed by autumn's leaves. I usually go with a friend or two. Sometimes they are wheelchair users, sometimes they are walkers, and we explore areas of the city that I never even knew existed."



Kathi Pugh sails a boat with BAADS in San Francisco Bay.

they made an offer she couldn't refuse: "We can rig up a chin-control joystick so you can sail the boat." Rubke responded, "Yeah, uh-huh. I'm pretty sure you're just saying that because you want me to join

your silly club, but I'll join because the yacht club parties sound like a lot of fun and it turns out I live two blocks from BAADS headquarters."

Sure enough, the folks at BAADS

rigged a chest-mounted chin control for her. "I started to get it and was hooked. I wear a harness with the chin control, and I control everything, including the switch to separately trim the jib or the mainsail, all with my chin."

Soon after joining BAADS in 2008, Rubke learned how to race. In 2011 she entered her first international race in Canada, the Mobility Cup, racing single-person Access Liberty boats on Lake Ontario. "I've done a lot of racing, and a lot of travel for races, including Switzerland, Germany and New York. In addition to freedom and camaraderie, sailboat racing has been my reason for international travel."

JUST DO IT

Although it is an old tagline for a famous shoe company, those words ring true. If money is a problem, be sure to ask. Many programs are free, and many more offer discounts or scholarships.

And don't forget your National Parks Pass, now called the Access Pass, a free, lifetime pass available to people who have a permanent disability. It provides free entry to national parks and a 50 percent discount on many park facilities, such as camping. Most states also offer a state park pass with similar discounts. Check with your state parks department — and have a great summer! **MM**

RESOURCES

- Access Ability Wisconsin, AccessAbilityWI.org
- Achieve Tahoe, achievetahoe.org
- Action Trackchair, actiontrackchair.com
- Adaptive Adventures, adaptiveadventures.org
- Adaptive Expeditions, adaptiveexpeditions.org
- Adaptive Outdoorsman [Fishing Gear], adaptiveoutdoorsman.com/handicapfishing.html
- Adaptive Aquatics, nchpad.org/Directories/Organizations/2883/Adaptive~Aquatics
- Bay Area Association of Disabled Sailors, baads.org
- Bay Area Outreach Program, borp.org

Celebrating 25 years

OF CONSUMER PROTECTION

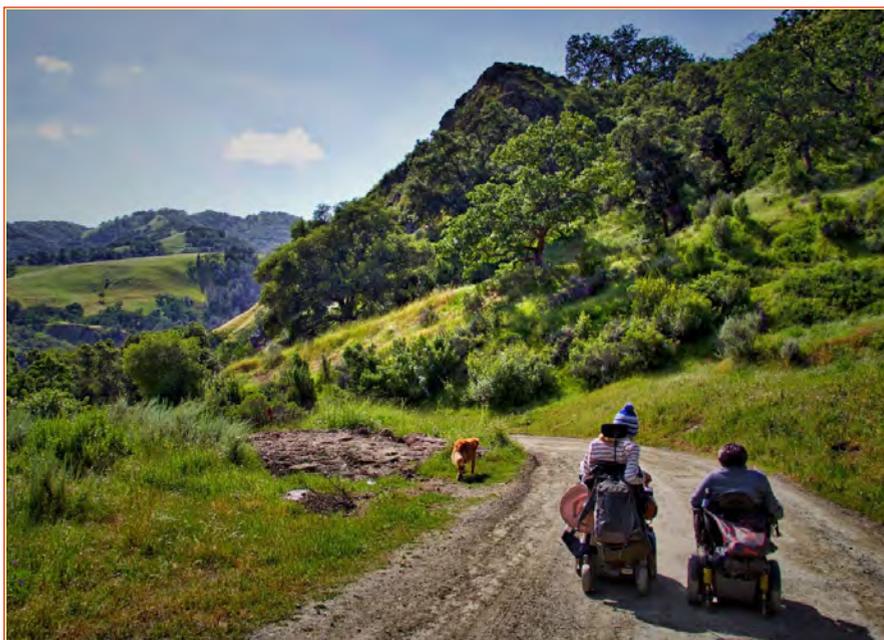
NRRTS 25th
anniversary
1992 - 2017

NATIONAL REGISTRY OF REHAB TECHNOLOGY SUPPLIERS

NRRTS is a professional association supporting individuals who provide Complex Rehab wheelchairs and seated positioning systems for people of all ages and diagnoses.

FOR MORE INFORMATION VISIT WWW.NRRTS.ORG

- Bionix power assist for handcycles, ridebionx.com/products/ebike/ebike-systems/
- City of Sacramento Access Leisure, cityofsacramento.org/ParksandRec/Recreation/Special-Needs
- Challenged Athletes Foundation, challengedathletes.org
- Chesapeake Region Accessible Boating, crabsailing.org
- CreatingAbility, creatingability.com
- Disabled Sports USA, disabledsportsusa.org
- Erie Canal Boat Company, ericanalboatcompany.com
- Environmental Traveling Companions, etctrips.org
- Jay Protector, sunrisemedical.com//seating-positioning/jay/cushions/protector
- Kelly Brush Foundation, kellybrushfoundation.org
- Madison SCI, madisonsci.org
- National Audubon Society, audubon.org
- National Parks Access Pass, store.usgs.gov/pass/access_pass_application.pdf
- National Sports Center for the Disabled, nscd.org
- NEW MOBILITY, "Adaptive Outdoor Adventure Sports," newmobility.com/2015/08/adaptive-sports
- Ornithological Societies of North America, osnabirds.org
- ReActive Adaptations, reactiveadaptations.com
- Rochester Accessible Adventures, rochesteraccessibleadventures.org
- Rock 'n Roll Adaptive Cycling Camp in Yosemite, newmobility.com/2016/10/adaptive-cycling-yosemite/
- Sail To Prevail, National Disabled Sailing Program, sailtoprevail.org
- Telluride Adaptive Sports Program, tellurideadaptivesports.org
- Vermont Adaptive Ski and Sports, vermontadaptive.org
- Vicair AllRounder, comfortcompany.com/product/Comfort%20Rehab/Wheelchair%20Cushions/AllRounder
- Water Skiers With Disabilities Association, usawaterski.org
- Wheeling California Coast, wheelingcalcoast.org
- Wilderness Inquiry, wildernessinquiry.org



"Hiking is the easiest and least expensive recreation option there is, and it doesn't require any investment other than gas to get to a trail," says Bonnie Lewkowicz, 60, of Berkeley, California, who is in her 45th year as a C5-6 quadriplegic. There are accessible trails all over the country. The trick is to go out and find them. To that end, Lewkowicz created Wheelingcalcoast.org, a wheelchair rider's guide to California's coast, accessible parks, trails, historical sites and other points of interest. "Check out the website, choose a trail, take along a picnic and go," says Lewkowicz, who is shown along with Kathi Pugh in the photo. "Cruise the trails, from coastal cliffs to redwood forests to spring wildflowers."

KEMPF

Enjoy driving with both hands on the wheel!

DARIOS digital accelerator ring and main hand brake

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



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

DO YOU HAVE A RELIABLE SOLUTION TO YOUR BOWEL PROGRAM?

CEO-TWO®

Laxative Suppositories



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

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

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

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

ORDERING INFORMATION:

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



ORDER BY PHONE

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



ORDER ONLINE

www.amazon.com



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



TEMPERATURE CONTROL

BY SETH MCBRIDE

In late summer I felt like I was baking myself as I pedaled my handcycle up a false flat. A thunderstorm gathered along the edge of the Cascade Mountains. The temperature was in the mid-80s, but the air was stagnant and thick with humidity.

The heat generated by my working muscles congregated in my core, and unable to escape, quickly built inside me. Ahead of me, my wife could not ride any slower and was disappearing into the distance. I rode at the limits of my steadily diminishing power, but my heart rate would barely rise.

Ten minutes later she turned off the road and I followed her to rest under the shade of an oak tree. We had ridden seven miles and I could ride no more. After 20 minutes I started to feel more functional, but I was despondent. We were set to leave on a very long bike trip in the fall, cycling south for thousands of miles. How was I supposed to ride through Mexico if I couldn't even cover seven miles on a summer day in Washington?



Seth McBride tries to cool off by sitting in a headwind while a friend provides shade.

What Science Tells Us About Our Bodies' Heating and Cooling Systems

Anyone with a neurological disability knows what a problem overheating can be. If you have a spinal cord injury or multiple sclerosis in particular, chances are the heat affects you far more than anyone you know without a disability. This was definitely true for me. What I didn't know is why, exactly, my body struggled so much, and what I could do

about it. Fortunately, recent research and practical experience helps to shed some light on what we all can do to stay functional in the heat.

Let's start with spinal cord injuries. If you have an SCI, you have issues sweating. Some people sweat above the level of their injury, some sweat some below, some not at all. Some sweat when they're hot, some only sweat when they're getting dysreflexic. Like the rest of your neurological function, this is all related to your level

of injury and its completeness.

T6 is a big dividing line for nervous system function. Injuries above T6 generally have a compromised sympathetic nervous system. Somewhere around T4 (depending on the individual and completeness of injury), people lose the ability to sweat, even above their injury. This is obviously an issue for temperature regulation, as the evaporative cooling of sweat is one of our body's primary means of cooling itself.

But people with injuries above T6 also have issues with heart rate and circula-

tion. We (I have a C7-8 mostly complete injury) can't get our heart rates as high as lower level injuries, or the nondisabled. Both muscles and organs generate internal heat. The body cools itself by shuttling that heat away from the core of the body via circulating blood to the skin, where it can be effectively dissipated.

When someone with a high level injury is sitting around (lounging by the pool, in a perfect world), we have ample capacity to shuttle heat from our core to our skin. As soon as we start working — pushing, handcycling, impromptu dance battling, you name it — our bodies' compromised circulatory capacities come into effect. The heart's primary responsibility is to maintain blood flow to the working muscles, and because we can't get our heart rate high enough to do much else, its other responsibilities get neglected. The heat we generate stays in our core, effectively baking ourselves from the inside. Metaphorically speaking, we are both the oven and the roast.

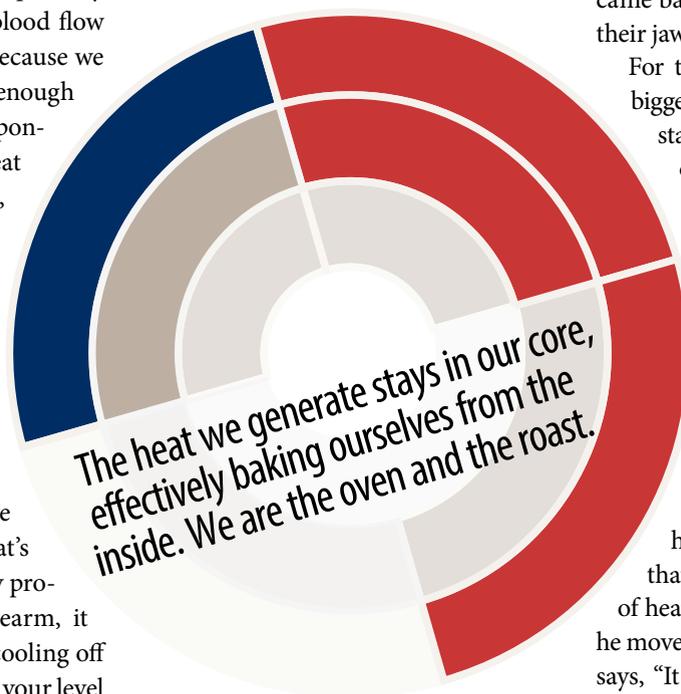
If you can sweat, it obviously does help cool you — it's one of the body's primary means of shedding heat. But sweating is only effective relative to the surface area that's actually perspiring. If you only produced sweat on your left forearm, it wouldn't be very effective for cooling off your whole body. So the higher your level of injury, the less cooling benefit you get from sweat — since people typically only sweat above their injury.

With all this data, researchers now consider temperature regulation in people with SCI to be proportional to their level of injury. In short, the higher your injury, the more you're going to have issues with heat (and cold). Nondisabled people or those with low paraplegia have a certain amount of temperature rise in hot weather or when they're working hard, but that temperature quickly settles out to an elevated but manageable degree. Because higher level injuries can't circulate and dissipate heat effectively, our temperatures rise ... and then keep rising.

How Hot Is Too Hot?

People with multiple sclerosis don't have any of the same issues with heat retention that those with high-level spinal cord injuries do. For those with MS, small changes in core temperatures — even what's caused by taking a hot shower — can have significant impact on their disease symptoms. Until recently, the test for determining if someone had MS was for doctors to measure their neurologic state after they'd taken a warm bath.

Mona Sen is a trained occupational therapist, author and activist who has multiple sclerosis. She now lives in upstate New York, where it's relatively easy



to manage the heat. At her house, it rarely gets too hot, but she still has to be careful: only going outside for short stretches during a warm summer day; occasionally wearing an ice vest; and always having an exit plan for the heat. She knows too well how much getting overheated can affect her.

"To me, heat is like kryptonite is to Superman," she says. "I just get weak ... almost like the demyelination (the disease process by which MS causes neurologic problems) in my body kicks in, and it's hard to move. It's hard to walk at all ... and my mind, it just kind of slows down."

Fortunately, the degradation in function is very temporary, often disappear-

ing as soon as you start to cool off. For Sen, this change in function can often be very dramatic.

"I was in North Carolina last summer and it was extremely hot, but my friend has central air in the house and it was fine," she says. "But my friends decided they wanted to go on this walk. I said nah, I think I'm going to stay in, I know how this goes. But they talked me into it. And as this walk proceeded, I got hotter, and we finally got back to the car and they had to literally help me out of my rollator (a rolling walker) and my speech started to slur because I was so hot. I got in the car, and the air was on full blast for about three to five minutes. My speech totally came back. Everybody just sat there and their jaws dropped. That's how it works."

For those with SCI, it takes a much bigger rise in temperature before we start to feel the effects. Usually our core temp has to rise to about 102 degrees or above, depending on the individual. Unfortunately, because there's such a large rise, it can take much longer to cool off again.

Joe Delagrave is an athlete with C6-7 incomplete quadriplegia who lives in Phoenix, Arizona. He has learned to live in an environment of extreme heat. Even so, Delagrave says that he's had the beginning stages of heat illness a number of times since he moved to Phoenix seven years ago. He says, "It happens with a combination of things — dehydration, exhaustion, just not being prepared for the heat."

When it does happen, heat illness can be debilitating and prolonged. "It kind of just zaps my energy, where I'm useless for the rest of the day. Lethargic," he says. "It usually takes a handful of hours, if I get really overheated in the early afternoon, either working out, or just being out running a bunch of errands, and I can't get into a cold shower. It can be 6 or 7 o'clock before I've actually cooled off."

What To Do

Obviously, preventing overheating is both a challenge, and extremely important if you have a neurological disability. In addition to heat related illnesses, for

some getting too hot (or too cold) can even precipitate autonomic dysreflexia. Dramatic changes in temperature are like any other noxious stimuli. To get a better handle on the science and best practices for staying functional in the heat, I talked with Elizabeth Broad, a dietician and sports scientist who currently works for U.S. Paralympics. She has decades of experience working with athletes with a variety of disabilities, and to her work, cooling strategies are of vital importance. “Overheating can be a big deterrent to being active outside for people with disabilities,” she says. “If we can work out practical ways to deal with this, then hopefully we get more people exercising!”

Broad says one of the simplest strategies for keeping cool in the heat is something that gimps have been doing for a long time: misting themselves with a spray bottle filled with cold water. When you spray yourself, the area of your skin that the spray touches is effectively mimicking the cooling effects of sweat. But like sweat, spray is effective relative to the surface area that’s actually wet. So spraying your face feels good, but spraying your face, neck, shoulders, arms, and whatever other skin is exposed, is going to do a better job of cooling you off.

Spray works best when humidity is low because evaporation rates are higher. When humidity is high, the water just sits on your skin and doesn’t actually cool you. If it’s really hot, or if humidity is high, combining a spray bottle with either a natural breeze or a fan is the best way to stay cool.

Paralympic handcyclists, Broad says, will fill leg stockings with ice and put them under the jersey, on the abdomen to help keep core temps from rising while they warm up for a race. Trainers will also put towels in a bucket of ice water, wring them out a bit and then put them over athletes’ heads or necks.

Things like ice vests, cold wet towels, or a gel pack that you keep in the freezer and then drape around your neck feel great when you first put

GOING AFTER CURES ISN'T FOR THE FAINT OF HEART.

GoBoldly.com



PhRMA is a proud supporter of the United Spinal Association.

Welcome to the future of medicine. For all of us.

GOBOLDLY



America's Biopharmaceutical Companies



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

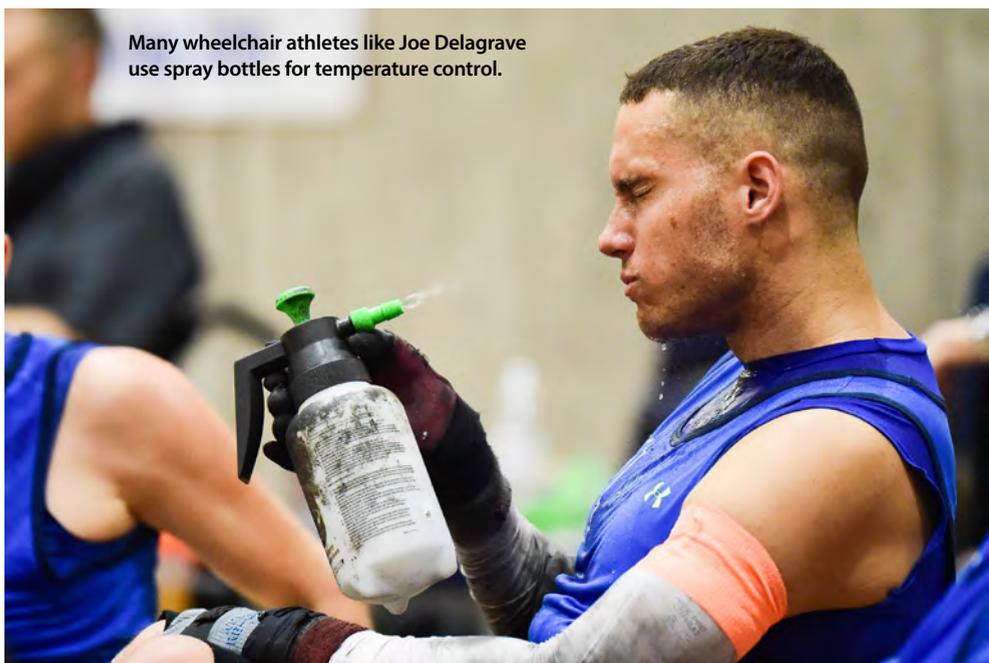
LifeChangingInnovation.org

MEDICAL TECHNOLOGY
life changing innovation

them on. But if you don't keep rotating them or have air circulating between their external surface and your skin, the heat from your skin warms up the outermost layer after a minute or two, creating its own little microclimate and stopping the cooling process. The solution to this is to either have multiple towels or neck wraps that you can rotate, or to get a breeze blowing between the external cooling source and your skin.

Research has also shown that simply placing a hand in a bowl of cool water (about 50 degrees, or cold out of the tap) for 10 minutes can lower core temperatures by one degree Fahrenheit, which may not seem like a lot, but could be the difference between being worthless and somewhat functional.

Precooling, or purposefully lowering your core temp before going out in the heat, can also be an effective strategy if you know you're going to be active in the heat for a long period of time. Most research studies have used ice baths as a method for lowering core temperature, which isn't exactly the most practical



Many wheelchair athletes like Joe Delagrave use spray bottles for temperature control.

way to cool yourself if you have an SCI. But taking a cold shower, drinking an ice slushy or even sitting in an overly air-conditioned room for long enough that you start shivering — all are effective ways of lowering your core temperature.

Combining precooling with other

cooling strategies — spray, fans, ice stockings or towels — is the most effective way to stay functional in the heat for a long period of time.

Delagrave doesn't typically do any precooling, but uses a cold shower as a way of quickly cooling down his core temp if

National Veterans Wheelchair Games
37TH
 NATIONAL VETERANS
 WHEELCHAIR GAMES

LIFE WITH LIMITS
 Cincinnati, Ohio • July 17–22, 2017

wheelchairgames.org

f WheelchairGames t #NVWG

Paralyzed Veterans of America VA U.S. Department of Veterans Affairs

QUANTUM®
iLevel®
 power chairs

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

Q 866-800-2002 | quantumrehab.com

QUANTUM® f y t p /quantumrehab

he gets overheated. He does his outdoor workouts early in the morning and carries a spray bottle around with him, even when he's running errands in the summer. He even decreases the amount of his bladder medication, Oxybutynin, in the summer because one of its side effects is increased heat intolerance. In addition, he makes sure to stay hydrated. "I probably drink twice the amount of water in the summer that I do in the winter."

Testing the Limits

After my ill-fated summer training ride, I had a friend design a spray system for my handcycle that included a water tank of PVC pipe equipped with a tire valve at one end and a line of automotive hosing running out the other. The hose ran to a release valve that I zip-tied to the seat of my handcycle and could operate with one hand before continuing along to a spray nozzle pointed at my face and upper body. I could fill the tank with cold water, pressurize it with a bike pump, and then spray myself with a quick tap of the valve while still on the move. Quadgrips is a company now selling a similar system — the QuadCool.

Not knowing much about the science of cooling, when I first tried it, I was amazed at how well it worked. I probably shouldn't have been. It allowed me to easily spray a relatively large surface area of my upper body while on the move, and the breeze generated by my motion helped quickly evaporate the water, drawing heat out of my skin. It instantly increased the temperature in which I could comfortably ride by 10-15 degrees.

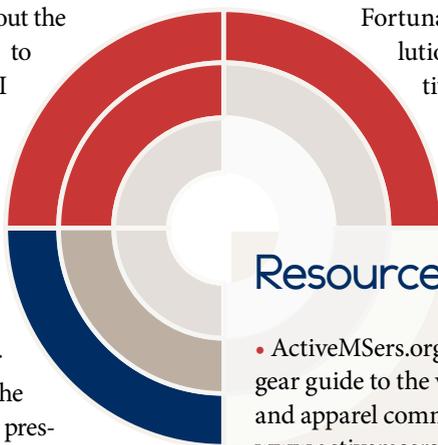
In the process of trying to ride a handcycle through the tropics, I learned a number of things about the limits of my body and my temperature regulation abilities. I learned that I could ride long distances in 90-degree desert temperatures if I consistently sprayed myself and stayed on top of my hydration. I

learned that it's possible, if painful and requiring many more rest breaks, to climb hills in the same conditions. Riding long stretches in 90-degree humid temperatures was technically possible, but right at the limits of my body's ability to shed heat. To add significant hills to the same conditions put my body over the top.

You may never want to try to ride a handcycle through Mexico. But if you struggle in the heat, wheeling around town on a particularly hot summer day can feel like just as monumental a task. Like anything else with a disability, learning how to better function in the heat comes down to being willing to try some different strategies, adapt them, and see what works best for you.

Fortunately, some simple solutions can keep you active all year long.

Now go grab a Slurpee and get outside. 



Resources

- ActiveMSers.org has a comprehensive gear guide to the variety of cooling vests and apparel commercially available, www.activemsters.org/tipstricks/choosingacoolingvest.html
- Gatorade's Sports Science Institute has a good overview of spinal cord injury and exercise in the heat, www.gssiweb.org/Article/sse-66-spinal-cord-injury-and-exercise-in-the-heat
- *The Journal of Applied Physiology* published this excellent research study on thermoregulation in people with multiple sclerosis, jap.physiology.org/content/109/5/1531.full
- QuadCool is a functional cooling spray system that can be attached to a handcycle. Available at Quadgrips.com
- United Spinal's Resource Center has a helpful breakdown of autonomic dysreflexia and how to manage it, www.spinalcord.org/resource-center/askus/index.php?pg=kb.page&id=248

Get the BEST catheter for YOU with Liberator Medical



Are you really using the best catheter for YOU?



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



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



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



Be certain you're using the BEST catheter for you.

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

BAIRD | LIBERATOR™
MEDICAL

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

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



National Disability Voter Registration Week

July 11-15, 2016

www.aapd.com/REVUP

 TELADOC.

A **better**
way to get
healthcare

Access to **U.S. board-certified**
physicians at your fingertips



IT'S THE EVERYDAY THAT CHANGES EVERYTHING

We believe in more than the big breakthroughs. And more than the next big thing.

We believe in the day-in day-out work of making science happen. And the millions of little victories — and failures — in between the breakthroughs. Because to us, it's the daily effort of everyday people that changes the future. So we don't stop. We keep working. Every day.

Genentech
A Member of the Roche Group

Jacki, patient



SEBASTIAN DEFRANCESCO: OUT OF THE RABBIT HOLE, INTO THE LIGHT

BY CINDY HALL RANII

When Sebastian DeFrancesco was an 11-year-old boy in the 1960s, his dog, Pudgy, decided to have a litter of puppies down a rabbit hole surrounded by a mound of dirt. One day, checking on her puppies, Pudgy got stuck in the hole. Sebastian descended into the birthing den to attempt a rescue. The puppies surrounded his face, squeaking and licking him, and before he knew it, he was stuck, too. After a long three hours, a friend came looking for him, saw

his feet sticking out of the hole, and managed to pull him out. It would not be the only time he got stuck down a rabbit hole.

The Vietnam War called in 1972 — his draft lottery number was six — and DeFrancesco, now 19, enlisted in the Army. By this time he had distinguished himself as a standout soccer player. Wiry, tall, fast and fearless, he graduated from Special Forces school as one of only six out of his original class of 300, having trained to jump out of C-130s and jets in

Airborne School. As a Green Beret he was deployed to northern Italy, the land of his ancestors. “I was excited about going to Europe. It sounded great,” he says, “but as we all know, life can turn on a dime.”

He and five other soldiers en route to a jump site on a training exercise were riding in a jeep with no visible stars and no moonlight. “Those were the worst jumps possible,” he says. “The most dangerous.” They never made it to the jump site. The driver lost control, rammed into a cement mileage marker and the vehicle full of soldiers went over an embankment and into a river.

DeFrancesco briefly remembers being dragged from the river up the embankment before blacking out. When he came to, he saw his injured buddies, all on stretchers, in a circle in a dimly lit room. His friend Patrick Davis, on one of those stretchers, had died, but not before he had pulled DeFrancesco, who sustained a broken neck, from the river.

Now 22 and a C5-6 quadriplegic, he was hospitalized in traction for five months, then in a ward with 40 beds and later in a room with nine others, some of them Korean War vets who had been there for decades. Then came rehab. He focused on fitness training and sports, but first he had to master the everyday challenges of being a quad. A steep ramp led from the cafeteria to outside. Each day he worked to go further up the ramp. It was all on him. No rehab staff pushed him to gain full independence, but independence was his goal.

When he left rehab, he had nowhere



Sebastian DeFrancesco (right) is shown with a fellow vet at the Vietnam Veterans Memorial.

to go: no long-term care facility, no accessible home. “There weren’t even curb cuts back in those days. And I had some fear of not being able to take care of myself,” he says. “Finally, I found enough courage to move into an apartment with another vet, and at first an aide came in the mornings to help us.”

Every day he pushed himself to a track near their apartment and circled lap after lap until he slumped over with exhaustion. “People said I was crazy. But I knew that being stronger would make me healthier.” Eventually the VA outfitted him with an Econoline 350 van with a lift and hand controls, and he took off into his new life.

FACING DISABILITY

“Facing a disability is like being reborn,” says DeFrancesco. “With focus you can do whatever you want to do, but the disability makes you really be aware of your life choices.”

He chose to return to his athletic roots and began competing in local, national and Paralympic athletics. Even a partial list of his athletic accomplishments is impressive. Beginning with his quad rugby successes in the 1980s, he moved into coaching, eventually becoming assistant head coach of the National Wheelchair Rugby Teams for two seasons, was inducted into the Wheelchair Sports Hall of Fame and named the United States Olympic Committee’s Athlete of the Year in 1993. He was also inducted into the New England Sports Hall of Fame, has competed in five Paralympic Games from 1984 to 2000 and has won four Paralympic medals and eight National or Para Pan-American Games medals.

DeFrancesco’s early success in sports led to a sense of gratitude and advocacy efforts on behalf of others. Since the 1980s he has lobbied the U.S. Congress regularly to improve hospitals and living arrangements for veterans, particularly the homeless. Also, he has been relentless in pushing businesses to follow the provisions of the ADA. He was instrumental in ensuring that the remodel of Boston Garden included upgrades to line of sight for wheelchair seating and went to court

to get the changes enforced.

In California’s Bay Area he is now working with the owners of the Warriors’ NBA Developmental League team to provide appropriate line of sight seating for wheelchair patrons at the arena in Santa Cruz. The Mountain Winery, a concert venue, now has seating that all wheelchair users can appreciate, and parking machines in Santa Cruz have been lowered so that wheelchair users can reach them, all due to DeFrancesco’s



Sebastian and Liz DeFrancesco on their wedding day.

efforts. “The world isn’t perfect,” he says, “but we can make it better. Sometimes it isn’t worth the fight. Sometimes it’s the way to go.”

His drive to make facilities accessible carries into his business endeavors. Today he is co-owner of Pacific Blue Inn in Santa Cruz, California, which provides nine fully accessible rooms. Along with Joe and Debbie Quigg, wheelchair users who he met through wheelchair sports 37 years ago, he founded Easy Access Developers to increase the accessible housing stock in Santa Cruz. Together they have developed multiple apartment complexes and houses.

“Joe and I wanted to make a difference,” says DeFrancesco, “and by invest-

ing in the Inn and apartment buildings, I was developing assets that I could give to my kids later on.”

With his focus on helping others, whether it’s his kids, other wheelchair users or veterans who can use a hand up, he is always generous with his time and efforts. The work that he does for the Veterans Administration, the local Veterans Hall, and the Palo Alto Veterans Hospital, is legendary. He serves as an executive board member of the Bay Area Western Paralyzed Veterans of America and is a member of the Veterans Council, Santa Cruz County. His work goes well beyond meetings to include one-to-one counseling, workshops and coaching. He encourages newly injured veterans to try out all sports, including billiards, bocce, basketball, rugby, track and field and table tennis.

Still, throughout all his years of competition and service, DeFrancesco’s major role has actually been as husband and father. Early on, he married and had a child, Alicia, who is now completing her doctorate in biology at Harvard. That first marriage ended in divorce, but he fell in love again and went on to marry Liz, who coached Paralympic swimmers. After several years of marriage, they decided to have children and adopted their daughter, Emily, from China.

Then came another crisis. In 1999, when he and Liz were arranging the adoption of their second daughter, Anna, he had to take batteries of blood tests as part of the process, and it was discovered that he had hepatitis C. Down the rabbit hole, again.

THE ULTIMATE CHALLENGE

“My prognosis wasn’t good,” he says. “I cried. I didn’t want to die. I didn’t want to get liver cancer. I wanted to be there for Liz and our daughters.” The adoption went through, but DeFrancesco was too sick to travel to China to welcome little Anna into the family.

Dealing with hep C over the years made him sicker and sicker. Treatments with interferon were not successful. Since his liver was unable to process waste and water, he ballooned from 145 pounds to 205

pounds. He tried to push on his handcycle every night, but it got harder and harder. One night he could only make one turn of the handles. "Then I knew I was getting bad, and I tried to prepare for the worst."

No quad had ever received a liver transplant, but after many trips to the local hospital to have his stomach drained, he was finally accepted onto three transplant lists: UC Davis, Stanford and the Mayo Clinic in Phoenix. In extremely poor health, he was admitted to UC Davis Hospital in hopes of receiving a liver transplant. On dialysis, he was so weak that he would not be healthy enough for surgery for much longer. His liver was like shoe leather. He was beaten down without enough energy to even say hello, hallucinating and seeing contorted shapes wherever he looked.

Several donor livers became available but were the wrong blood types. No matches. Then a call from Stanford Hospital came in. They had found a matching donor liver. He was rushed to a helicopter, but before it could take off, it was grounded for mechanical failure. With the drama ramping up like a thriller movie script, he was then transferred to an ambulance, and with Liz and Alicia in the front seat, they sped the 100 miles to Palo Alto, California.

"I was aware of what was going on," says DeFrancesco. "When they got me prepped for the operation, I was joking with the doctor and saying, 'Hey, lighten up. I'm going to get a new liver.' But I was really in bad shape, worse than I even knew at the time," he says. "I was right at the end of the tunnel ... close to dying."

But once again death would have to wait. DeFrancesco got the transplant he needed, and in doing so added another accomplishment to his list: first quad to receive a liver transplant.

The recovery from the ordeal took many months, and during that time, his weight went down to a mere 98 pounds. He struggled to regain his health. Finally, in 2013, when new hep C treatments became available, he was cured.

Now 63 and 10 years post-transplant, he is as active as ever before. He has circled back to sports, competing regularly in table tennis, including the

Parapan American Games in Toronto in 2015. He won silver in the 2016 U.S. Nationals for the quad class and was named to the Quad Rugby Hall of Fame. His family, business, advocacy and VA efforts are ceaseless.

Today he even finds time to sing with Wreckless Abandon, a blues band led by his buddy, business partner, and fellow quad, Joe Quigg. At a party celebrating the tenth anniversary of his liver transplant, he ad-libbed the following blues riff:

*Yeah, I got the liver blues
But I had a beautiful woman who took care of me
She's 5 foot 10 with blue eyes
I fell in love with her and she kept me strong
Doctor said he's too far gone
She said "Hey doc, give him a chance"
They found a liver and here I am.*

It was the first time he'd sung in public as an adult, and it felt a little like being pulled out of that rabbit hole one more time. **MM**

At Hollister Incorporated our mission is to make life more rewarding and dignified for people who use our products and services. Our ultimate promise is to make a positive difference in the journeys of the people and the communities we serve. We share the ongoing commitment of the United Spinal Association to enhance the quality of life of all people living with spinal cord injuries and disorders and are a proud supporter of the Roll on Capitol Hill.

Proud Sponsor of the Roll on Capitol Hill







Continence Care
People First

(MOTORVATION)

Accessible Power Boats for Fishing



By Uncle Mike



ADA Boats are built to be accessible and stable so all you have to worry about is how to land that big one.

As the weather warms, many individuals who use hand controls to drive motorized vehicles seek out recreational opportunities on the water. Many features of standard boat controls are similar to hand controls used for driving on land; the operator's station usually has no foot controls, unless it is a high-powered racing boat of some type, while the gear shift and throttle are often controlled with the operation of a single lever. Remotely operated accessories like trolling motors for fishing make it possible for people with all types of disabilities to get out on the water, sometimes independently.

Fishing is one of the most popular uses for power boats, as they provide an opportunity to reach the best fishing grounds without being restricted to fishing from a single location on shore or a pier. A variety of boats used for fishing have been adapted to allow

boarding or operation by individuals who use wheelchairs or are otherwise unable to walk. Some are constructed in that manner, and at other times individuals make modifications to meet their particular needs.

When Donald Holland, a fisherman from Placerville, California, sustained a



Donald Holland says his modified dream boat works great for him.

spinal cord injury in 2011, he made a point of getting back out on the water as soon as possible once released from rehabilitation. He purchased a smaller boat, but soon upgraded to one that was able to travel at higher speeds and had more room and capabilities.

Holland purchased his craft from Willie Boats of Central Point, Oregon, and made the modifications he needed to one of their sturdy aluminum boats. "I started by drawing up my new dream boat with a stepped swim deck and custom side console that I could roll up to, and a ramp up to the front casting deck," he says. "I've had this boat for a couple of years now and it works great for me. Now I'm able to get out on the water on hot days and take a swim to cool off." Willie Boats also manufactures a ramped accessible drift boat that appears roomy enough to accommodate two manual wheelchairs.

When it comes to fishing, Rory Calhoun required a boat with plenty of versatility for the different locations and types of fishing he and his family enjoy. Calhoun administers grants that improve access to outdoor recreation in Washington State, and on his days off he can frequently be found fishing on rivers, lakes or the ocean in the Pacific Northwest.

Some of Calhoun's fishing trips require the ability to handle rough waves and bad weather up to 50 miles offshore in the Pacific Ocean while seeking tuna, salmon or halibut. At other times he is hauling in traps containing crab or shrimp on more protected waters. While it is possible to fish with an open-topped boat in those locations, something with an enclosed



Left: Rory Calhoun enjoys shrimping with his family. Above: Calhoun's cabin has been modified with double doors to accommodate his manual wheelchair.

cabin makes the most sense, for both comfort and safety.

The boat he purchased from North River Boats of Roseburg, Oregon, has an enclosed cabin along with an open back deck for fishing. It has been modified with double doors into the cabin in order to accommodate Calhoun's manual wheelchair. He has done a few other things to make it possible for him to operate it

independently. "I had the power tilt and start/stop switch for the kicker, or trolling, motor added inside the boat where I could reach it, along with a Garmin remote control autopilot that is programmable by GPS to steer itself while trolling a pre-set course," he explains, "or I drive with a pushbutton control."

Since his boat has no ramped entry, Calhoun has devised a simpler means

of gaining access: "I just transfer onto the side of the boat and then my chair is loaded in and I transfer back down into it and roll away. Getting out, I reverse the process, only I use the crab trap puller boom (swung out over the dock area) to allow me to pull up on the lift to transfer back into the chair on the dock." He says the process works for any active para, and for quads with some help.



National Coalition For Assistive & Rehab Technology

NCART works with consumers, clinicians, advocacy organizations, and others to protect access to Complex Rehab Technology for individuals with disabilities.

For more information, visit www.ncart.us or www.access2CRT.org

BEACH MOBILITY Solutions

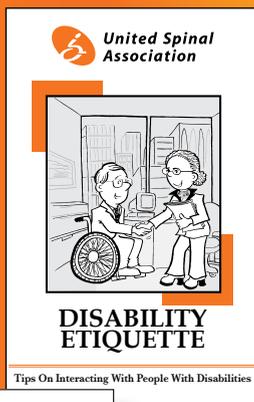


DIY with WheelEEZ®
Beach Conversion Kits
for Walkers and Wheelchairs



www.wheeleez.com

Did You KNOW...



United Spinal Association produces more than 30 brochures and pamphlets on subjects like *Disability Etiquette*, *Fire Safety for Wheelchair Users at Work and Home* and *Understanding the ADA*. You can download them for FREE or order printed copies on our website at www.unitedspinal.org



This beautiful lunker was caught by Dwight Bateman on his Stratos bass boat.

Many people can get their needs for a fishing boat met with fewer modifications. Dwight Bateman, a grant administrator for the California Department Of Rehabilitation, describes himself as a “waddling quad” — as he can stand for brief periods but uses a power chair. He requires only a Stratos Bass Boat, 75-hp Mercury outboard and a self-deploying MinnKota Ulterra80 Bow-Mount Trolling Motor with i-Pilot Link and Spot-Lock with foot paddle and hand-held remote. Bateman lives near the Sacramento River Delta, which offers prime fishing for bass and several other species. The only other accommodations needed to allow him to fish are a step stool to get into the boat and an ice chest with a flat lid to scoot across to reach the fishing seat in the bow.

While his favorite fishing companion is his dog, Bateman advises to always fish with a partner in case something goes wrong. One of his cardinal rules, which everyone involved in boating needs to follow, is to always wear a personal flotation device or life jacket while on the water.

Although he is not a boat owner, J.R. Harding, a quad from Tallahassee, Florida, has found that a 24-foot pontoon boat or larger works well for getting him out onto the water to fish or just enjoy a ride. Through personal experience, he has also found that the driver of the boat must be careful riding the waves, accelerating and so forth, because, as he says, “once, without

warning, the driver ‘gunned’ the boat and my manual wheelchair flipped over — imagine how surprised I was.” Although he was not injured, the person operating the boat was probably just as surprised.

ADA Boats of Fort Myers, Florida, sells a purpose-built, wheelchair accessible catamaran that was in development for five years so that it would be extremely safe. Mike Mayes, president and founder of the company, insisted on high standards so it would be completely safe for its occupants. The largest model, 20 feet in length, has enough capacity to carry two power wheelchairs plus additional passengers, and can float in just 3 inches of water. The front of the boat is ramped, which makes loading and unloading wheelchairs very easy. The boat has been thoroughly tested, including a load test that far exceeded the weight of a full load of occupants, to assure that the boat would not sink under conditions of normal use.

Those interested in purchasing a boat for use in fishing, or for any pur-



A 24-foot pontoon boat — or longer — works best for J.R. Harding.

pose, should check out the resource list below, as well as the links that appear after an internet browser search for accessible boats.

A future Motorvation column will cover more of the wide variety of accessible power boats for fishing and cruising, including some luxury models capable of reaching highway speeds.

Resources

- ADA Boats, www.adaboats.com
- North River Boats, www.northriverboats.com
- Stratos Boats, www.stratosboats.com
- Willie Boats, www.willieboats.com

Experience Abilities Expo!



Achieve greater independence through:

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

FREE
ADMISSION

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



Chicago
 June 23-25, 2017

Houston
 August 4-6, 2017

Boston
 September 8-10, 2017

San Mateo
 October 27-29, 2017

DC Metro
 December 1-3, 2017

Toronto
 January 19-21, 2018

Los Angeles
 February 23-25, 2018

New York Metro
 May 4-6, 2018

RAISING A RUCKUS



By Allen Rucker

“If you are a male in a wheelchair, how can you project a manly image in such an overly masculine world?”

The Alpha Male is Back

We are now in the era of super-duper machismo, with Donald Trump leading the charge. As one of his aides recently said, “The Alpha male is back!” Forget the orange hair and bottle tan, Trump is the most macho-acting man to take the reins of power since wood-chomping Ronald Reagan. He has no problems “down there,” as he announced, and he’s supremely confident, takes no guff from anyone, and of course, has oodles of the do-re-mi.

But it’s not just Trump. Bill O’Reilly, currently unemployed, has had an unapologetic, in-your-stupid-liberal-face personality for years. And then there’s Dwayne “The Rock” Johnson, currently the biggest box office draw in the world. Or the whole crew of the most popular movie in the galaxy, *The Fate of the Furious*. We haven’t had so many icons of virility since Rocky roamed the earth.

To the point, and it’s a thorny one: If you are a male in a wheelchair, and lack the use of some of your extremities, how can you project a manly image in such an overtly masculine world? Of course, there are male chair users doing uber-aggressive sports, like indoor rugby, indoor basketball, and indoor bull fighting, for all I know. But how does the average male wheelchair user broadcast his masculinity? Don’t say through quiet courage or stoic mettle or magnanimous empathy for others. That stuff only cuts it in a feminist age, which may be coming

soon, so stash those virtues away.

Let’s face it, for most of us, it is hard playing a tough guy in a chair. Everything you need to fake your way through a tough guy confrontation — the eye-to-eye glare, the menacing, too-close body language, the ability to snatch a chair and whack your opponent over the head — are all hard to do while sitting. You may have once been in a situation where you wanted to hit some punk in the nose, only to realize that you’d first have to ask him to get within arm’s length from your chair and then kneel down with his chin protruding. It kind of loses the element of surprise.

I was raised in small-town Oklahoma, where men have never ceased being chaw-chewing, dirty-joke-telling, gun-toting, boar-killing, steak-gorging men. It’s a cliché, sure, but the truth is even stranger. Wandering off the reservation, I moved to California, enough said, and then became paralyzed. Out went the steel-tipped cowboy boots and the half-friendly, half-intimidating back slap. I was forced to man down.

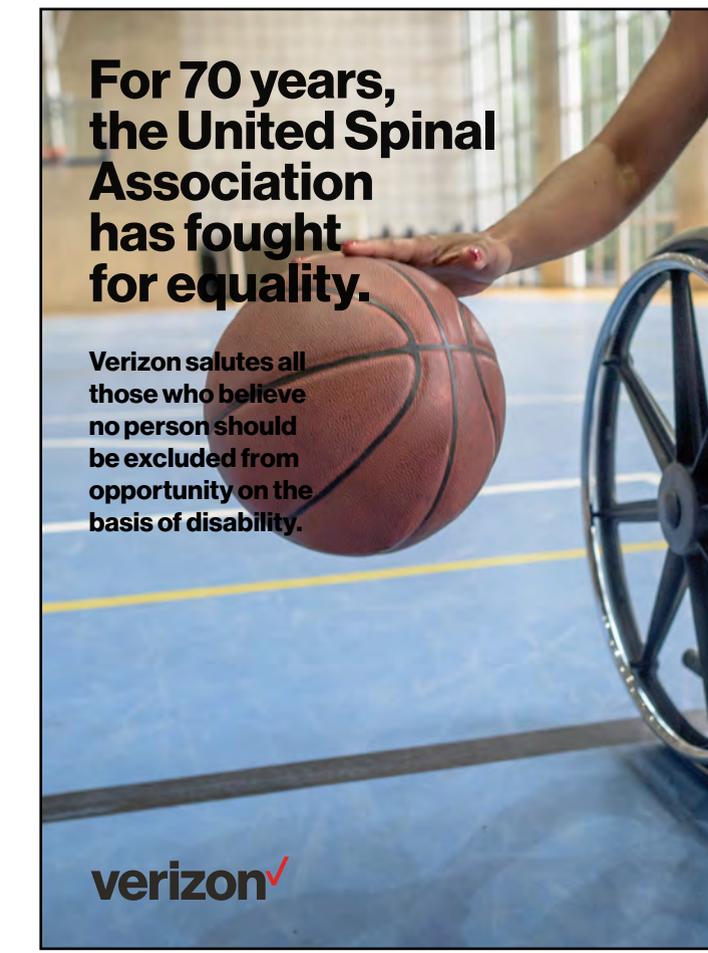
There are a couple of ways out of this dilemma, to my thinking, though you may have your own.

Number one, you can take an acting class, then adopt the persona of the flinty-eyed hombre you always wanted to be. You could spend years trying to beef up like The Rock or even become the first wheelchair-using pro wrestler — call yourself “The Wheel of Pain” —

or you can take a short cut and simply aspire to the demeanor of a psychotic ex-con. For style tips, see the MSNBC prison series, *Lock Up*. Lose a couple of front teeth, surgically remove half of your left ear, and cover every inch of your face and body with menacing tattoos, including one on the back of your shaved head reading, “Ready To Die?” Even in a chair, someone with a Charley Manson “X” hand-carved between his eyebrows will get the Alpha hand stamp just rolling into the room.

Your other road to salvation is easier: Facebook. Facebook allows you to express your dirty-T-shirt maleness without ever leaving the comfort of your dirty-T-shirt apartment. If you don’t want to get tattooed up like a lifer, use peel-off tats and those fun, Halloween facial scars for your Facebook profile. Photoshop your arm around Pamela Anderson or as Mr. July in the Fireman’s Bare-All calendar. It’s amazing what they can do with CGI these days.

On the other hand, maybe you hate Facebook and don’t look good as a snaggle-toothed serial killer. Then your wisest course is to remain cool and memorize your lawyer’s cell number. If some nondisabled troglodyte challenges your manhood and is stupid enough to hit a guy in a wheelchair, he’ll soon be in jail having his own manhood challenged. And with the fat settlement, you’ll be checking into Mar-a-Lago.



**For 70 years,
the United Spinal
Association
has fought
for equality.**

Verizon salutes all those who believe no person should be excluded from opportunity on the basis of disability.

verizon✓



CMSA 27TH ANNUAL CONFERENCE & EXPO
JUNE 26-30, 2017
AUSTIN CONVENTION CENTER, AUSTIN, TEXAS
500 E. CESAR CHAVEZ ST.



REGISTER TODAY FOR THE PREMIER EVENT
FOR CASE MANAGEMENT PROFESSIONALS.
WWW.CMSA.ORG/CONFERENCE

SAVE \$100 OFF CONFERENCE REGISTRATION
BY USING THE PROMO CODE US2017



**Turning Innovative
Science into Value for Patients**

Astellas is committed to turning innovative science into medical solutions that bring value and hope to patients worldwide. Every day, we work together to address unmet medical needs and help people living with cancer, overactive bladder, heart disease and transplants, among other conditions. We remain dedicated to meeting patients' needs, and our support for them will never waver.

At Astellas, we're focused on making changing tomorrow a reality.



   @AstellasUS www.astellas.us

**REGISTER BEFORE JUNE 30TH
& SAVE \$100**



SEPTEMBER 3-6, 2017
**HYATT REGENCY DENVER
& COLORADO CONVENTION CENTER**

DOWNLOAD THE ASCIP MOBILE APP FOR UPDATED INFORMATION.



Apple West
Home Medical Supply

"A small family business making a big difference in people's lives."

**-Catheters +
-Any disposable
product on the
market!**



No cost shipping nation-wide

Accepting

- Medicare,
- Medi-Medi &
- Most private insurances

Switching is easy,
call or email us today.

Call (888) 579-3765 or email
Tom@AppleWestHMS.com
www.AppleWestHMS.com

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

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




Homecare
Proud Supporter
of United Spinal
Association

Get the Facts. Get Active.
AAHomecare.org/crt

Introducing the
ULTRA™
for Men



Ready-to-Use

- > No DRIP!
- > Smooth eyelets
- > Easy gripper
- > No scary chemicals like DEHP or BPA
- > FR 8-18



GET A FREE SAMPLE
www.curemedical.com



MERCK

INVENTING FOR LIFE

WHY WE INVENT

AT MERCK, WE ARE INVENTING FOR LIFE.

We are not inventing for invention's sake – we are on a quest to cure – and to have an impact on countless people's lives worldwide.

Merck is inventing because the world still needs cures for cancer, Alzheimer's disease, HIV, and so many other causes of widespread suffering in people and animals.

We are taking on the world's most challenging diseases to help people go on, unburdened, to experience, create and live their best lives.

Merck. **Inventing** for Life.

To explore our commitment to invention, visit www.merck.com and connect with us on Facebook, LinkedIn and Twitter.

Copyright © 2017 Merck Sharp & Dohme Corp., a subsidiary of Merck & Co., Inc. All Rights Reserved. CORP-1064987-0044 02/17



**Like Us
on Facebook!**

Join our growing Facebook community to share SCI/D resources, tips and encouragement. You'll also learn about upcoming stories and how you can contribute your experience to the publication!

www.facebook.com/newmobility



Rare Patient Voice is a market research company that helps patients and caregivers voice their opinions, through confidential interviews and surveys, to improve medical products and services.

Patients and caregivers receive cash rewards for participating. To show our appreciation, we will send you a gift card just for signing up!

YOU CAN SIGN UP HERE:

<https://www.rarepatientvoice.com/sign-up/>

JUMP START YOUR SEX LIFE



VIBERECT

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

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

FERTI CARE® PERSONAL

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

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

Orion Medical Group, Inc.

(Full D.M.E. Pharmacy Specializing S.C.I.)
 Tel. 714-649-9284 / 1-888-64-ORION (67466)
 Fax. 714-594-4038

info@medicalvibrator.com

www.medicalvibrator.com



QUANTUM Q100 Bathchair

NEW SEATING!



- Pressure relieving
- Injection Molded foam
- 25% better than ensolife
- 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

7000

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

NEW EXERCISES!



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



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



SG-A601
\$102

Z4
\$288

AZ-1
\$279

Portable Hand Controls
 & Spinner Knobs

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

SUN PROTECTION

Stay cool & comfortable
 ALL SUMMER LONG

The original
 Weatherbreaker®
 Canopy.

- ★ Most universal canopy in the industry
- ★ Fits hundreds of mobility models
- ★ Protection from both sun & rain



Available at your
 local VAMC &
 mobility dealer.

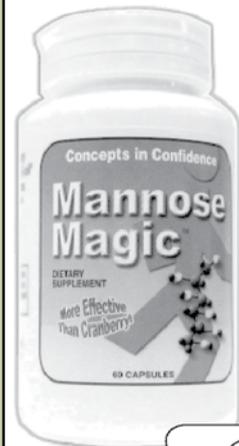
MADE IN USA!



1.800.795.2392
 DIESTCO.COM

YouTube f /diestcomfg

Don't Become ANTIBIOTIC RESISTANT



**Fight and
 Prevent
 UTI's**

**Flush
 Away
 E-Coli**

Concepts in Confidence
 60 capsules for only \$25.95

www.conceptsinconfidence.com

2500 Quantum Lakes Dr. #214

Boynton Beach, FL 33426

(800) 822-4050

numotion®



TK Robot
Mobilization
Device

Numotion Exclusive

The Tek Robotic Mobilization (RMD) allows users to independently sit, stand and navigate environments that were once inaccessible - all while standing at eye level.

Learn more at
ShopNumotion.com

Experience the All-New
BraunAbility® Pacifica



BraunAbility

braunability.com

844-297-9410



Yes, you can.®

Invacare proudly supports individuals with complex mobility needs, preserving their rights and access to mobility products.



©2017 Invacare Corporation. All rights reserved. Trademarks are identified by the symbols ™ and ®. All trademarks are owned by or licensed to Invacare Corporation unless otherwise noted. 17-109 170415

SmartDrive
now with PUSHTRACKER



Independence...Rediscovered.

SmartDrive® is an elegant and lightweight power assist device. The new PushTracker band combines fine grained SmartDrive® control with activity monitoring, giving greater freedom to chair users than ever before. Visit Max-Mobility.com to learn more.

max mobility

Trouble
cathing?

Try instantly
ready-to-use
coudé tip
catheters
for ease in
cathing...



For more information contact
Coloplast at www.coloplast.us

Coloplast

M7519N 05.17

American Airlines

As nonstop as
you are.

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

So, where's your next stop?



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

FOR SALE

Permobil Chairman HD3 Electric Wheelchair Excellent condition. Used for 1 yr. This chair tilts, reclines and elevates Max weight 400 lbs. For additional information contact 973-934-1391 for photos. Asking \$3800.00

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

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

40' ft 2000 Beaver Patriot Motor Home. NEW Low Price! Immaculate – REALLY LOADED!!! – only 84,000 miles! LIKE NEW, ONLY \$70,000. 2 slide outs, Caterpillar Diesel, Pusher 3126B Truck Engine, SuperArm, Roll-In Shower / HC Bathroom, Hand Controls & Digi-Pad. Call or e-mail for any additional info and pictures. Cell (951) 218-4023 ~ Ask for William. Email: wlb21666@hotmail.com

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

WANTED

Wanted, used Quickie II --- the older the better. litalark@yahoo.com

ISO

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

VACATIONS

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

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

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

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

VACATIONS

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

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

Cape May farmhouse near beach. First floor entirely wheelchair accessible. Sleeps eight. Visit www.beautifullyaccessible.com for more info and reservations.

Accessible Journeys

making the world more accessible since 1985

- Holland's Spring Tulips*
 - Rhine River Cruises*
 - Barcelona & Madrid*
 - Venice & Ljubljana*
 - Accessible Italy by train*
 - Vietnam-Thailand-Cambodia*
 - Kenya-Tanzania-Zambia-South Africa*
- 800.846.4537**
www.accessiblejourneys.com

TO PLACE A CLASSIFIED AD IN NEW MOBILITY

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

Print Rates:
• \$1.30 per word
• \$1.00 per word for USA Members

- Boxed Ads - \$105 per inch
- Pre-Payment Required: VISA, MasterCard, AMEX, Discover
- All Paid Print Classifieds get a 1 month FREE Web Classified

Online Only Rate:
1 month = \$16
3 months = \$36
6 months = \$72
9 months = \$108
12 months = \$144

newmobility.com/classifieds

A SPECIAL THANKS TO THOSE THAT SUPPORT



PREMIER LEVEL

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

LEADER

Abbvie, www.abbvie.com

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

ASSOCIATE

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

Allergan: www.botox.com

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

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

SUPPORTERS

- Cure Medical,** <https://curemedical.com>
- The Krist Law Firm, P.C.,** www.houstoninjurylawyer.com
- Michigan Auto Law,** www.michiganautolaw.com/personal-injuries/back-injury/spinal-cord-injuries
- Rare Patient Voice,** www.rarepatientvoice.com
- Trusted Mobility,** www.trustedmobilityrepair.com

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

Acknowledgements on our website, in NEW MOBILITY, in United Spinal e-news or any other United Spinal publication should not be considered as endorsements of any product or service.

SAY WHAT?

Sometimes doctors don't know best, as was seen on the May 10 episode of *The Doctors* when the panel of medical experts expressed shock and disapproval that a woman with quadriplegia chose to become a mom via in vitro fertilization.

"I understand her desire to have a baby," says ob/gyn Dr. Nitra Landry on the show, "But I don't agree with it. I feel as though it's unfair to the baby." The panel sensationalized standard accommodations such as the woman's mom agreeing to help with some of the personal assistance and even with the woman's use of pillows to lay her son on. They don't even name the woman, and muse about "when IVF goes too far."

"It's not their decision to make!" said Julie Caldwell



Harrell on *NEW MOBILITY*'s Facebook page. "I'm quadriplegic and have had two children and [am] innovative in learning to care for them! People who spend their daily living activities having to find accommodations in a generally unaccommodating world become quite resourceful!"

"Great Grandmother of God! The only 'ethical' question here would be why the @\$%! these television pundits think it's any of their blessed business who does or does not have a baby," commented Starr Luteri. "It's the family's business, and from the information presented here, the family is fine. So no one else has any say in the matter. Period."

Watch the episode here: www.thedoctorstv.com/articles/4121-quadruplegic-mother-has-baby-via-ivf

MY RECENT EXPERIENCE FLYING WITH MY POWER CHAIR

I read everything I could find with tips and advice for flying with a power chair. I relied on friends who had experience to give me advice on what I needed to do ahead of time and



With duct tape and a bungee cord, this joystick still operates.

what to do when boarding the plane. I spoke to the American Airlines Special Assistance agent and had everything ready to wrap and protect my joystick. And I took a direct flight to limit the number of times that my wheelchair would need to be moved. I was ready on March 23, 2017 to start my adventure. The results were a mixed bag. My chair did sustain damage, but it was not inoperable. The majority of staff from American

Airlines were very helpful and well trained. Transfers to the aisle chair and into the seat were smooth and the aisle chair was in good condition on the trip out and on the trip back.

— Sheri Denkensohn-Trott, www.newmobility.com/2017/05/flying-power-chair/

THE GIFT OF MOBILITY

"Six-year-old Tipra from north Yogyakarta, Indonesia, was born with CP. For the past year, as he's seen all of his friends transition into kindergarten, his only wish has been to join them at school. Unfortunately without access to a wheelchair this was a impossibility. Until now! He came by the Ohana warehouse where we just fitted him for his first chair, he couldn't stop giggling as we rolled him around and all he kept asking was "I get to go to school now?!" Yes little buddy, yes you do!

The crew here at Ohana and Global Mobility are doing stellar work, and as long as they are out in this world giving the gift of mobility, I've got their back!



Christiaan "Otter" Bailey and young Tipra at Global Mobility's Ohana Warehouse. "Ohana" is a Hawaiian word for "family."

— Christiaan "Otter" Bailey, via a Facebook post



STEALTH
authentic

ACCESSORIES SHOULDN'T BE AN AFTERTHOUGHT



i2i Chin Prompt



i-Drive



ARMS-Elbow Support



Stealth Ultra



Support Plus



ADI Carbon Fiber



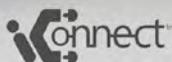
ADI Disc Brake System



TWB Lateral



ADI AL



WITH STEALTH AUTHENTIC, quality, ingenuity and innovative design come standard. You deserve top-of-the-line products, and Stealth Authentic lets you customize your ride based on your individual needs and preferences. From comfort and durability to safety and intelligence, we have an entire line of products to help maximize your mobility and enhance your daily life. Be sure to check out our products today. Choose Stealth Authentic...truly an original.



stealthproducts.com

permobil

POWER WHEELCHAIRS



20° OF
ANTERIOR TILT

YOUR WORLD WITHIN REACH.

Your world isn't one dimensional. Your seat elevator shouldn't be either. ActiveReach™ technology is the ultimate advantage in accessing your environment. By combining 12" of seat elevation and up to 20° of forward tilt, Permobility's ActiveReach™ technology enables you to reach beyond obstructions, into high cabinets, and can even assist in transfers. Truly putting your world within reach.

M3 FEATURING **ACTIVE REACH™**

FOR MORE INFORMATION VISIT WWW.PERMIBILUS.COM