



**NEW MOBILITY**

— life beyond wheels

**Person of the Year:  
Reveca Torres**



# PACIFIC PE



TEK-RMD user Rudy Berger and her husband David enjoy the view from their deck on the coast near Tillamook, Oregon. The TEK-RMD allows Rudy to enjoy the benefits of standing while remaining mobile and able to access places (and views) traditional standing wheelchairs simply cannot reach.

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# CONTENTS

VOLUME 27 NUMBER 268

January 2016



## FEATURES

- 14 EXPLORING THE YUCATAN PENINSULA** Mexico's Yucatan Peninsula has great beaches and a rich history. BY ASHLEY LYN OLSON
- 19 GRANNIES VS. THE WORLD** Two grandmothers with 14 grandchildren between them and one goal: A Ping-Pong title. BY CINDY HALL RANII
- 35 PAINTING SUCCESS** In figuring out how to have a career as an artist, AJ Brockman ended up creating one of south Florida's hottest spots. BY ALLEN RUCKER
- 39 PHLEGM IS NO PHUN** Keeping your lungs free of mucus could be the difference between staying healthy and staying in bed. BY RICHARD HOLICKY



## COVER STORY PERSON OF THE YEAR 22

Reveca Torres wants to start an image revolution and change the way society sees people with spinal cord injuries and disorders. MIKE ERVIN profiles the 34-year-old Chicago quad and how she has dedicated herself to transforming the world of SCI through art, film and the non-profit she founded, Backbones. She has a unique vision and a powerful voice, and she is the 2015 New MOBILITY Person of the Year.

Cover and Contents Photos by Kyle LaMere

## DEPARTMENTS

- 4 BULLY PULPIT
- 5 CONTRIBUTORS
- 6 LETTERS
- 8 NEWS
- 10 EVERYDAY ADVOCACY
- 12 SCI LIFE
- 13 EAT WELL, LIVE WELL
- 32 SPOTLIGHT
- 33 UNITED SPINAL NEWS
- 42 INNOVATIONS
- 44 RAISING A RUCKUS
- 48 CRIP BUZZ



JANUARY 2016

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## ( BULLY PULPIT )



### Advocacy by Image

We live in a world of imagery, especially since the advent of the smart phone with advanced digital photo and video capabilities. In the old days we carried our snapshots around in albums or maybe a box or two. We had hundreds of photos and were prone to lose some as we moved from place to place. Now we have thousands stored in our computers and smart phones and are still prone to lose them — through hard drive crashes, lost thumb drives or just sheer unmanageable numbers.

The *NEW MOBILITY* issue you are reading now is proof of how important images have become to disability advocacy. Our Person of the Year, Reveca Torres, is being honored, at least in part, because her project, “Reinventing the Wheel,” a traveling photo exhibit, depicts wheelchair users in ways that break stereotypes. It is advocacy by image, a hybrid of advertising technique, realism, creative photography and intentional promotion. We are saying to the public: Look at us — we are more than you thought; we are like you, but we are also unique.

NM’s Person of the Year issue goes back to 1998. In all, we have chosen 20 POYs from then until now — 12 men, 7 women, and one fictitious television character. Of the first 15, most were chosen because of their advocacy involving disability issues. But four out of the last five POYs were chosen because of their ability to improve the image of disability. Besides Reveca this year, we have honored, looking back, Jason DaSilva for his filmmaking achievements in telling the story of his battle with MS; Deborah Davis, for her one-woman fight for inclusion and realism in media images; and “Artie,” a character on *TV’s Glee*, for attracting so much attention.

We are saying to the public: Look at us — we are more than you thought; we are like you, but we are also unique.

Admittedly, Artie was a stretch, and some NM readers were upset because they thought we were honoring the nondisabled actor who portrayed Artie. Our choice was intentionally ironic: We wanted to show the power of images to get it wrong as well as get it right.

While mainstream media still gets it wrong where wheelchair users are concerned, more and more real-life wheelers are finding their way into the media mix. The world of advertising may be doing a better job of representing us authentically than the occasional TV series or movie. Advertising is supposed to move us to action, so it is aimed at demographic groups, and disabled actors are appearing in more and more TV spots. In our April issue, Allen Rucker will interview movers and shakers in the ad world and show us why and how this is happening.

But don’t wait until April to look for positive images of disability in ads. As I write this, it is holiday season, and a national grocery/department chain is running a TV ad of a 20-30 something male para hosting a holiday party where he and his “millennial” friends are celebrating. The ad concludes when the group sits down for dinner and the para hoists a glass of wine and leads a holiday toast — from the head of the table.

Now that’s progress.

— TIM GILMER

# ( CONTRIBUTORS )



JANUARY 2016

## CONTRIBUTING EDITORS

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A retired superintendent of schools and grandmother of 12, Cindy Hall Ranii entered the wheelchair world 10 years ago when an acute onset of transverse myelitis paralyzed her at the T3 level. A lifelong athlete, she discovered wheelchair table tennis four years ago and has competed throughout Europe and the Americas, including the Parapan Am Games in Toronto. She lives in Santa Cruz, Calif., with her partner, Shelly James, and has written a memoir, *Parakeet Races and Other Stories*, available on Amazon.com, which humorously chronicles an often intensely competitive family of six kids raised by a single dad.

Mike Ervin says he has written for *NEW MOBILITY* since before water was invented. His writing has been published in everything from the *New York Times* to *The Progressive* to *Jobber and Warehouse Executive* magazine. Mike has also been active in ADAPT for decades and boasts of being arrested about 20 times, which no doubt has something to do with his pen name: Smart Ass Cripple (read his blog at [smartassripple.blogspot.com](http://smartassripple.blogspot.com).) *Smart Ass Cripple's Little Red Book*, which has a blue cover, and *Smart Ass Cripple's Little Yellow Book*, which has a red cover, are available at [lulu.com](http://lulu.com).



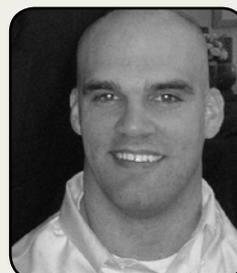
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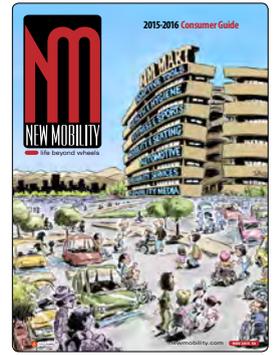


Tom Scott is chief marketing officer for United Spinal Association. Tom coordinates United Spinal's web, PR, social media and direct mail efforts, and has more than 15 years of experience in nonprofit communications. Tom is currently working to strengthen United Spinal's brand and national visibility. He assists key staff to ensure our organization can effectively engage the public through our various programs and initiatives. Tom lives with his wife and two daughters in Nesconset, N.Y.

Born and raised in Richmond, Va., Richard Bagby is proud to carry on the familial lineage that began in the first settlement at Jamestown, Va., in 1607. He has, however, ventured out, accepting a scholarship to play basketball at Boston University, before returning home to play football at the University of Richmond. In 2008, Richard became a C5-6 complete quadriplegic due to a diving accident. He is currently enjoying the responsibilities of helping found Richmond's chapter of the United Spinal Association as deputy director.



# LETTERS



I think this product  
is a great idea.

## Great Idea, Too Expensive

As a wheelchair user for over 35 years, and being in the healthcare industry, I think this product [Lillypad Scale] is a great idea ["Finally, A Home Wheelchair Scale," November 2015]. Having said that, I find it very disappointing that the developer wants to charge nearly \$700 [\$638] for this product. I get tired of paying outrageous prices for products because they are created to support the wheelchair user. Is research and development that expensive?!

*Bubba McIntosh*

*Via newmobility.com*

## A Simpler Way

Years ago when I was still using a lightweight manual chair, I bought a metal device that fit over a standard bathroom scale — just had to pop a wheelie to get on it. Then you had to balance on it and make sure it wasn't touching the floor on either end (which wasn't too hard to do) to get your weight. It worked pretty darn well and, as I recall, didn't cost that much.

*Julie A. Wysocki*

*Via newmobility.com*

## More Affordable Power Devices?

Wouldn't a scooter that disassembles into 35 pounds of parts or less be much more affordable? ["The Spinergy ZX-1," November 2015]. I'm in this same situation now: I love my manual lightweight wheelchair, but I'm losing stamina and can't deal with inclines well. I don't want a van yet, and my SUV is a bit long to put a carrier on the back.

*Maureen Bennett*

*Via newmobility.com*

## Spend Wisely and Save

Every time I read an editorial like this one ["The Numbers Game," Bully Pulpit, November 2015] I think of The Three-Penny

Opera. Disabled people have no claim on nondisabled people, even rich ones. So, yes, there will be all of this new medical technology that will benefit only a minority of those whose lot might be improved.

The solution to this sad paradox is that nondisabled people should spend money on disability insurance, rather than spending it foolishly. Similarly, people like myself, who are living on disability income, should put money aside in case a medical procedure or device becomes available, rather than spending it foolishly.

*Bob Gustafson*

*Via newmobility.com*

## Action Deserves Thanks

I've never experienced being unable to buy tickets in advance online for a movie [Everyday Advocacy, October 2015]. However, a local concert venue offered pre-public sale tickets online only and didn't have an option for wheelchair accessible seating! I called the box office immediately, mentioned the words "unfair discrimination" and "supervisor" and immediately they put a manager on the line who manually processed my tickets and waived the phone convenience fee! I did follow up with a letter to the board of directors thanking them for hiring people who can think outside the box.

*Anita Geismar*

*Via newmobility.com*

## Time to Push Back

I think it might be time for folks to push back via the legal system in relation to wheelchair funding ["Funding for Wheelchair Equipment In Serious Jeopardy," November 2015]. Currently people with disabilities are virtually locked out of Group 4 chairs altogether. Group 4 are technically classified as "non-covered" items and getting even commercial [insurance] plans to consider

them is nearly impossible. Our society judges folks on whether they work, but when it comes to providing the equipment to actually go to work, it isn't "medically necessary." Talk about conflicting messages!

*DJ Stemmler*

*Pittsburgh, Pennsylvania*

## Being 'Invisible'

Re: Nancy Xia's blog post, "Step Away from That Accessible Stall or Meet the Lioness!" [Oct. 7], I love your post! I understand what this is like after having it happen to me several times, and I have only had an SCI for six months. It's amazing the people who think you are "invisible." When in this situation, or when I have to break down or put my wheelchair together, some people pretend they just don't see me. It's amazing.

*Lorri Jensen Taylor*

*Via newmobility.com*

## DIY Parking Space

I do think Claire Lomas ["DIY Parking Space," Crip Buzz, Nov. 2015] is trying to tell us something: DIY is the wave of the future for the hopes of disabled people for improved quality of life. The still failing economy will not do it for us; politics will not do it for us, nor will the media! We must do it for ourselves! This is something ADAPT and the British social model [of disability] understand quite well. I hope we do!

*Marquita V. Doohan*

*Hawkinsville, Georgia*

## Timely Article

Thank you for this very thorough article ["Fashion Enabled," October 2015]. I have been wondering lately how to dress for being seated. This article was so helpful and gave me wonderful resources.

*Cynthia Buchanan*

*Via newmobility.com*



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## Penalized for Working: Teacher Loses Appeal, Attendant Funding

On Nov. 27, Jenny Weast, a teacher from Oakmont High School in Roseville, Calif., lost her appeal to retain her government-funded personal assistance because, according to the Social Security Administration and MediCal, she makes too much money. Weast, a quadriplegic, had received a raise last year, which the court ruled pushed her income too high to be eligible for Social Security's Section 1619(B) — a program set up to help people with disabilities be employed without losing their benefits. "It's a school district and a contract so you can't turn down raises, and if I go part time I wouldn't be able to afford my impairment-related work expenses and pay my living expenses," says Weast, who became a quad at the age of 16 after a skiing accident.

A math teacher and former cheer-leading coach, Weast has been teaching for 29 years, but fears her career may be over. Without 1619(B), if she remains teaching, she would need to pay thousands for her personal assistance out of pocket, and that would not leave her enough money to live on.

According to a Dec. 10 legal opinion by her attorney, Richard L. Manford, Weast has now exhausted all appeals and her only recourse is to work with Congress to change the law. "I know to fight this law that has unfairly shut me out of the system will take a long time," said Weast. "I simply refuse to give up on the independence I have worked nearly three decades for. The thought of it ter-



Jenny Weast fears her 29-year-long teaching career may be over.

rifies me, but I know that even fears that seem unconquerable can be conquered."

More information about Weast can be found on her Facebook page, Jenny's Battle for Independence. Also,

## People in the News: Jay Ruckelshaus Named Rhodes Scholar

The Rhodes Scholarships are the oldest and among the most celebrated international fellowship awards in the world. Jay Ruckelshaus, a Duke University senior and a quadriplegic since 2011, is among the 32 U.S. winners for 2016. "I'd heard about the Rhodes for a long time, and admired many public figures who are Rhodes Scholars, but it's not something you ever really think you would achieve," says Ruckelshaus, an Indianapolis native majoring in political science with a triple minor in philosophy, history and English.

A Rhodes Scholarship is a full post-graduate scholarship to England's prestigious Oxford University. Established in 1902, it is intended to promote civic-minded leadership among young people with, as Cecil Rhodes wrote circa 1900, the "moral force of character and instincts to lead," in hopes of "rendering war impossible" through promoting understanding between the great powers. Some Rhodes Scholars, such as Bill Clinton, have gone on to become heads of state.



Since his injury, Ruckelshaus has become a passionate disability advocate and has founded the nonprofit organization Ramp Less Traveled, which is dedicated to supporting people with spinal cord injuries in their pursuit of higher education. He also is a member of the U.S. International Council on Disability and serves on an advisory board at Atlanta's Shepherd Center.

"My spinal cord injury has caused me to look at the world differently, to examine the architecture of the physical world and the architecture of social relations and discover how some people are marginalized and oppressed," says Ruckelshaus. He plans to pursue a master's degree in political theory while at Oxford.

During his time at Duke, Ruckelshaus has interned for Indiana Governor Mike Pence, where he researched policy focusing on mental health and the criminal justice system. He also was a research fellow for the American Bar Foundation in Chicago, where he investigated the legal history of lunch counter sit-ins during the civil rights era.

Weast's friends have set up a special needs trust so that she would be able to keep her job and her home at [www.youcaring.com/medical-fundraiser/caregiver-funding/262944](http://www.youcaring.com/medical-fundraiser/caregiver-funding/262944).

— JOSIE BYZEK

## Suicide More Acceptable for Disabled than Nondisabled?

A joint Utah State University and Mississippi State University study finds that most people, including those with disabilities, say it is more acceptable for a disabled person to kill themselves than a nondisabled person. Results from "Is suicide an option?: The impact of disability on suicide acceptability in the context of depression, suicidality, and demographic factors" will be available online in the January 2016 issue of the *Journal of Affective Disorders*.

The findings aren't surprising, says lead researcher Emily Lund, a fourth-year disability disciplines doctoral student at Utah State University. "The fact that we still found disability made suicide so much more acceptable — and that none of the demographics, attitudes, or experiences

we controlled for accounted for that difference — shows, that, yes, disability itself does change how we view suicide," says Lund, who has cerebral palsy.

The study asked 500 adults to read five pairs of vignettes about individuals with and without disabilities who experienced suicidal ideation following a life stressor. Participants were asked questions regarding the acceptability of suicide for each vignette, and in each situation, Lund says suicide was seen significantly more acceptable for the person with a disability.

Lund did find one surprise in her research. "We expected people with personal experience with disability would be less likely to see disability as something that creates greater suicide acceptability, but that wasn't the case," she says.

## Amtrak Under Pressure to Comply with ADA

The Americans with Disabilities Act, passed 25 years ago, gave Amtrak 20 years to make its stations accessible. Now it's five years past that deadline, and nearly 500 Amtrak stations in the country

aren't yet accessible. However, Amtrak is committing resources to make its stations more friendly to wheelchair users.

"Things are moving in the right direction, but the reality is that Amtrak did little with the 25 years they've had," says Kenneth Shiotani, a senior attorney with the National Disability Rights Network. His organization is the major watchdog, ensuring Amtrak takes accessibility seriously. "Our organization is in the middle of a major push to get the Federal Railroad Administration to look at Amtrak's spending on ADA issues right away, and the Department of Justice is now trying to negotiate a consent decree."

One reason for the delay is that some of the stations are owned by Amtrak, some are leased from the freight railroads and some are owned by local governments. "It's complicated, and it was somewhat complicated when the ADA was passed because all of these were properties of the former railroads," says Shiotani. Prior to the Rail Passenger Service Act of 1970, the nation was served by a hodge-podge of private railroads.



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By Michael Collins

## Poor Wheelchair Service

**Q.** *I am paralyzed due to childhood polio and was bedridden for more than two weeks last month because my power chair (bought through Medicare) broke down and the vendor who sold it to me was so busy that they could not even look at it until 10 days later. They did say they could check it sooner if I brought it into their shop, but I don't have my own transportation, and there is no way an inoperable wheelchair could travel by itself on a bus. When the problem was finally diagnosed, they advised me I would need to pay extra for expedited shipping of the part that was needed unless I wanted to wait another week for the repair.*

*I need some guidance about what to do the next time this occurs. Lying in bed all day and night made me realize how dependent I am on services out there in the "real world," and it is depressing. If I was working outside the home right now, I wouldn't be able to get to my job.*

— Stranded, and hating it

**T**he level of customer service you received should not be acceptable in any type of business, especially not in health care. The Centers for Medicare and Medicaid Services is responsible for all things Medicare. In reviewing the multiple documents posted on their website, the only reference I could find is from Medicare's *Supplier Quality Standards and Beneficiary Protections*: "The equipment will be reliable and will work for the beneficiary without worry;" and "beneficiaries receive the equipment at their convenience, in a prompt manner and according to both the prescribing physician's recommendations and the beneficiary's assessed needs." Requiring beneficiaries to deliver their

power wheelchairs to a supplier's location for repair is not consistent with Medicare requirements and should be part of any complaint.

You did the right thing by first calling the vendor who serviced your wheelchair. If you have a problem obtaining needed items or services, or if you are concerned about the quality of the supplies and services you are receiving, there are several additional ways that you can get help.

You should first contact your supplier with full details about your complaint and follow that up in writing. I recommend addressing it to the highest-ranking person on the organization's management team. Names and addresses can usually be found on its website. Your supplier must provide regular business hours and after-hour access telephone numbers; must let you know they received your complaint, and are investigating it, within five calendar days; and must send you the result of your complaint and provide their response in writing within 14 calendar days.

Call 800-MEDICARE to get help or lodge a complaint. If you still need help, ask the Medicare representative to submit your complaint or inquiry to the *competitive acquisition ombudsman*. The CAO helps to ensure that your complaint is resolved.

Send copies of your detailed complaint letter to CMS and your congressional delegation; otherwise there will be no record of your complaint in subsequent CMS reports to Congress. That is important because Congress monitors the agency closely, requiring CMS to keep costs down on everything from prescriptions and orthotics to

mobility devices. To accomplish that, Congress tasked CMS with establishing a *competitive acquisition program*, which began in 2011. The upshot of this program is that there are vendors, or contractors, that have been awarded exclusive rights to sell certain products within specific regions of the country.

The CAO is required to report to Congress about how the competitive acquisition program is working, but so far the only year reported on is 2011. CMS says they are currently compiling a report covering the years 2012 through 2014, but if recipients of poor service or inadequate equipment do not file formal complaints, the CMS reports may not be an accurate representation of how well that program is working. Perhaps of equal concern is the fact that most of these regional contracts will be advertised for rebidding in the next two years, and if there are no complaints on file, it increases the likelihood that the same companies will be serving those regions in the future.

### Resources

- CMS Ombudsman, [www.cms.gov/Center/Special-Topic/Ombudsman-Center.html](http://www.cms.gov/Center/Special-Topic/Ombudsman-Center.html)
- Competitive Acquisition Ombudsman, [go.cms.gov/1O6t3MK](http://go.cms.gov/1O6t3MK)
- Medicare info, 800-Medicare; [www.medicare.gov](http://www.medicare.gov)
- Please take a few minutes to help United Spinal learn about the extent of problems with Medicare wheelchair repairs by taking the United Spinal Association Medicare Beneficiary Wheelchair Repair Survey at this link: [svy.mk/1MEO7W9](http://svy.mk/1MEO7W9).



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By Tiffany Carlson



**“My accident didn’t just mean losing my body. It meant losing a job that I loved and people that I loved.”**

### Dutch Paraplegic Fighting for a Cure

Growing up in Northeast France, then moving to the Netherlands as an adult, Corinne Jeanmarie relished her nondisabled life. In her early 30s, she was living in Java, Indonesia, and working as a purchasing manager, a career full of travel and meeting new people every day.

At 47, while taking a cab with a friend, the car veered off the road, and Jeanmarie was ejected from the car. “I woke up on the side of the highway, being hardly able to breathe and not feeling anything below my waist,” she says. Following the accident, as a T10-12 paraplegic, she was forced back to Amsterdam — something that broke her heart. “My accident didn’t just mean losing my body, it meant losing a job that I loved. It meant losing Indonesia, the country that I loved living in. It meant losing people that I loved.”

After her injury, she went into

a deep depression, but like so many before her, she sincerely believed she could walk again if she worked hard enough. “But I didn’t,” she says, “in spite of getting a second opinion and going to France for a second surgery.”

Trying to adjust to a new normal, she worked a different job with the same company in the Netherlands, but was never truly satisfied. When her job went away in 2014, she decided to finally start Endparalysis, a foundation dedicated to finding a cure for spinal cord injury.

The foundation’s current focus is on chondroitinase research. And although it’s a one-woman show, she flies around the world, committed to the cause. A true believer in a cure and living a full life while she waits, Jeanmarie has figured out the hope/real-life balance perfectly.

Check out her website: [www.endparalysis.org](http://www.endparalysis.org)

### World’s First ‘Smart’ Catheter

Derek Herrera, a T6-7 paraplegic from San Clemente, Calif., injured when he was hit by an enemy sniper while serving in Afghanistan in 2012, has used his time since becoming paralyzed to create a device the paralyzed community has been waiting for — the world’s first “smart” catheter. Intended to be changed monthly, this semi-permanent catheter has a sensor inside that tells your smart phone when your bladder

is full. For those with flaccid and neurogenic bladders, this technology could be life-changing.



Called the Connected Catheter, it has a valve and miniaturized pressure sensor, and it can be inserted by the user. The device is still in development and Herrera is seeking funding (he was holding a crowdfunding fundraiser at the time this article was written). Provided it does get the funding and FDA approval, the Connected Catheter could change the future of catheterization.

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

### Amped Up Hair Tool

Attention quads sporting long locks: A new hair-straightening device called DAFNI essentially enables a C5-7 quad to straighten her hair independently. It is a heated brush that straightens your hair as you slowly brush it. The cost is a whopping \$300, but standard hair straighteners usually require full dexterity, so it just may be worth it. Female quads are raving about this device on Facebook.

## Boosting Your Immune System

For many of us with spinal cord injuries, the winter season means we need to be prepared to do battle with the elements and the onslaught of nasty bugs that often come with it.

It is well documented that people with SCI are at high risk of developing pneumonia and other respiratory infections because of our compromised immune systems, especially those with cervical injuries. This is due in part to the changes that take place in our nervous and endocrine systems, as well as our tendency to be deficient in the consumption of immune boosting nutrients — namely vitamins A, C and zinc.

Vitamin A helps maintain the protective mucosal surfaces of your gastrointestinal and respiratory tracts, which act as barriers to micro-organisms.

Vitamin C helps activate neutrophils, powerful white blood cells that work on the front line defense in fighting bacteria. It also increases the production of lymphocytes, the white blood cells that play important roles in antibody production and coordinating immune system functions.

Zinc helps reduce incidents of infection by increasing the production of white blood cells and enhancing their function. Studies identify that zinc can help reduce the incidence of pneumonia, respiratory infections and bronchitis.

One of the best foods you can arm yourself with this winter is kale. This nutrient-rich green leafy vegetable packs an immune-boosting punch with its high vitamin A, C and zinc content. An added bonus of this hearty vegetable is it doesn't wilt like other leafy greens and will last in your fridge for two to three days after it's made. So kale is a great time, money and energy saver for individuals looking for healthy, cost-friendly

and easy to prepare foods.

So keep yourself safe from invading germs this winter by adding a handful to your smoothies, stir-fry dishes, or favorite soup.

Better yet, try making this delicious salad and give yourself a real immune system boost.

### Immune Boosting Salad

- 1 large bunch kale, torn up into bite-size pieces
- 2 carrots, shredded
- ¼ cup (60 mL) extra virgin olive oil
- 2 tbsp (30 mL) red wine vinegar
- 1 clove garlic, finely chopped
- ½ tsp (2 mL) sea salt
- ¼ cup (60 mL) sunflower seeds
- ½ cup (120 mL) sun-dried tomatoes, drained and chopped
- \*optional grated Parmesan cheese to garnish

1. Whisk olive oil, vinegar, garlic, salt and pepper in a small cup and set aside
2. Toss all other ingredients in a large bowl and then cover with olive oil dressing
3. Let sit for at least an hour, then garnish with cheese

*Joanne Smith and Kylie James are co-authors of the book Eat Well Live Well with SCI and Other Neurological Conditions. For more information on nutrition for neurological injuries, go to [www.eatwelllivewellwithsci.com](http://www.eatwelllivewellwithsci.com).*



By Joanne Smith and Kylie James

# MEXICO'S

## DISCOVERING AN ANCIENT

People come from all over the world to soak up the year-round sun on Mexico's Yucatan Peninsula. Besides the turquoise waters, warm inviting climate and delicious food, what drew me and my boyfriend to this part of the world were the historical ruins of one of the world's oldest known civilizations, the Maya. Their ancient sites, mostly located in the north-central part of the Yucatan Peninsula, have been uncovered and carefully preserved. But our trip began in Cancun on the beautiful Caribbean coast of Quintana Roo, Mexico's easternmost state.

### The Hotel Zone

Upon arriving at the Cancun airport in early November, we were greeted warmly by Cancun Accessible, a private tour company that serves the Cancun area, Riviera Maya, Puerto Morelos, Tulum, Playa del Carmen, Akumal, and most of the Yucatan Peninsula. For accommodations I selected the Westin Lagunamar Hotel on a narrow strip of sand known as the "Hotel Zona," where you will find hotel after hotel mixed with shopping areas and restaurants. The Mayan Museum and Cancun Aquarium are also located on this strip. Many curb ramps have been installed in this tourist area, but they're not everywhere. Many entrances were not accessible, so be forewarned.

Modern Cancun began in the 1970s as a government-funded project to lure tourists to the area. In 2005 Hurricane Wilma destroyed nearly all of the hotels, many of which have been successfully rebuilt. The Westin Lagunamar is one of the rebuilt hotels and is the only one along the beach that is equipped with a pool lift. Disappointingly, there was no balcony access in any of the rooms and no beach access from the hotel.

Downtown Cancun is a 15 to 20 minute drive from the Hotel Zona, and that's where you'll find the Four Points Sheraton Hotel — the only other hotel with a pool lift. In addition to the Westin Lagunamar, the other hotels that have barrier-free entrances into their pools are the Secrets Playa Mujeres Golf & Spa Resort, the Occidental Grand Xcaret Resort, and the Grand Bahia Principe.

### Chichen Itza

Following our stay in Cancun, we headed to Chichen Itza — the ruins of one of the largest Mayan settlements, one of the Seven Wonders of the World and my primary reason for coming to the Yucatan Peninsula. A few small historical sites are located within urban areas, but the major ones require traveling a good distance into the jungles of the peninsula.



There are thousands of miles of beautiful beaches in Mexico, and some of the best are on the Caribbean coast.

The Westin Lagunamar is the only hotel in Cancun's "Hotel Zona" that offers a pool lift.



# YUCATAN: WORLD IN MODERN TIMES

BY ASHLEY LYN OLSON



The highlight of Chichen Itza is the iconic pyramid called El Castillo, used for many Mayan cultural and religious purposes. Today, in an effort to preserve the landmark structures, people are not permitted on all the major archeological sites, so everyone gets the same ground-floor view, including wheelchair users — no one is allowed on the stairs. Despite lacking modern day telescopes and technology, the Mayans possessed a depth of knowledge about the universe, and many think they used this knowledge to build and place the structures of Chichen Itza. Spring and fall equinoxes draw the most tourists, who come to marvel at the play of light and shadow that make it seem as if a cosmic diamond-back snake is moving down the stairway of El Castillo. A guided tour showing the many details and explaining the history is highly recommended.

The generally flat landscape at Chichen Itza made getting around doable for manual wheelchair users and no problem for those who use power chairs, but there are some areas of caution. Designated parking is offered and the entrance fee is determined by one's physical mobility. Since we use manual wheelchairs, we got in free because parts of the pathways present some challenges. The majority of the area was very firm and easy to navigate over. Local vendors selling hand-carved arts and crafts are everywhere.

Across from the ticket office at Chichen Itza is the beautiful Posada Hotel. The area around the hotel is paved and the hotel itself is a good place to eat while visiting Chichen Itza. Ramps allow you to move through the hotel to the buffet dining area where you can sample Mayan, Mexican and international foods. The taco stand with fresh, handmade tortillas was our favorite; hotel staff is all around to assist



**Much of Chichen Itza is flat, and wheelchair users get the same view of the iconic El Castillo pyramid as everyone else — no one is allowed on the stairs.**

For decades these world treasures have been nearly unreachable for wheelchair travelers, but now Cancun Accessible does all it can to make touring this area possible. Currently the company has three wheelchair accessible vans that can transport six wheelchair users and nine companions at the same time. Their vans are spacious and provide ample head room with tie-downs for wheelchairs and seatbelts, but they have not been lowered, so the ramps into the vehicles are steep. However, the driver is always able to assist with a push. Cancun Accessible set up an excellent tour of the excavated structures that highlighted how much is still covered by the jungle — and how much we do not know.

carrying your plate if needed. The dining room has an enormous patio for seating and a partially enclosed space with beautiful stained-glass windows where you can watch frequent dance performances.

The most unfortunate aspect of Chichen Itza is the lack of an accessible bathroom. I found the two sets of women's bathrooms to be too small for my 22-inch wide manual wheelchair, but the men's bathroom on the patio was just big enough for me to get in and close the door. However, there were no modifications and space was very tight.

## Tulum

About two hours east of Chichen Itza, perched on Mexico's stunning Caribbean coast, sit the Mayan ruins of Tulum. It is said that Tulum was built to protect the Mayan people against invaders but was also used as a key trading post for merchants with access to the land and sea routes. The most famous structure is a cliff-top watchtower, also called El Castillo. Like Chichen Itza, the price of admission was determined by a person's physical mobility, so once again we got in free. I found this reasonable considering that the hilly and sandy terrain of Tulum poses challenges for some wheelchair users. The information center by the parking lot has a special wide-tired wheelchair you can borrow for free.

From the parking lot, it is a good 10 to 20 minute stroll to the archeological site. Along the way you will pass a few tourist



Being in the water with the dolphins brought Ashley Lyn Olson an incredible feeling of joy.

shops and restaurants. Flooding can make navigating the mix of cobblestones, bridges, ramps and a tunnel tricky for wheelchairs; we had to be carried over parts. Only a few areas and pathways can be fully accessed by a wheelchair, due to deep sand barriers; one in particular takes you to a small beach cove below the Castillo and another directly in front of it. Tulum is still worth visiting to explore the details in some of the standing structures, but it is a lot easier for manual wheelchair users.

Again, the biggest challenge is the bathroom. At the gate there is a set of men's and women's bathrooms. The women's was small and only permitted a side transfer. There were grab bars and a foot pedal flush; however, power chairs wouldn't fit.

## Swimming with Dolphins

After Tulum we made our way to El Dorado Maroma, a resort about an hour away, to swim with dolphins. In Mexico there are a plethora of companies offering the opportunity to swim with dolphins. However, according to Cancun Accessible, Dolphin Discovery has the best overall experience and treatment of their animals, including an enclosed habitat in the actual ocean.

Getting to the saltwater pool from the parking lot was easy using the very smooth paved asphalt pathways. Not counting the ramp up to the pool deck, the ramps were not too steep. Dolphin Discovery is equipped with a beach wheelchair that takes you from the pool deck down a ramp into the pool. Lifejackets are put on every visitor, and Dolphin Discovery provides a person in the pool with you for extra assistance. Three different packages are offered, depending on how much interaction with the dolphins you want and what's physically possible. We got to touch and kiss the dolphins a lot, but just being in the water with them brought an incredible feeling of joy.

One inaccessible lowlight was that the changing rooms and the bathrooms were not wheelchair accessible. We secretly changed into our swimsuits at a cabana next to the pool deck, which was not ac-

## Starting Off With a Shaman Cleanse

My first full day in Mexico was a day I'll never forget. After watching a glorious sunrise, we left our hotel for a date with a shaman at the Jardines del Colibri Dorado in Sisbicché, Yucatan. Translated literally, Jardines del Colibri Dorado means the Gardens of the Golden Hummingbird. It is a beautiful ranch that is impossible to find unless you know where you are going. We had no idea what to expect and neither did the tour company; it was a new exploration for all of us and the first time someone requested seeing a shaman. We were greeted by a few friendly dogs and four healers, including the shaman known as Abuelo (grandfather) Antonio. We connected immediately. Following Abuelo Antonio into the barrier-free meditation room, we talked while drinking water from a sacred cenote (water well) over Santa Maria before the main part of the ceremony.

Once it was time, we lay on a massage table and received our treatment. Specific candles were lit next to burning incense. The shaman explained that incense grounds us and nourishes the

earth (ashes), and the smell (smoke) is a gift for the heavens. Different oils were rubbed onto our skin and prayers were whispered as a special kind of acupuncture was performed. Each session was customized, and sometimes all four healers were working simultaneously on me. At one point the skylight painted rainbows on our skin. After the treatment we remained on the tables for a good while in a deep meditation, feeling the vibrational frequencies flow. I snapped out of it upon hearing the shaman quietly tell our driver and guide that we were almost finished. When I was finally able to move, I felt as light as air and embraced the shaman with a long, loving hug.



cessible and not entirely closed off. We got back into our clothes in the men's main locker room area while our driver stopped anyone from coming in; the main entrance had no door. The women's locker room was way too revealing for people passing by. We made it work but it is definitely a detail to be aware of.

## Beach Life

After the dolphin swim we made a quick visit to the nearby beach area, Playa del Carmen. There are thousands of miles of beaches in Mexico, and some of the best are along the Caribbean coast.

Playa del Carmen, which lies between Tulum and Dolphin Discovery, is a great place to start. Fifth Street is where most of the shops and restaurants are located. It is colorful and definitely worth visiting. Some restaurants have access but, as seen throughout Mexico, most shops have one step. A small hill leads down to the ocean with women selling fresh fruit and other tropical items; getting back up the hill requires a good push for manual wheelchair users.

Just beyond the sand you can find the Portal Maya (The Mayan Gateway), a famous sculpture designed by José Arturo Tavarez. You can't miss it. It towers into the sky and is the site of regularly scheduled

traditional dances with ceremonial dress and music. The sculpture marks the entrance to Playa Fundadores. There's another beach nearby called Playa Punta Esmeralada. Playa Fundadores has accessible bathrooms and showers and 15 to 20 beach wheelchairs you can borrow for free, thanks to Playa Inclusiva, a government accessibility program.

At one of these accessible beaches we met Inez Gonzales, a power chair user who moved to Playa del Carmen from Spain about four months ago. Having recently gone scuba diving with whale sharks, she told us about a company in Playa del Carmen that assists people in wheelchairs with scuba diving — Love to Make Bubbles Underwater. They can train and get you out to sea in one day. Playa Fundadores in Playa del Carmen is also close to the dock where a ferry takes visitors to the island of Cozumel. Lifewaters.org, a U.S.-based nonprofit that trains people with disabilities to dive, offers extensive packages there. Cozumel has an airport along with

places to stay, eat, sleep, and enjoy the beach life. It is especially known for its clarity of water and scuba diving.

Besides Playa del Carmen, the other accessible beach in the area is Playa Delfines, by the Hotel Zona and the Cancun airport. A little more than two years ago a storm damaged the pathway to Playa Delfines, and when we were there, it still needed significant repairs. The pathway starts at the parking lot with several designated spaces and leads to a set of cabanas specifically designated for those with limited mobility. A few bathrooms are accessible

## Access in General: Eating, Bathrooms, Ramps

Access to bathrooms is the biggest infrastructure improvement needed in the Yucatan Peninsula. In developed areas you really don't need to go that far to find an accessible bathroom, but rural parts are much more challenging. Even American chain restaurants can't be relied on for always being accessible.

Commonly, shops have a step or two inside, even at the nicest shopping areas. More restaurants than shops seemed to have ramp access. Sidewalks may end abruptly due to a barrier or lack of a curb-cut. Sometimes riding in the street may be the best way to get around, but can be risky. Designated parking spaces for wheelchairs exist but do not have the crosshatch space to get in and out.

along the quarter-mile paved promenade and are often locked, but a guest services employee at one of the regular bathrooms can unlock it. These were the most spacious bathrooms I saw on my trip, big enough for any chair and/or changing in and out of a swimsuit.

In the Hotel Zona and many other areas, you can rent jet-skis and parasail off the back of a boat. There are no modifications made, but for some travelers these activities may be possible. Fashion Harbor Mall in the Hotel Zona rents boats and less accessible water options.

Another option is to explore one of the area's many resort parks, which offer everything from snorkeling to zip lines, inner tubes and much more — all with the goal of soaking up the sandy white beaches and crystal clear water. The most accessible options are Xel-Ha and Xcaret. The two are about an hour and a half away from each other. Of the two, Xcaret has more options with access. Like the archaeological sites, these parks also discount tickets based on a person's physical mobility — determined only in-person to prevent fraud. Even if an attraction is semi-accessible, ask for a discount. We did at the aquarium on Fashion Harbor in Cancun and got 50 percent off even though it was pretty much entirely accessible.

## Underground Worlds of Water

Our tour guide told us there are 14,000 known cenotes (water wells or sinkholes) in the Yucatan Peninsula area, but more





The Rio Secreto tour is a great way to explore the cenotes and underground rivers.

certainly exist. Cenotes are natural sinkholes that expose underground rivers. Some are considered to be sacred spaces, while others are used as town drains during rainfall. Most cenotes are inaccessible for wheelchair travelers, but some can be viewed from the surface, like Ik Kil — perhaps the most famous one in Mexico — located near Chichen Itza.

An incredible way to experience a cenote and the underground rivers is the Rio Secreto, a tour of cenotes and underground waterways just west of Xcaret. After a 15-minute drive deep into the jungle to the entrance of the cave, a guide performs a five-minute ritual to ask the

universe permission to enter. Everyone then strolls about 10 more minutes to reach the cave's paved ramp. About 15 minutes are spent exploring the cave's stalactites and stalagmites with the guide, followed by a short movie.

## Fiesta on the Water

For the first time, Cancun Accessible decided to include a unique dinner on a boat through the jungle with a company called Xoximilco. The night consists of lots of eating and drinking with live music, starting at the reception area before boarding the boats. This area is smoothly paved with a large accessible bathroom. A side ramp allows wheelchair guests to get to the boat dock. Everyone else on the boat gets on first, then the crewmen stand at the front of the boat to make it level with the dock to just roll right on. Chairs were removed upon request to remain in your wheelchair. The slope to the dinner table was short and required a bit of finesse to navigate.

Every boat has a guide to explain things and also encourage people to par-

ty. The whole experience is about three hours long. Once on the boat, the meal showcasing traditional Mexican food begins. Tequila is offered along with beer, soft drinks, and water — all you can drink. As the boat flows on along with other party boats, stops are made at parked boats for food service and entertainment. The dark river and surrounding jungle make every turn a mystery. Cactus, different meats and treats were offered as samples and served directly to us without our having to leave the table. Once we got our next course, the following stop would be at a boat with live band playing Mexican music. At the halfway point guests can get out, drink more alcohol, check out the gift shop, or use the restroom — one of which was modified for wheelchair access. The remaining ride continues with more music over dessert and coffee. It was an impressive production, like a Disneyland ride that replicates a Mexican dinner and show. **M**

## Resources

### Accommodations:

- Westin Lagunamar, 52-998-891-4200; [west.tn/1OKpx9b](http://west.tn/1OKpx9b)
- Playa del Carmen, 888/537-9797; [www.playadelcarmen.com/hotels](http://www.playadelcarmen.com/hotels)
- Cancun Accessible, 52-998-884-2156; [www.cancunaccessible.com](http://www.cancunaccessible.com)
- Chichen Itza, [www.chichenitza.com](http://www.chichenitza.com)

### Swimming with Dolphins:

- Dolphin Discovery, 866/393-5158; [www.dolphindiscovery.com](http://www.dolphindiscovery.com)

### Scuba:

- Love to Make Bubbles Underwater; [www.facebook.com/Love-to-make-bubbles-underwater](http://www.facebook.com/Love-to-make-bubbles-underwater)
- Lifewaters.org, [www.lifewaters.org](http://www.lifewaters.org)

### Tour and Transportation Companies:

- For Handicap Travelers, 52-998-251-5385; [www.forhandicaptravelers.com/transportation.htm](http://www.forhandicaptravelers.com/transportation.htm)
- Cancun Plus, 866/800-0570; [www.cancunplus.com/disabled-transportation-services.html](http://www.cancunplus.com/disabled-transportation-services.html)
- AdaptA, 800/223-2782; [www.adapta.com.mx](http://www.adapta.com.mx). Click on the U.S. flag for English.
- Cancun Airport Taxi, 866/800-0570; [www.cancunairporttaxi.com/wheelchair-accessible-cab.html](http://www.cancunairporttaxi.com/wheelchair-accessible-cab.html)

## Costs and Getting Around

Costs vary widely depending on time of year. May to November is the most affordable window, especially September and October, the rainy (and sometimes hurricane) season. The expensive season runs from the end of November to early March — during the holiday season and the best weather. If you can plan to go during a “shoulder season” — early December or April — you can get the best combination of prices and weather.

Low season airfares generally run between \$300-\$450 per person from any major U.S. airport. Fly during Christmas week and your cost will just about double. Accommodations in the Cancun area are likely to follow the same pattern, but costs depend mostly on the rating of the hotel or resort. In April prices range from as little as \$50/night for a two-star hotel to \$700/night or more for a five-star resort. It pays to do a lot of research to pin down the best deal at the quality you can afford.

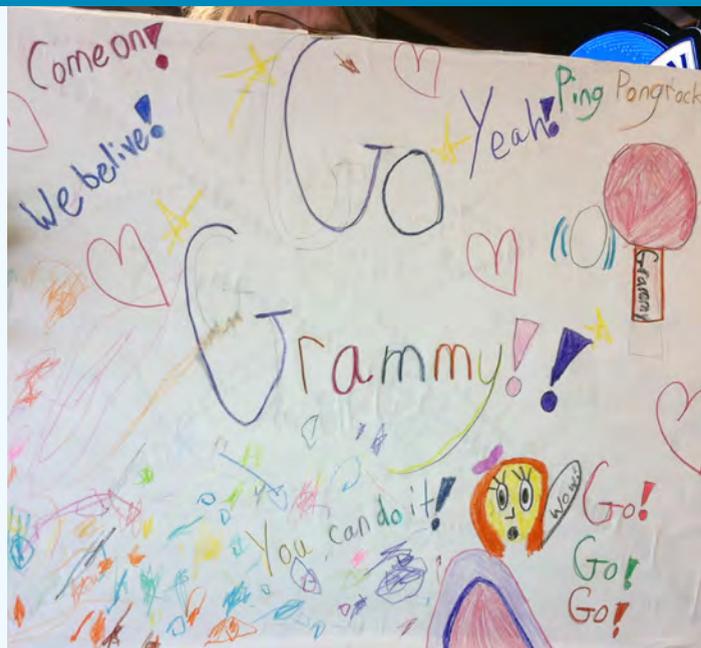
Cancun Accessible Tours can pick you up at the Cancun Airport in an accessible

van with tie-downs and drop you off at your hotel, but once there, accessible transportation becomes a problem. You can arrange for Cancun Accessible to take you on tours, but they can be expensive, and the only other way you can travel in a wheelchair is in a rental car with no hand controls, or perhaps an accessible taxi. If you choose Cancun Accessible for touring, the more people in your party, the cheaper the cost per person. A day trip to Chichen Itza might cost \$297 per person for two people but \$187 per person for a group of four and even less for five or six. A three-day tour that includes Chichen Itza, Tulum and Swimming with Dolphins ranges between \$430 to \$750 per person, depending on the group size.

To sum up, a weeklong vacation for two near Cancun at a three-star hotel in the low or shoulder season (including airfare) will run between \$2,000-\$4,000, depending on where you eat and how much time you spend hanging out at the hotel pool and/or day-tripping from location to location.

# WHEELIN' GRANNIES BRING HOME THE BRONZE: A TRIP TO THE 2015 TORONTO PARAPAN AM GAMES

BY CINDY HALL RANII



I have not often been rewarded for being annoying, or for being a senior citizen, but those traits seemed to do the trick for Jennifer Johnson and me at the 2015 Parapan Am Paralympic qualifying tournament in Toronto in August. Playing doubles in the class 4-5 wheelchair table tennis team event [see sidebar], we were certainly underdogs. At ages 66 and 68, we were more likely to be taken for our competitors' grandparents than their opponents, but tenacity and wile served us well.

As a Hall of Famer and winner of Paralympic gold medals in 1988 and 1996, Jennifer, a grandmother of two, was an early pick for the 2015 Parapan Am team. I came to the sport just four years ago as a grandmother of 12. Jennifer is originally from Jamaica and contracted polio at age 53. I was stricken with transverse myelitis at age 58. I felt honored to be Jennifer's doubles partner, and, it turned out, her roommate, too. We were a perfect pair. We laughed easily together and cautioned each other not to put too much pressure on ourselves and to have fun.

Our first laughs came when we picked up our coveted Olympic "swag" at the credentials and uniforms processing center, which served the 1,608 para-athletes from 28 countries, competing in 15 sports. Volunteers presented us with Nike

sports bags, T-shirts, track suits, jackets, backpacks, caps, and Oakley sunglasses. Jennifer and I each had a "dresser" assigned to help us try on clothes. My dresser would hold up an item of clothing and say, "This size looks good." I would say, "Looks a little small," then she would try to squeeze me into the garment. At the same time, on the other side of the room, Jennifer's dresser was doing exactly the same thing.

Apparently, only Jennifer and I were aware of the echo in the room. We knew our granny bodies. We knew that the clothes cut for nondisabled young women were not made for our gravity-enhanced figures. But the dressers didn't catch on easily; they would bring out one size larger and say, "This looks good," and we would individually answer, "I don't think so." It was almost midnight, and we grew goofily tired.

Then, the dressers showed us the red bikini underwear. We looked at each other and laughed. "No way." There was no way we would ever fit into that underwear, nor would we wear it if it did fit. Then, the dressers shared that athletes were encouraged to post pictures of themselves wearing the briefs to promote "Team USA." Once again we laughed and responded in unison, "I don't think so!"

## COMPETITIVE CLASSIFICATIONS

In para table tennis, athletes are grouped by their functional abilities resulting from their impairment. Classes are designed to group athletes equitably for competition. Classes 1-5 are for those in wheelchairs; classes 6-10 for those who have disabilities that allow them to play standing. Within those groups the higher the classification, the more function the athlete has. Class 11 is for players with an intellectual disability.



Jennifer and Cindy's strategy was to be as annoying to the other, younger, team as possible.

We finally agreed on our clothes, although many were still too small, and we headed to the athletes' village. We dragged into our smallish room, transferred out of our wheelchairs, and grabbed some quick sleep before practice early the next morning. A teammate's nondisabled mom came by in the morning to see if we needed any help with our luggage or to set up our rooms. She looked at the nightstand, pointed and said, "What's that!?"

"Oh, that's Tawny," Jennifer answered. It was her wig. She had brought two, but this one, a tawny shade, would be the one she would wear for table tennis. A nickname was born. "Come on, Tawny," I said. "Let's get down to breakfast."

After practice we took stock of our physical challenges. After months of intensive training we were fit and ready to play, but also we had to take care of special issues. Jennifer had barely finished rehabbing a hurt shoulder, and Biofreeze was her constant companion. She regularly sought out the chiropractor and physical therapist, and she iced and rested her shoulder as much as possible.

A UTI visited me almost as soon as we arrived, as did an abrasion on my backside, compliments of a bad transfer by ill-trained airport special services staff at the Toronto airport. So I had daily trips to the team doctor for cleaning and dressing of the small wound.

Although we didn't recover as quickly from day-to-day as we had when we were younger, we kept to the schedule of multiple hours of training and two hours a day of bumpy, jarring bus rides to and from the table tennis venue. We ate and rested prudently.

## BRAIN OVER BRAWN

After a week of training, the competition began with the pomp and circumstance befitting the stakes of the event and the effort that every athlete had made to get there. A gold medal in singles would send either of us to the Paralympics in Rio in

2016. Neither Jennifer nor I prevailed in singles, although she was just a few points away from a victory against a Venezuelan that would have earned her a medal.

My most noteworthy singles match was against the eventual gold medal winner from Mexico. Two of my grandsons, Caden, 13, and A.J., 12, who had travelled from Utah and California to support me, were in the stands with my partner, Shelly. Their excitement and cheering helped me to play my best. I won one set in losing 3-1, but it was a joy to have the boys see me as a contender.

That left us with the doubles team event for a chance to medal. We were not surprised that the Mexicans and the Brazilians were too tough for us, but we thought we had a chance against a young Colombian team whose players were less than a third of our age. We took care to watch them train in the practice hall, and we saw that they were strong hitters. They didn't show a great variety in their shots, however, and they seemed impatient.

Both Jennifer and I had worked with a coach who had said, "At your age you are not going to beat opponents with power. You are going to beat them by being consistent, by outthinking them, and by being mentally tough." His main advice: "Be as annoying as possible! Do not give them anything to hit." So that was our game plan: Outfox the young ones. Be annoying.

Our coach for the match urged us to play persistently and not get into a hitting match with our young opponents. It worked. We won the first two games and we could see the Colombians growing more and more frustrated. Still, it was obvious that they had trained as a team. They had hand signals for how they were going to serve, and between points they shared strategy by whispering to each other behind their paddles.

Jennifer and I had never played together before. We didn't have any elaborate strategy, and we didn't want to change the rhythm of our serving by having to remember hand signals. At the same time, we didn't want to let on that we were basically keeping to one serving style. So before each point we put our paddles in front of our faces and whispered to each other. We



Cindy's grandsons, Caden and A.J., travelled from California to support their grandmother.

feigned serious exchanges when all along we were saying things like, “How’s it going, Tawny? You going to wear that same wig out to dinner?” or “That was sure nice of the grandsons to come watch us play.” We hid from them that we were laughing, and showed only our game faces.

The patience of the grannies won the day and the match, 3-0. To win the bronze we also had to win one singles match. Jennifer did exactly that to earn our “podium moment” and the bronze medal. Neither of us qualified for the Paralympics, but we felt as if we had represented ourselves, our country, our kids and our grandchildren well.

## BE LIKE GRAMMY

After returning home to California I sat down to Sunday dinner with my daughter, her husband, and their four children. I hadn’t seen them in several months, and I was feeling guilty for having spent so much time playing ping-pong. I feared that I had misplaced what’s important in life. So I was hesitant as I announced that I had some show-and-tell and passed around my bronze medal. “Wow, it’s heavy! This is pretty cool, Grammy! How’d you get this? This is awesome. There’s Braille on the back!”

Then 7-year-old Berlin went upstairs and came back down holding a small, zippered makeup kit. She was reaching inside to show us something. Was it lipstick or gloss or blusher that her mom had given her?

Berlin had recently and reluctantly agreed to play on a recreational soccer team with her two brothers. For the first game

she sat on the sidelines unwilling to participate. She claimed she was too tired, having walked from the car to the field. During another game she went out in the field, and actually did a bit of running. She handed me the little makeup case. “I want you to see it first, Grammy.”

I opened it and pulled out a simple plastic medal about the size of a half dollar attached to a red, white and blue ribbon. On the medal you could see a soccer shoe with Mercury wings. “I won it for playing soccer,” she said demurely.

I told her how proud I was of her, and I could tell by the smiles around the table that they were all proud of me, too. At that moment I decided that the 2020 Olympics in Tokyo weren’t really that far off. And the Parapan Ams? They will be in Lima, Peru in 2019. I’ll be 72, and Jennifer will only be 70. M

## RESOURCES

- For more information about table tennis in the United States, explore [www.teamusa.org/USA-Table-Tennis](http://www.teamusa.org/USA-Table-Tennis), click on “Para” at the top of the home page. Para program director: Jasna Rather, 817/715-4062; [jasna@usatt.org](mailto:jasna@usatt.org)
- For information on international table tennis tournaments and camps, explore the International Table Tennis Federation’s home page: [www.ittf.com](http://www.ittf.com), click on Para TT, or go directly to [ipttc.org](http://ipttc.org)

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PERSON OF THE YEAR:

# Reveca Torres



BY MIKE ERVIN

Regardless of whether you have experienced her beaming smile in person, or heard of her work, or the organization she founded, Reveca Torres is changing the way you think about people with spinal cord injuries and disorders. An artist, storyteller and humanitarian, the Chicago-based quad is promoting an exciting new identity for the SCI/D community — one that moves beyond the dichotomy of the inspirational and the depressing to a more approachable and real depiction of what people face every day. She understands the importance of empowering people within the SCI/D community, while connecting with and educating people outside the community, and her unique approach to achieving those ends is at the heart of why she is the 2015 NEW MOBILITY Person of the Year.

**R**eveca Torres is too restless to sit behind a desk every day. She devotes most of her time to running Backbones, the SCI/D nonprofit she founded, out of her home in suburban Chicago, but she loves to leap into adventures, both large and small. Variety keeps Torres, 34, motivated and stimulated. “It keeps it exciting. I like trying new things, new activities. I might not always get good at them, but I like to try.”

This week it’s a group harmonica lesson

at the Old Town School of Folk Music in Chicago, where I agree to meet her. The instructor is named Skip. He’s a robust and avuncular white man with a gray beard. He wears an Irish motorist cap. His black pants are hiked up high around the equator of his waist.

The five students join Skip in singing a few rounds of the blues song he is about to have them take turns playing.

*How long? How long?*

*Has the evenin’ train been gone?*

Torres sings tentatively as she stares in-

tently at the song lyrics spread out on the music stand in front of her wheelchair. In her lap rests a small black case containing a wide array of harmonicas.

*How long? How long?*

*Baby how long?*

It’s Torres’ turn to play the tune solo. Her sound is faint and thin. She has a bit of a struggle keeping up the tempo. The song ends with everybody singing one last round. And then Skip says, “Such a gloomy song.”

Yes, but it goes well with the gloomy

autumn day. Outside the window, the afternoon sky is slate gray. Golden leaves still cling to bare black tree branches. Torres looks at me after the song ends and says, "I'm out of breath." But then Skip announces that the next song for everybody to play will be Cabaret. It's a much faster tempo. Hang on tight!

After class Torres and I chat in the lobby of the Old Town School. She says she played much better during her round of harmonica lessons earlier in the year, but she got rusty over the summer because she didn't keep up practicing. She says she played violin before her injury happened on the last day of 1995. As a kid, she fantasized about being in a Mariachi band. After the injury, she says, "I tried playing the violin to see if I could adapt it somehow.

But you really need fingers for that. I was looking for something to play." And then a few years back her nephew gave her a harmonica "just to mess around with," she says. "I told him, 'I can probably do this. And it'll probably help my breathing, too.'"

Torres had a good excuse for not keeping up with the harmonica last summer. She was busy helping organize a Chicago version of the ReelAbilities film festival. The four days of disability-themed film screenings and panel discussions was intended to commemorate the 25th anniversary of the signing of the Americans with Disabilities Act. One of the festival sponsors was Backbones. The Backbones mission statement says it's there "to help people with spinal cord injury or disease and their families connect with

their communities ... by creating events and experiences that promote awareness and engage people of all abilities." That description could just as easily apply to Torres' mission since she was paralyzed at the age of 13.

## A Fateful Trip

New Year's Eve, Dec. 31, 1995. Adam Torres is driving his van back to Chicago after visiting family in Guadalajara, Mexico for the holidays. He's in a hurry to get across the U.S. border. The auto insurance he purchased to cover this trip expires at midnight.

In the front passenger seat is his son, Noe, 11. In the rear seat is his daughter, Annie, 6. Adam's wife, Francisca, sits





Creative photography exhibits showcasing everyday lives of wheelchair users, including hers, is a favorite technique of Reveca Torres for increasing disability awareness.

behind him on the middle seat along with their one-year-old son, Jacob, and Reveca, 13.

It's raining as they travel along a desolate Mexican road. Francisca lifts Jacob out of the baby seat and onto her lap to change his diaper. A truck swerves. Adam swerves to avoid contact. His van skids off the road and tumbles down a ravine. Annie and Noe are thrown from the van. Adam climbs out of the wreckage. He says to Reveca, "Get up and help me with your brother and sister!" Reveca tries to sit up, but she can't. It feels as if something heavy has landed on her and is pinning her down.

Adam and a man Reveca doesn't know are climbing into the wreckage. Who is this man? How long has the family been lying in the ravine waiting for someone to notice? Reveca doesn't know. She's going in and out of consciousness. Time has no substance. Adam and the man hoist Reveca up in a cradle lift and pull her from the wreckage. Her neck is limp and her head falls back. She knows something is seriously wrong.

They carry her out of the ravine and slide her into a Chevy Suburban that's parked on the side of the road. The man she doesn't know is an American who drove by, spotted the family in the ravine, pulled over and hurriedly removed the seats from his Suburban to make room to transport all the injured family. He delivered the family to what Reveca refers to today, with an exasperated laugh, as "the shittiest clinic ever." It was the closest place to get medical help. From there she was taken by ambulance to a "less shitty clinic," where they screwed a crown ("halo") into her head. Then she was airlifted to a Texas

hospital where she spent three weeks stabilizing before being airlifted again to the Rehabilitation Institute of Chicago.

Reveca had injured her spinal cord at C5-6. Adam injured his shoulder. Francisca fractured her pelvis and sustained a deep gash. Noe was also severely lacerated. Annie had whiplash. Francisca held on tight to baby Jacob throughout the tumbling and hurtling and his only injury was a broken tooth.

### Artist With a Mission

Watching how adeptly Torres navigates the world of wheelchairs today, it would be easy to forget that past and assume she had always used a chair. Last week she spent a lot of time taking pictures of herself "just out and about" and engaging in some of her favorite weekly activities, like producing visual art and practicing yoga. The camera was mounted to the back of her wheelchair so all the pictures show her from behind. "The idea is to show that a wheelchair is not restricting," she says. She'll display selected photos at an upcoming Chicago-area art exhibit called *The Art of Normal*, featuring the work of artists with disabilities.

The exhibit is her latest effort to raise awareness of what life in a wheelchair is really like. In 2013 she cultivated *Reinventing the Wheel*, a striking exhibit where she paired 21 nondisabled photographers with 21 wheelchair users to depict their everyday lives. The project grew out of her own dissatisfaction with the stock images she had to choose from when launching the *Backbones* website. "You end up seeing the same people in wheelchairs over and over and often doing the same things," she says.

"I wanted to have new people representing different experiences all over the country."

The exhibit started in Chicago and has toured around the country. It is now available online. "It's been really, really well received," says Torres. "It's been nice to hear what people say about it and how it changed the way they view disability." (See some of the images on pages 28-29.)

### With Confidence Comes Purpose

After her injury, Torres didn't return home from RIC until April. She was the third of six children in a Spanish-speaking household. Her father always said, "English is for school. Spanish is for home." Being 13 is crazed and jumbled up enough without piling on the tumult of jumping back into life with a spinal cord injury. Still, Torres graduated from middle school on schedule a few weeks later thanks to assistance from a tutor during rehab.

As she looks back on that time today, Torres says the key word that repeatedly comes to mind is connection. Connecting with the disability community was of indispensable importance for her recovery. Connecting with and getting to know other people in her situation helped motivate her and give her hope. She started *Backbones* because she wants to hasten those connections for others.

As a teenager, sometimes hope came from a connection with a supportive professional. Before her injury, her strongest ambition was to be a fashion designer. She timidly shared that dream one day with her high school home economics teacher. "But that's not gonna happen," she told the teacher. "I can't sew." Sewing machines weren't very accessible for people who couldn't use their feet or fingers. "I was all



When Torres discovered she could still sew post-injury, she enrolled in a fashion design program.



Peer support is vital, and is core to Backbones' mission.

Photo by Kyle LaMere

pouty. And she said, 'Yes you can. Come to my office tomorrow on your lunch.'" The teacher showed her a high tech sewing machine where everything was controlled by pushing buttons that were easily accessible. "I was amazed! I was like, 'Oh my God! I can sew!' I ended up not going to lunch for the rest of high school. I would go to her classroom and take my lunch and sew and make things."

After high school, Torres took a leap. She enrolled in the fashion design program at Harper College in suburban Chicago. And then she took another leap when she entered the prestigious Fashion Group International Costume Design Competition. Her entry, which she made herself with some physical assistance, was a Victorian dress with all the undergarments, including a corset. She was a finalist.

Even after becoming the first student in a wheelchair to complete the program at Harper, Torres still had doubts about herself. She'd never lived away from home. Only family members had done her personal care. It was time for yet another leap. In 2002, she signed up to travel to England on an exchange program with Mobility International USA. Rather than bring her own assistant, she opted to work with whatever assistants Mobility International

could arrange for her abroad.

That adventure gave her the confidence to go further. Immediately after her return she applied to the University of Arizona. In 2004 she obtained a bachelor's degree in theater arts, with an emphasis in costume design.

The next trip Torres took with Mobility International was to a Costa Rican rain forest in 2006. This time she was a group leader. All this and more taught her that the deepest connections are made with peers. "I didn't have peer support after my injury. Not until much later," she says. As a teen, Torres had good family support. While she was in rehab, her father and older brother, Adam Jr., adapted the family ranch house to make it accessible, or at least accessible-ish. It was accessible enough for Torres anyway. But there's nothing like peer support. It's great to be able to talk shop sometimes. And the more disabled folks she met as she got older, the more she heard painfully familiar stories about lack of peer support. "I kept seeing it over and over again.

One of my favorite parts is seeing what other people bring to the table, and not trying to guide it all the time.

People were going into rehab and coming out after three weeks. What possibly can you learn in three weeks? People were asking me about things I learned in rehab, like about things like bowel programs, that you think they would've learned."

### Backbones Comes Together

It took Torres a while to officially pull the trigger on starting Backbones. She almost didn't do it. "I thought about it many times before I actually decided to do it. My background was in art and I dedicated a lot of time to art." A series of internships with a variety of nonprofits helped her build the skills and confidence to finally take the plunge. She taught herself how to prepare the Backbones tax-exempt, nonprofit application to submit to the state. "I was ready to submit it and it sat on my desk for weeks. I asked myself, 'Are you ready to do this? Are you really, really ready to do this?' I felt like if I didn't have time to be creative, I would lose my creativity. So I went to a



**Matt Lauterbach, Reveca Torres and Grishma Shah co-directed the Chicago ReelAbilities Film Festival.**

teacher who eventually just became my friend. I was in tears and I said, 'I don't know if I want to do this!' She goes, 'You're a creative person. Whatever you do in your life, you'll bring creativity to it. You will be OK.' And I submitted it."

Not content simply to launch Backbones, Torres focused on ways to keep growing and improving the organization. She moved to Portland, Ore., and completed a certificate program in nonprofit

management and interned with Mercy Corps Northwest. Executive Director John Haines, a quadriplegic himself, remembers her stay fondly. "From the start she was exceptional. She was a step above in terms of motivation, and she had an ability to absorb information on sight."

On top of her dedication and obvious work savvy, Haines says Torres' personality is what separates her from her peers. "Whether she is in a chair or not, she is somebody that people want to be involved with. She has built a wider cadre of supporters and colleagues that benefit from her work," he says.

She designed Backbones to provide the kind of support and opportunities she finds interesting. Another thing she found missing in the transitional years after her accident were social interaction opportunities besides wheelchair sports. So Backbones organizes events that facilitate face-to-face connections. It could be the ReelAbilities film festival or maybe spending a summer afternoon at a Chicago Fire soccer game. Or it could also be a wine tasting in Sacramento, Calif., or a yoga class in Portland, Ore.

While Torres initially worried that her background in the arts had not prepared her to run a nonprofit, she found the opposite to be true. "Doing stuff with theater and the arts, you work with directors and actors and costumers and stage people — all these people have to come together to create this amazing production. Everyone comes to the table with a certain skill. A lot of that transfers over into Backbones. That's one of my favorite parts, seeing what people bring to the table, whether it's volunteers or collaborations with other organizations, just seeing how it all comes together and kind of leaving it open to become what it becomes instead of trying to guide it all the time."

That freedom leads to many of Backbones' most important connections being made online between people who never meet. Mona Pinon of Grants Pass, Ore., connected with Torres after her son, Isaac, was paralyzed by a tumor. "I needed help building a wheelchair accessible playground at my son's school," she says. "Reveca connected me with different people in the spinal cord injury community to



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help me spread the word on the need for accessible playgrounds.” Shortly thereafter Pinon helped organize the Blue Slide Project, which raised \$150,000 to build an all-inclusive playground in her hometown.

Kennedy Nganga [“Painting So Others Can Live,” October 2015] refers to Torres as his “sis/comrade.” Nganga, a talented quad artist who lives in Africa and has gained fame through Facebook, credits Torres with helping him spread the word about his art and philanthropy. In addition to including his paintings in a 2014 Backbones-sponsored exhibit entitled *Unbroken: Art After Spinal Cord Injury*, he says Torres “has also connected me with many of her American friends coming to this part of the world in mission work as well as tourism, and whenever they are around they come to my place. They also bring with them stuff that I may need from the U.S., like art materials, etc.”

Torres says in 2014 Backbones connected over 100 people with mentors and fellow travelers through the disability experience. She begins making connections by attempting to talk to everyone seeking Backbones’ help personally, either by

phone or email. She is currently working on developing an app for mobile devices that would facilitate the connection process. She wants to keep growing Backbones to more cities and is looking to find ambassadors to help her do that.

“I’m trying really hard with the things that I do to change a lot of perceptions and make people see that disability isn’t something that should be hidden or pitied or that needs to necessarily always be cured,” she says. Her mere presence as a young, disabled woman of color as the head and founder of a nonprofit for people with disabilities shakes up perceptions. “There have been times when I haven’t been taken seriously. There have been times when I’ve tried to get meetings with certain people and I don’t necessarily get noticed. But then I have a board member do it who’s a white male and he gets attention right away. It’s like, ‘Hmmm.’”

Torres says, “There isn’t a lot of representation of people who look like me in the

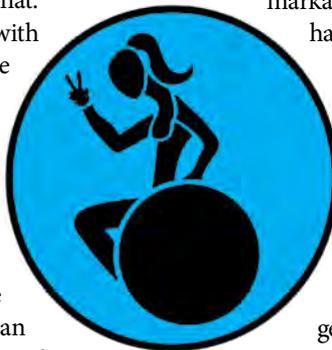
leadership of the disability community. But I think it’s getting better.”

Haines says it would be unwise to underestimate Torres just because she does not fit the traditional profile. “She is remarkably upbeat all the time and has this amazing smile, but she is persistent and strong and she is no pushover,” he says. “When she has an impulse or an idea, she implements it.”

But still, here’s one of the most frequently asked questions Torres gets about Backbones: “Why is your logo a female?” The logo is a variation of something Torres drew in her sketchbook one day when she was riffing on the idea of feminizing the access symbol. The Backbones logo also faces left. The access symbol faces right.

“I feel like I have to do a lot of defending. ‘She has boobs!’ Yes, she does. She’s a woman.”

But why is the Backbones logo a woman? “Because I thought it was time,” she says. NM



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# SELECTIONS FROM Reinventing the Wheel

For the Reinventing the Wheel traveling art exhibit, Reveca Torres paired 21 nondisabled photographers with 21 wheelchair users going about their daily lives. Done in partnership with the National Museum of Health and Medicine Chicago, the exhibit has toured the nation and can be seen in its entirety at [vmuseum.com/rtw](http://vmuseum.com/rtw). To bring Reinventing the Wheel to a gallery or venue near you, contact Backbones, [info@backbonesonline.com](mailto:info@backbonesonline.com).



## Ashley Schahfer

Currently an architecture student at Portland State University in Oregon, T12 para Ashley Schahfer says she'll make any excuse to go outside. Photo by Giles Clement/[www.gilescllement.com](http://www.gilescllement.com)

## Joel Brown

A professional dancer with Oakland, Calif.-based AXIS Dance Company, Joel Brown, a T4 para, appeared on *So You Think You Can Dance* in August 2012. Photo by Allen Myers/[www.nomadsight.com](http://www.nomadsight.com)



## Josh Spencer

Owner and operator of Los Angeles' The Last Book Store, Josh Spencer, a T11-12 para, has always been fascinated with books, especially the Bible. Photo by Neil Kremer/[www.kremerjohnson.com](http://www.kremerjohnson.com)



## Katie Terry

Through Adaptive Athletics, Katie Terry, a T12-L1 para, discovered her love for downhill skiing and handcycling. Photo by Angelina Giles/[www.saansphotography.com](http://www.saansphotography.com)



### **Russell Moon**

A 2011 car accident brought dentist Russell Moon a C2-3 injury and severe depression, "which made me realize I needed to get on with my life," says Moon. Photo by Dominic Greco/[www.domgrecofoto.com](http://www.domgrecofoto.com)



### **Marcela Turnage**

Marcela Turnage, a para and above-the-knee amputee, enjoys time with her husband, Gabriel, and their daughter, Mikaela. Photo by Sean Dackermann/[www.seandackermann.com](http://www.seandackermann.com)



### **Miriam Pare**

Professional mouth artist Miriam Pare, a C5-6 quad, is a founding member of STEAM Studios, which provides art education in Chicago's underserved communities. Photo by Jessica Pierotti/[www.howcouldiknow.com](http://www.howcouldiknow.com)



### **Jerry McGill**

Born in Brooklyn, raised in Manhattan, and now living in Oregon, Jerry McGill, a quad, has written and produced several one-act plays and has taught playwriting. Photo by Francisco Xavier Vargas/[www.fxvargas.com](http://www.fxvargas.com)



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## MY TAKE

Historic cities tend to be dismissed by people with mobility issues, given the conflict between accessibility and antiquity; however, RVA has found ways to marry the two rather eloquently — for the most part. As a lifelong resident and a wheelchair user for the last seven years, I can't say Richmond is the quintessential model for accessibility. But it is the capital of Southern hospitality, which translates to good-hearted accommodations — if an issue is brought to light, it is solved reasonably. People here care. They care about their history, their eclectic, nationally recognized food scene, entertainment, and they don't want anyone to be excluded from enjoying all of it, including those with mobility impairments. This consideration is evidenced in Governor Terry McAuliffe's office recently extending an invitation to representatives of the United Spinal Association of Vir-

## SKINNY ON THE CITY

Richmond, Va., affectionately known by its residents as "RVA," is a large town that covers the spectrum from historic to modern within its cozy boundaries. Steeped in a rich history highlighted by Revolutionary landmarks, numerous Civil War-era points of interest, and much more, Richmond has embraced its past while looking forward.



Photo Courtesy of visitrichmondva.com

ginia to privately tour the governor's mansion and discuss viable ways to make the accessible property even more welcoming to wheelchair users.

Learn about the Virginia Chapter on next page

## PLACES TO GO

While Richmond is an older city with accessibility challenges, the downtown area has been revitalized and includes newer buildings such as the Greater Richmond Convention Center and a performing arts center, Richmond CenterStage. The city is also known for its many restaurants and growing number of craft breweries. But Virginia's accessible variety extends far beyond its capital city. A scenic 90-minute drive west to Shenandoah National Park lands you on Skyline Drive and some of the most majestic mountain scenery on the East Coast. In the winter months, Wintergreen Resort offers many activities for wheelchair users, including adaptive skiing. In the summer months, Virginia Beach boasts a three-mile concrete boardwalk, accessible deep sea fishing adventures, and Grommet Island Park, a one-of-a-kind fully accessible on-beach park. From May through October, Grommet Island Park Beach offers 15,000 square feet packed with an accessible playground and tons of fun, accessible activities for kids with all types of disabilities. Beach wheelchairs are also available for daily use.

## GETTING AROUND

Transportation in and around Richmond, and subsequently the state, is easy if you have a vehicle you can drive. Accessible parking is on par with most cities, if not

more abundant, further eased by free metered parking with handicap plates or a placard. The state also offers free E-Z Pass transponders for those who may have difficulty with tolls. When public transportation is needed, Richmond operates the Greater Richmond Transit Company, a fully accessible bus system. The GRTC also offers door-to-door service for people with mobility impairments through a program called CARE Van, which unfortunately has come under heavy fire for poor scheduling and lack of reliability.

## MUST SEE, MUST DO

Historical sites and landmarks abound in Richmond. Fully accessible, historic St. John's Church, the site of Patrick Henry's "Give me liberty or give me death" speech, has been beautifully preserved. Tours cost \$8 for adults, and group rates are available. For a more low-key endeavor, you can cruise Monument Avenue and the beautiful sculptures of Confederate Generals Robert E. Lee and Thomas "Stonewall" Jackson, as well as other Richmond notables, like tennis pioneer Arthur Ashe and 19th Century oceanographer, Matthew Fontaine Maury. The street was named one of the 10 Great Streets in America by the American Planning Association in 2007 and is on the National Register of Historic Places.

## AVAILABLE HEALTH CARE

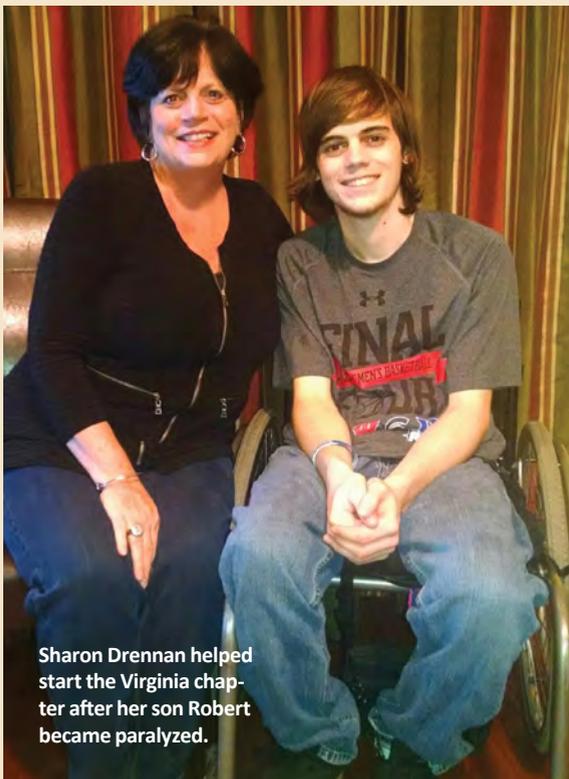
Virginia Commonwealth University Health System provides the Richmond area with a one stop system for diagnosing and treating spinal cord injuries and neurological diseases. From the moment of injury to inpatient rehabilitation, outpatient rehab, and research, VCUHS does a god job of helping people with SCI/D attain their highest potential level of independence and then maintain it. The physical medicine and rehabilitation department is a well-established award-winning program led by United Spinal Association of Virginia board member, Dr. William McKinley.

## Virginia Launches Chapter to Fill Void for SCI/D Community

As United Spinal's director of chapter relations, Nick LiBassi is always looking for ways to connect the organization with new and established SCI/D groups around the country and expand the United Spinal network. Sometimes that role goes beyond simply connecting with existing groups and helping interested parties found new chapters. So when LiBassi kept hearing about the need for some sort of SCI/D group in Virginia, he set the wheels in motion for the new Virginia chapter of United Spinal.

"After countless conversations with people from Virginia, it became clear to me that there was a need for some sort of organization to support people there with SCI/D," says LiBassi. "I started thinking about people I know in the area who might be interested and capable of starting a chapter and taking on that responsibility. That's when I came up with Sharon."

LiBassi is referring to Sharon Drennan, a United Spinal member who lives in Richmond. Drennan got involved with a different chapter when her son was paralyzed after surgery to remove a mass on his back six years ago. Drennan had a background in nonprofits and happened to be job hunting. "It felt like the uni-



Sharon Drennan helped start the Virginia chapter after her son Robert became paralyzed.



This artist's rendering shows a proposed ramp to make the governor's mansion more accessible.

verse was saying go do this," she recalls. "But, I didn't want to take that leap of faith without knowing I was going to have some organizational support behind me."

To that end, she and some local nurses gathered a group of local stakeholders — people with SCI/D, nurses, therapists, community activists — and hashed out the idea of starting a chapter. There had been a chapter in the area but it closed down in 2013. "There was a tremendous amount of positive response," says Drennan. "It was so exciting. Everybody signed up for something. It was clear that the community needed this and was going to get behind it."

All of this happened in just a little over a month in the fall of 2015, and the frenetic pace didn't slow down. Since that initial meeting in early October, the chapter has obtained its 501(c)3 status, solidified its board, settled into office space in a building owned by Virginia Commonwealth University Health System, the local trauma and rehab center, and presented all around the

state, looking to sign up members. "We've done a lot in a short time," says Drennan.

That's not even including a trip to the governor's mansion to consult on the design of a new accessible entrance. The governor was spurred to action after a visit from a group of wounded warriors highlighted the historical mansion's inaccessibility. "In order for these disabled veterans to have access to the mansion, they had to go around, through the back door, through a utility room and into an elevator ... it wasn't received very well," she says.

The chapter held its first monthly meeting in November and is excited about launching its first program — a peer mentoring/family support program. United Spinal's Lindsey Elliott will host a training and certification for the chapter in January, and Drennan envisions the program growing rapidly from there.

Looking back on the whirlwind of the last few months, Drennan is proud of what the group has accomplished and how the process of forming the chapter worked. "There was a void, we stepped up to fill it and it's happening quickly," she says. "What's inspiring to me is that people spoke up. Nurses and therapists said to Nick, we need this in Virginia and we don't have it. The system and the process worked. The national organization got word from a community that was in need, Nick reached out and it came together."

## Oklahoma Chapter Pushes for Foot Safety

There isn't much that is sexy about foot safety, but that doesn't mean it's not important. The Oklahoma chapter is working hard to raise awareness about just how important it is for wheelchair users and people with spinal cord injuries and disorders to make sure that their footplates are safe and don't unnecessarily endanger their health. "We're trying to start a discussion about the alarming rate of injuries caused by the rotating front casters on certain power wheelchairs," says Willis Washington, chapter president. "It's amazing, almost every person you talk to says, 'Yeah, I've gotten my foot caught.'"

Washington says that based on a number of casual conversations with users of qualifying power chairs, almost half of them said they had caught their feet in the casters or received medical care to treat injuries suffered. That includes a number of extended hospitalizations for injuries that required multiple visits. Washington and the chapter recently presented their findings to the Rehabilitation Engineering and Assistive Technology Society of North America in hopes of enlisting the organization's support and expertise about solving the problem. The decision to take the issue to RESNA came after the chapter received a disappointing amount of interest from manufacturers. "If we can't get the manufacturers or the contractors to do anything, we decided we had to go above them," says Washington. "Hopefully this will make a difference in the end."

Washington's presentation explained the problems with a series of pictures showing how easy it is for users' feet to slip off the footplate and get caught in the casters. It also showed a simple possible fix that RESNA could push manufacturers to include in future designs. "We got a really positive reception," says Washington. "We just need to keep on this, keep raising awareness and working to better define the number of injuries." The chapter is looking for any wheelchair users who have experienced similar issues to get in touch and share their stories. You can contact them through [neuroresourcesoutreach.org](http://neuroresourcesoutreach.org) or on Facebook at [on.fb.me/1R1ro7T](https://www.facebook.com/on.fb.me/1R1ro7T).

## Keeping up the Fight for Ride Sharing Access

United Spinal continues to be at the front of the battle to ensure Uber, the fast-growing ride share company, provides access for wheelers.



Uber should give all riders the same options, says Dustin Jones.

In response to complaints about the company's lack of wheelchair accessible vehicles in Washington, D.C., on Dec. 11, Uber announced the rollout of UberTaxi. As announced, the program promises Uber will partner with D.C. cab drivers who have wheelchair accessible vehicles. United Spinal's Carol Tyson told the *Washington Business Journal* that the new service is "inadequate and unsustainable."

"What we'd like them to do is find a way to increase the number of accessible vehicles rather than using what we have," said Tyson, who is also the chair of the D.C. Taxicab Commission's Accessibility Advisory Committee.

A day earlier, as part of a celebration of Human Rights Day, United Spinal organized a protest at Uber's Manhattan office to demand the company makes all of its black cars accessible. "We deserve to have the same options as nondisabled people," wheelchair user Dustin Jones told *amNewYork*. "It's insulting almost ... Uber is a \$60 billion company. They can definitely invest in the disability community."

United Spinal President James Weisman also lobbied New York legislators to keep wheelchair users in mind as they consider Uber's proposed expansion to upstate New York. "Before lawmakers give Uber a license to operate in Utica and across the state, they should examine the company's accessibility record in New York City and ask whether they'd be handing over a license to discriminate," he said in a statement. "Uber has failed to put even one wheelchair accessible vehicle on the street. Uticans should take this opportunity to demand that the company make its services fully accessible so that everyone has equal access, not just those who can walk."

## Mission

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

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# AJ BROCKMAN:

## *Portrait of an Artist as a Young Quad*

BY ALLEN RUCKER

**A**J Brockman — professional artist, entrepreneur, brew house proprietor, and snappy dresser — grew up on television. At age 3, in his hometown of Palm Beach Gardens, Fla., he was spotted in his power chair and put on camera by someone at the local Jerry Lewis Telethon. As he says now, he was nothing more than “a cute kid in a wheelchair.” For the next 15 years, he worked on the telethon in various capacities, including a five-year stint as a goodwill ambassador, and became a local celebrity. He can go back on YouTube and see himself at ages 3, 6, 9, on up to 18. “We’ve seen his whole life documented,” enthused a local anchorman, “from toddler to teenager.”

Now, all of 27, Brockman is a full-time,

largely self-supporting artist, working with the latest digital technology to produce elegant, sure-handed representational paintings. Fleeting fame with Jerry Lewis had little to do with it. Born with spinal muscular atrophy, he developed a passion for art and learned to use ever-advancing digital technology to forge his own artistic path and live life on his own terms.

With a mellifluous voice, he set out to be a broadcaster of some sort, but according to his mom and current business partner, Jo Brockman, he was introduced to art by an inspiring middle school teacher who had no interest in excusing his disability. In the beginning, he had use of his hands to manipulate a paint brush and work on canvas with acrylics. Because SMA

is a progressive disorder, by the time he reached high school, his hand movement had diminished. In his own bio, he describes what happened next:

“While registering for classes in high school ... I came across a brand new elective course called commercial art technology [i.e., digital graphic design], and I thought it would be an interesting alternative to learning French or joining the volleyball team. As it turned out, the class was more than just interesting. It was a game changer.” Brockman had found his *métier*.

As his art days were beginning, his telethon days were ending. Asked about the experience now, he says, “I always considered myself to be very comfortable

One of AJ Brockman's professors said, "He was more ambitious than 10 of my other students put together."



in front of a camera and at one point wanted to pursue broadcasting as a career, so my involvement with the telethon was a bit opportunistic." He loved the MDA Summer Camp most of all, and at 15 he even hosted the local telecast — a Jerry in training? No, it was some local firefighters, not Jerry, who drew him to the event. "At the end of the day," he says, "Jerry Lewis did a tremendous job in raising awareness and funds. Whether it was patronizing or not, there is no such thing as bad publicity."

Jo Brockman says that AJ has always been a risk taker. "He doesn't see himself as disabled at all," she says. "A perfect analogy was when he announced he wanted to play hockey in school. 'How are you going to do that?' I asked. 'I can do it, Mom,' he replied. 'I can be the goalie!'"

Because Jo was a nurse and had insurance — a huge factor, she says — AJ got the best health care possible, and when her insurance couldn't cover something, others stepped up to help. His critical back-straightening operation at 12 was funded by the local Shriners. He went to the top of his class in high school and was valedictorian of his college class at the Digital Media Arts College in Boca Raton, Fla. He was on a mission. One of his college professors was later quoted as saying that "he was more ambitious than 10 of my other students put together."

In Brockman's words, "Dedication, hard work, and perseverance have always been super important to me." His mantra: "The message is, 100 percent, not having an excuse ... If I can have the drive, there is no reason or excuse why you can't follow your dream and stop working the 9-to-5 job at McDonald's you hate."

No doubt helped by all of that MDA camera time, Brockman puts himself out there. His mother says, "You cannot *not* like the boy." He was awarded the Distinguished Artist Award by his college professors. After he graduated, they invited him back to be the commencement speaker and helped spread his name around as he searched for work. He landed a job working for Vision Haus, a commercial design studio turning out artful brochures and ad campaigns. And he lived and prospered happily ever after? No, after three years, he quit.

## Into the Unknown

He didn't like doing work on demand and made a huge and potentially disastrous leap from commercial art to fine art. You can count the number of successful fine artists in America on two hands and one foot, and you can count the number of successful artists with a disability on two or three fingers, or in Brockman's case, one finger and a joystick. The art racket is hard. Damn hard. In addition to having to make art that people might want to buy, he says, "you have to learn to be a great business person and marketer because that is half the battle in the art world. It's more about how well you get your name out there and treat your work like an actual business, not a hobby."

Brockman set out to do just that. His mother sold all of her gold belongings to help finance his new dream. His work certainly seemed marketable — portraits, oceanscapes and dogs are prevalent in his portfolio. As the technology constantly improved, his ability to use visual apps like Corel Painter 10 and Adobe Photoshop expanded his aesthetic tool bag. But the tech was just the vehicle. It's all in the eye. Technology without talent, dedication, drive and vision is like you and me making stick figures on our 11-inch MacBook Air.

Describing art, including Brockman's, is tricky. It's much like describing music, or as artist/actor Martin Mull once quipped, "Writing about music is like dancing about architecture." Brockman's art shop is called Single Handed Studio. You can go to his website, [singlehandedstudio.com](http://singlehandedstudio.com), to see his work and a video demonstration of his technique. A fellow



President Obama was blown away by the portrait of his family that AJ and his mother presented to him as a gift. It's now hanging in the White House family quarters.

South Florida artist, Craig McInnis, sums up Brockman's style like this:

"What I love about AJ's work is, besides the fact that it is created with top-notch skill, regardless of his disability, is the warmth and magic that it projects ... the use of color, the pallet choices, the balance, and of course the passion."

McInnis also points out that Brockman is compassionate, funny and cuts a dandy-esque figure. "He can always be found with a cool hat, his curly mustache, funky shoes, and cutting edge tattoos."

But back to the art biz. To do in-person sales at an outdoor, weekend art fair or the like, Brockman had to get somewhere at four in the morning, set up, hawk his wares all day, and hope to make enough to cover his expenses with a little profit left over. Being on the road like that is a drag for anyone, but for someone with his condition, it's also a potential health risk.

Established art galleries are even worse. Assuming you find a reputable one to exhibit your work, they will demand an onerous commission of anywhere from 25 to 60 percent, before you subtract your own expenses — transferring images from computer programs to wall art, framing, delivering and promoting. The art dealers always walk away with a healthy profit. You don't. Ever enterprising, Brockman kept looking around for a way to promote his name and his work.

## Brush with Fame and a New Venture

In 2012, President Obama was in South Florida campaigning for his second term as president. Brockman traveled to a campaign stop and managed to shake his hand and present him with a painting. The painting, created from a photograph, featured the entire first family, including Bo the dog. President Obama was blown away. He handed the painting to an aide and told Brockman it would fly back with him in Air Force One and find a home in the White House family quarters. That sounded exactly like what a president would say and never do.

Later, a news photographer grabbed a shot of one of Obama's assistants carrying the large Brockman painting onto Air Force One. The portrait was fully visible

and the photo was soon in newspapers all over the country. If that wasn't enough of a thrill, the same photo was later selected for The New York Times' coveted collection, "2012: The Year in Pictures." Brockman's work was immortalized.

This made him proud, but not an overnight art world phenom. He still faced the same barriers as every other young artist. He had a brainstorm. Since he and other local artists needed a place to exhibit and sell their art, and he had a condition that would progressively limit

set of thorny interpersonal problems. As Jo says, "What 27 year old wants to spend all of their time with their mom?" Conversely, what mom would want to do the same with her precocious artist/entrepreneur son? Jo is also the managing partner of The Brewhouse, the person who orders up the kegs and pays the bills. Hard-nosed capitalist by day, generous caregiver by night. All said, she appears to be as indefatigable as her talented son. As they both have a major stake in the place, her final word on the Brewhouse is: "I'm go-



The Brewhouse Gallery is a unique blend of art gallery, coffeeshop and bar. Says Brockman's mom, "I'm going to franchise this thing."

what he could do, why not start a coffee/beer emporium of sorts that is both a permanent revolving art gallery and a great place to hang out? As another wit once pronounced: "The business of art is the art of business." You could put that little dictum on Brockman's tombstone.

Again with the help of AJ's tireless mother, Jo, and a timely investment from a generous stepbrother in Colorado, the Brewhouse Gallery was born. Within a year of its opening in May 2014, the Lake Park, Fla., destination had taken off. According to Jo, The Brewhouse has expanded from a venue of 1,000 square feet to one of 4,000 square feet, enough space to fill a calendar of eclectic events. During the day, the draw is soy milk lattes and art gazing. At night, the lights dim for beer and musical performances, poetry readings, or board game or trivia night. Full-time art gallery aside, The Brewhouse is a gathering place for every other fun-loving hipster from Palm Bay to Fort Lauderdale.

AJ is the star and the dreamer here, but his mom, Jo, a single mother and nurse, is the rock. She is his single caregiver, which is wonderful in itself, but invites its own

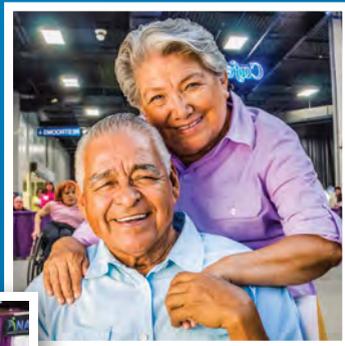
ing to franchise this thing."

Because SMA is progressive, Brockman is forever faced with having to adapt his work, and his life, to a changing body. What will he do when he has zero movement in his arms and fingers? "If it happens, it happens. I'll deal with it and move on ... I'll figure out something I can do with my eyes, or maybe the technology will have progressed so much that I can just talk into the computer" — and tell it how to draw or paint.

There is no formula for a life like AJ Brockman's, but if you tried to create one, it would certainly require one or all of these elements: perseverance, a mom for the ages, love of risk-taking, and the ability to use everything you can get your hands on — even a voice-activated computer that can paint like Picasso — in the quest for personal fulfillment. If you want further illumination, I suggest that you take a trip down South, drop by the Brewhouse Gallery in Lake Park, Fla. — open 12 p.m. to 12 a.m., Tuesday through Sunday — and bend the ear of the resident artist in the wheelchair. **MI**

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# HELPFUL TIPS FOR HEALTHY LUNGS

BY RICHARD HOLICKY

In the 15 years since Nicole Miller sustained a spinal cord injury at the C1-5 levels, she has battled respiratory distress and pneumonia almost every year. Miller, a 35-year-old quad who works as the outpatient clinical care counselor at Craig Hospital, has dealt with collapsed lungs, MRSA, complications from esophageal surgery and the everyday difficulty of clearing her lungs. “I’m prone to mucus plugs, which collapse the lung,” she says. “I was in the ICU on a trach when I got my first pneumonia, shortly after the initial surgery. The pneumonia came with MRSA, which has been an ongoing problem, as it flares up every time I run into lung problems.” Like many people with SCI/D, Miller’s main problem is simply not having the lung power to expel the secretions, which often leads to respiratory distress and pneumonia.

While respiratory diseases account for only 3 percent of all deaths in the general population, those same respiratory diseases account for more than 22 percent of all deaths in people with long-term SCI. And that’s only part of the picture according to Dr. Stephen Burns, who is the director of the SCI Service at the VA Puget Sound Health Care System and an associate professor at the University of Washington Department of Rehabilitation Medicine. “Because people die at a somewhat younger age with SCI, especially those with higher level injuries, the actual difference in risk is much greater,” he says. “The average person with an SCI’s risk of dying of pneumonia is 37 times higher than in the general population.”

Those statistics raise the questions: What are the causes of SCI respiratory diseases (especially pneumonia)? What is most effective in treating pneumonia once you contract it? And what can we do to prevent respiratory diseases?

## THE BASICS OF BREATHING

Respiratory infections are much more prevalent for people with SCI and neuromuscular disease due to the mechanics of

breathing. The main muscle used in breathing in (inspiration) is the diaphragm, which is innervated at C3-5. People with central nervous systems compromised above C3 usually require a ventilator for breathing, while people with C3-5 injuries are able to take small breaths. Those with impairments below C5 are able to take deeper breaths.

However, infection problems often stem from the inability to adequately move air out of the lungs (expiration). Expiration requires both intercostal and abdominal muscles to squeeze the ribs together and expel the air. Under normal conditions most wheelers have little problem doing so. But quads like Miller, as well as paras with injuries as low as T12, often experience compromised ability to cough. Without the ability to cough, people are unable to adequately clear the mucus produced daily. This can block the airways and prevent the lungs from absorbing oxygen, and can result in atelectasis, the collapse of part of a lung, as well as open the door to infections.

## STAYING AHEAD OF SECRETIONS

In order to expel mucus before breathing becomes impossible and infections develop, wheelers may need to resort to multiple options to expel secretions, none of which are pleasant. Most require assistance from a friend, caregiver or healthcare professional.

Quad coughing, which usually involves the wheeler lying flat while someone presses hard inward and upward on the abdomen to simulate coughing, is probably the most common solution for wheelers in need. It can mobilize and expel mucus but is only about 50 percent as effective as a nondisabled cough. Quad coughing is also often anxiety-provoking for those who have never done it before, but learning comes quickly and most eventually feel comfortable performing it.

Suctioning is an option for more serious mucus buildups, but it comes with increased invasiveness, as someone removes the

## DOES MEDICAL MARIJUANA HARM LUNGS?

Given the widespread availability of medical marijuana across the country, it seemed prudent to ask about the wisdom of imbibing in this alternative medical approach. Responses were mixed, though all cited ethical concerns. No professional recommended or condoned use; all discouraged smoking. Burns suggested that while the evidence regarding smoking is not nearly as definitive and clearcut as for cigarettes, he did say, "Smoking will cause harm, perhaps enough to set off an episode."

He quickly pointed to alternative delivery systems, including vaping, edibles and tinctures/oils, all of which carry fewer risks of causing breathing problems. Dumont feels that vaping is still degrading the lungs and should be avoided, suggesting that usage should be limited to edibles and tinctures/oils as prescribed. For those using MMJ to address spasticity, know that a particular strain known as CBD, or cannabidiol, is marketed specifically for spasticity and seizures; CBD strains normally do not deliver the euphoric high associated with THC strains.

mucus from the lungs using a suction tube. Not for the faint of heart, suctioning requires skill and is invasive enough to cause trepidation for caregivers and anxiety for recipients.

Enter the mechanical insufflator-exsufflator device made by Philips [formerly available from J.H. Emerson Co.]. Often called a mechanical cough assist, the CoughAssist T70 first inflates the lungs, and then simulates a cough with the air flow reversed. The device requires wearing a mask over the mouth and nose to deliver its punch. Some people use a mouthpiece, or attach it to a trach tube.

For many quads like Miller and Jeff Epp, a 56 year old living with a C5 injury from a diving accident in 2007, the CoughAssist has been a literal and metaphorical breath of fresh air. "It works well," says Epp, who has ended up with a trach twice from post-surgical complications. "I have a routine now and use it to expand my lungs and open up the airways." Miller says she finds the device to be less stressful on her body and more beneficial than either quad coughing or suctioning.

Pam Lauer, a nurse practitioner at Craig Hospital's outpatient clinic, reports, "We have had good success with cough assist devices in both treatment and prevention of pneumonias, especially in our high tetras." Burns reports good success with sending units home with families. Not surprisingly, he says it's strongly preferred over suctioning.

## BRONCHITIS AND PNEUMONIA

Even with proper care, infections can still take hold. Bronchitis and pneumonia are the most common lung infections wheelers face. Both present the problem of expelling mucus build-up. Bronchitis is an infection in the tubes leading to the air sacs (alveoli) in the lungs, while pneumonia is an infection of the alveoli. Neither is pleasant and both are serious, causing significant shortness of breath and difficulty breathing due to chest congestion and the inability to expel secretions. Though chest colds can also compromise breathing, Burns says that most chest colds do not progress into bronchitis or pneumonia.

However, he does say that anyone with a SCI and a cough impairment should be concerned with any type of respiratory distress or problems mobilizing and expelling mucus. "We know two things," he says. "People with SCI are much more likely to contract pneumonia, and if they do, they are much more likely to die from pneumonia. As a result, our VA hospital has a low admission threshold for pneumonia, especially if people have cough impairments and difficulty mobilizing secretions."

Burns' recommendations mirror those of health care professionals connected to Craig Hospital and other facilities familiar with treating SCI. They all recommend a similar approach to chest congestion.

Everyone stresses the necessity and importance of staying hydrated to keep the secretions mobilized, which helps in expelling them. They also find no harm in trying some type of over-the-counter expectorant medication. Keep track of your temperature, pulse and oxygen saturation, and use quad coughs or a cough assist device to clear your lungs. However, should the congestion or chest cold/flu-like symptoms persist or worsen, get thyself to a physician ... quickly. Pneumonia is serious and most likely requires powerful prescription meds and professional medical attention, preferably by someone familiar with neurological conditions.

Pneumonia treatments vary. In addition to suctioning, quad

## SLEEP APNEA

No review of potential respiratory problems would be complete without mention of obstructive sleep apnea, which may affect as many as 40 percent of all people with SCI. Sleep apnea occurs when the throat muscles intermittently relax and block the airway during sleep. In essence, breathing repeatedly stops and starts during sleep, often without any awareness. The most noticeable sign of obstructive sleep apnea is snoring, though others include restless sleep, waking with a dry or sore throat or a headache, and daytime fatigue, sleepiness or not feeling rested after sleeping.

Some of the factors contributing to sleep apnea are obesity, smoking, swallow dysfunctions, being over the age of 50, using alcohol, sedatives or tranquilizers (including baclofen and other anti-spasmodics), family history, nasal congestion, being male and sleeping on one's back.

Proper diagnosis normally requires a night in a sleep lab. The most common lab test records brain activity, eye movements, heart rate, and blood pressure, in addition to oxygen saturation, air movement through your nose while you breathe, snoring, and chest movements to indicate whether the presence of an effort to breathe. Testing can also be done at home to monitor oxygen level through the night, which will normally indicate the more serious forms.

Normal treatment is continuous positive airway pressure, which requires wearing a mask over the mouth and nose to deliver pressurized air, keeping the airways open. CPAP use is normally quite effective — if tolerated. Dumont considers using CPAP at least four hours a night a success. Quads may have more difficulty due to limited hand function for adjusting the mask.

coughing and/or using an MI-E, many suggest a variety of other types of cough assist methods and devices, which are usually quite individualized and specific to each person.

“Every time I got sick, I’d go to the doctor and they’d admit me because we knew what was going to happen,” says Miller. Most of those incidents landed her in ICUs and often required a trach and vent. Her most recent encounter, in 2013, followed an esophageal surgery. Her lungs collapsed. “The guy who was using the ambu bag on me overinflated my lung and popped it like a balloon; more chest tubes. I coded twice. I told them to withdraw care and then suddenly I got better.”

Formally known as intermittent positive pressure breathing, breathing treatments are another option. IPPB uses a mechanical respirator to deliver a controlled pressure of a gas to assist in expanding the lungs as well as deliver aerosol medications. While widespread use is no longer in vogue, professionals at Craig and elsewhere continue to advocate for the efficacy of IPPB use. “Though it’s a relatively old treatment, I like it and often send people home with a disposable device to use,” says Cate McGraw, a nurse practitioner with Denver’s National Jewish Health. Darlene Dumont, manager of respiratory care at Craig Hospital, also recommends it as a way to mobilize secretions and expel them.

“When I was in the hospital they gave me these breathing treat-

ments,” says Epp. “I hated them at first until I realized they worked. They loosened up the gunk in my chest so I could get it out.”

For Beatrice Duran, 35, a C2-4 quad since a motorcycle accident nine years ago, breathing treatments helped but didn’t solve the problem. “I had to stay in the hospital for a week or 10 days each time,” she recalled. “I got breathing treatments every four hours and got suctioned every hour or so. There were times when it felt like I just couldn’t get any air at all.” Four years ago she received a diaphragm pacer, which freed her of both a vent and the yearly bouts with pneumonia she’d been deal-

ing with. Since she got the pacer, she’s been free of pneumonia.

Chest percussion therapy is another method of mobilizing and removing secretions from the lungs. CPT consists of two therapies: percussion and postural drainage. The percussion consists of lightly clapping or tapping on the chest, back, and area under the arms. Vibrating chest vests or wraps can also be used to apply external vibration. Postural drainage removes mucus from specific parts of the lungs using gravity and different body positions to drain the mucus to the bigger airways where it can be expelled. Miller recalls her bed being inverted so that her feet and chest were higher than her head, allowing the mucus to drain to the upper parts of the lungs, making it easier to remove.

Draining the lower lung areas (Continued on page 46)

**“We’ve had good success with cough assist devices in both treatment and prevention of pneumonias.”**

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By Mark E. Smith

## DME Funding Problem: How to Get What You Need

Over the years, I've written about countless innovative products in this column, mostly in the mobility realm. However, right around the time I started this column in 2007, mobility funding began getting slashed. Year after year, funding has decreased or codes have changed, making it more difficult to get the mobility products we need. In fact, at this writing, we're on pins and needles at year's end waiting to see if Congress rescinds Medicare's scheduled Jan. 1, 2016, funding cuts that may affect 171 complex rehab manual and power chair components.

However, as with funding cuts in recent years — and yes, we arguably live in a tougher time than ever when it comes to access to mobility funding — all is not without hope. In fact, by understanding basic funding policy, debunking funding mythology and using self-advocacy, you'll be amazed at how many presumed funding denials become possible funding approvals.

### Debunking the 'Medicare-Rules-All' Myth

Ask most people who are familiar with mobility funding, and they'll tell you how omnipotent and restrictive Medicare is: *Medicare sets mobility funding policy; they only fund mobility for in the home; and they don't fund features like power elevating seats.* We've all heard and been told this, right?

Here's the problem with that line of thinking. For most complex rehab users, it doesn't apply. With few exceptions, most complex rehab beneficiaries don't have Medicare as their primary insurer. Most have a state's Medicaid, private insurance, workers compensation, or Veterans Affairs benefits. Therefore, while Medicare is the most vocal and recognized policy

that affects mobility funding, it's not applicable toward many complex rehab users under age 65.

Fortunately for these complex rehab users, individual state Medicaid programs, private insurers, workers compensation, and the VA are typically far more considerate of aspects like use outside of the home, quality-of-life features, etc., than Medicare. So the first move toward maximizing mobility funding is to realize it is far more expansive than Medicare policy for most complex rehab users. That is, let your actual insurance lead you, not Medicare policy.

### The Real World of Funding

Your insurance very well may cover far more than you assume. State Medicaid programs, for example, often consider one's activities of daily living in their entirety, so they not only look at in-home use, but they also often consider your community needs, from school to career to everything in between. The result is that for, say, over-sized knobby tires, if you live in snow country, your state Medicaid may cover them because they look at your overall activities of daily living more than Medicare ever would. The same "big picture" funding approach extends to most private insurers, workers compensation and VA benefits. These funding sources are far more open to considering expanded mobility funding than many realize.

### Elevating Funding Success

Power seat elevation is a fantastic recent example of how dispelling funding myths and applying funding protocols is enhancing lives. For decades, everyone said that power seat elevation wasn't funded, period, because that's Medicare's policy. Everyone accepted it, and users went with-

out the life-enhancing technology.

However, some of us began looking into each state's Medicaid policy on power seat elevation. To our amazement, 46 states have processes that allow beneficiaries to have power seat elevation considered for funding. As word spread, providers and beneficiaries began explaining in their funding submissions that power seat elevation is a vital tool of activities of daily living. The result in a current market sampling is now a 65 percent successful approval rate for power seat elevation nationwide. The impact is proving profound, allowing users to function in the home and community more independently.

### How It's Done

Funding isn't simply *ask and ye shall receive*. Rather, funding is a methodical process, but it's a logical one. Using power seat elevation as a further example, state Medicaid programs and other insurers want to know the *whys* of your needing the feature. Rather than you and your provider just submitting for coverage of power seat elevation, an explanation of how it increases your activities of daily living should be included:



Photo courtesy of Permobil

- Allows safer, independent transfers due to adjustable seat height
- Allows independent shopping by reaching top shelves
- Allows independent access to closets and cabinets in the home
- Allows greater access to work environments vital to your job duties

In short, itemize how and why the technology will benefit you in meaningful ways that are concise and obvious to your activities of daily living. This approach works with items ranging from a power assist system on an ultralight manual chair to an outdoor power chair package, and many technologies in between.

### Stacking Funding Sources

As accommodating as state Medicaid, private insurers, workers compensation, and VA benefits are, they're not always foolproof. Sometimes you will need a back-up plan, technically called a "secondary." For example, say you're on your spouse's insurance, and that plan covers the basics, but denies power seat elevation. You shouldn't stop there. You may qualify for, or already have, Medicaid as a secondary insurance provider that would cover the denied technology. Also, if you're seeking employment, in school, or already employed, state occupational and vocational rehabilitation programs are tremendous funding sources. (When I was in college, my insurer covered my power chair, and vocational rehabilitation covered the lighting package because I had night courses). When needed, a secondary and even a third funding source may cover a denial of equipment.

### What if I do Have Medicare?

For those with traditional Medicare (Part A — hospital coverage), adding Medicare Part B (regular doctor's visits, supplies, etc.) will not cover most items deemed non-medically necessary or for use outside of the home. However, these limitations may not extend to Medicare Part C (more costly), which allows opt-in coverage with private insurers (Medicare Advantage plans). These plans must meet the minimum of Part B, but often also offer durable medical equipment funding beyond basics. Not unlike other insurers, many Medicare Advantage plans have

processes to consider mobility technologies for expanded aspects of activities of daily living. Therefore, even if you have "Medicare," a Part C Advantage plan may liberate you from funding roadblocks by offering more encompassing mobility funding. Advantage plan open enrollment is Oct. 15 through Dec. 7 each year, and researching as much as you can about prospective insurers' DME coverage is vital since there are so many different Advantage plans available.

### No Rarely Means No

When it comes to funding mobility technology, no rarely means no. Going back to where we started on this topic, we need to remove preconceived notions of what's covered and what's not. Instead, as savvy consumer-beneficiaries, let us elect the technology truly needed, state a valid case, and work with all funding source possibilities. By doing this, denials become approvals and we can become part of the latest 65 percent success rate that is still climbing!

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# RAISING A RUCKUS



By Allen Rucker

Even if we're not a real community, we could pretend we're all one big happy tribe if we had a collective acronym — a brand name.

## In Search of the Disability Brand

Ever wonder why “the disability community,” of which you, dear reader, are a member or fellow traveler, is rarely mentioned in public discourse? Compare it to LGBT, an acronym that is now part of the English language but one that people couldn't remember only a few years back. And maybe that's no longer even correct — I've seen LGBTQ thrown around recently. In any case, LGBT is not even that easy to say, has no vowels, rhythm or snap to it, like NAACP or AARP. AARP sounds like an old dog with gum problems, just like many of its members.

The disability community is not a community in the sense that everyone identifies with one single definition of “community.” If you are a member of AARP, for instance, you are old, period. It's tattooed on your forehead. If you belong to MADD, you can't be a dad or a swinging single. The disability collective is a loose, sometimes quarrelsome confederation of cliques where one clique — say, active wheelchair users — is seldom invited to a party thrown by the deaf clique or the autism clique or the Downs clique. Nor does the little people clique often sit around and worry about people with MS because they're pretty sure the MS people aren't sitting around and worrying about them. You get the point. So many disability groups are so completely different from each other that all they have in common is the catch-all term, “disability.” Of course, they do have the common experience

of being ignored or devalued in the nondisabled world at large, but because each has its own little financial and cultural fiefdom, it will take someone of the stature of Otto von Bismarck to transform them into a single, unified brotherhood (or brother/sisterhood.)

The Ls, Gs, Bs and Ts don't have this problem. They see themselves as a single force with a common political agenda. Individually, they are probably as different as you and your obnoxious brother-in-law, not to mention as different as anyone of the other 56 gender options listed by Facebook — androgynous, pan gender, gender fluid, two-spirit, et al. To my knowledge, Facebook has yet to list 56 disability options.

Even if we're not a real community, we could pretend we're all one big happy tribe if we had a collective acronym — a brand name — that stuck in people's heads. Unlike LGBT or MADD or the PTA, we can't just use the first letters of participating subgroups or you'd end up with an absurd acronym like ... BDCPMSPQAADATBI.\* And even then, someone would feel left out — “Wait a minute, I don't see an MD in there! What, we're not good enough for the BDCPMSPQAADATBI? Well, we'll just hook up with the chronic traumatic encephalopathy crowd and create the MDCTE! How do you like that?!”

All right, let's all take a deep breath and come up with a catchy acronym to get our collective brand out there. I am open to submissions here, but the

best I could come up with is “Bunch of Disabled-Somethings,” better known as the BOD. You can just hear that rolling off the tongue of the next president of the United States:

“My fellow Americans, it is time that we invite the BOD community into mainstream America, so today I am announcing a new cabinet position — Secretary of BOD Affairs — who will oversee all BOD outreach programs in this administration.”

BOD will get us headlines like “BOD Voting Bloc Could Swing Election” or “BOD Stages Annual BOD Pride Parade.” People will soon be sick of hearing about “those damn BODS all the time” — as Donald Trump has abundantly shown, constantly irritating people is a sure path to massive media coverage.

An expensive Madison Avenue branding expert could probably do better — hey, brand names like Skype or IKEA didn't just appear out of thin air — but I'm not sure. I kind of like being part of the BOD community. It sounds vigorous and healthy, doesn't it? “I saw two great BODS today, one blind, the other in a wheelchair ... they really stick together, those BODS.”

See you at next year's BOD pride parade.

\* BDCPMSPQAADATBI Blind/deaf/CP/MS/paraplegic/quadruplegic/autism/Alzheimers/double amputee, traumatic brain injury ... (add your own letters; it's a work in progress).

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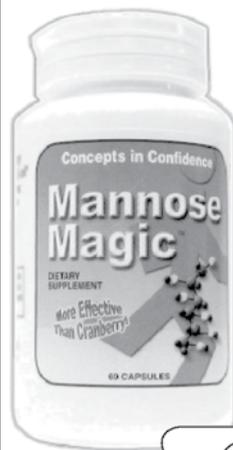


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*HEALTHY LUNGS (Continued from page 41)*

requires the chest area to be tilted 10-20 degrees below the hips by propping firm pillows or cushions under the hips with the head pointed down, usually on a bed. CPT is usually used in conjunction with some type of cough assist, i.e., quad coughing or an MI-E device. Deep breaths should be taken intermittently throughout the treatment to help expand the lungs and strengthen the cough.

Another option is a self-assisted cough, which involves extending the arms above the head and bending forward as far as possible while coughing. An alternative method is wrapping your arms around your trunk just below the rib cage, taking a deep breath and throwing your upper body forward while applying pressure to the abdomen, essentially a self-applied quad cough.

**AN OUNCE OF PREVENTION**

Given their experiences, both Miller and Epp are committed to doing what they can in the way of preventive maintenance. In addition to regular use of the CoughAssist, Miller has also become something of a germophobe. "I try to steer clear of anyone who might be sick and carry hand sanitizer with me all the time. Now that I'm settled in Denver, I'm trying to get established with a pulmonologist."

When it comes to tips for staying ahead of chest congestion, there are few surprises and a lot of common sense. In order to keep secretions mobilized, it's also important to stay mobile,

which means being up in your chair as much as possible, sitting up in bed if possible and when necessary, sleeping with your head elevated.

Don't smoke and avoid second hand smoke. Be aware of high pollution, smog alert days and air quality in general. Try to stay away from people with respiratory infections, and get flu shots annually. Doctors also recommend getting a pneumonia vaccine and getting revaccinated if you are over 65. An additional vaccine has also been developed specifically for the older crowd; consult with your provider regarding timing and current CDC guidelines.

Burns and Dumont both suggest having baseline pulmonary function tests to determine normal oxygen levels and strength of breathing and coughing muscles. Doing so will provide a target in the event of a respiratory infection. **MI**

**RESOURCES:**

- Respiratory Health and Spinal Cord Injury: [www.msctc.org/sci/factsheets/respiratory](http://www.msctc.org/sci/factsheets/respiratory)
- SCI Forum Reports on Respiratory Problems: [sci.washington.edu/info/forums/reports/common\\_respiratory.asp](http://sci.washington.edu/info/forums/reports/common_respiratory.asp)
- Mechanical Insufflator-Exsufflator Device (CoughAssist): [www.usa.philips.com/healthcare/.../coughassist-t70-ventilator](http://www.usa.philips.com/healthcare/.../coughassist-t70-ventilator)
- Sleep Apnea and CPAP Use: [www.mayoclinic.org/diseases-conditions/sleep-apnea/in-depth/cpap/art-20044164](http://www.mayoclinic.org/diseases-conditions/sleep-apnea/in-depth/cpap/art-20044164)

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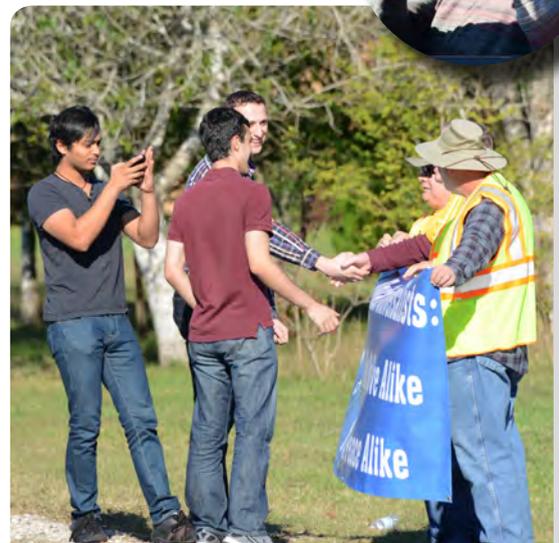
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### INCLUSION, MEET TOLERANCE

Wheelchair user Lydia Nunez greets a member of the Clear Lake Islamic Center at the Love Thy Neighbor rally held by the Bay Area Unitarian Universalist Church. The church and the mosque are neighbors in Houston, Texas, and on Dec. 4, dozens lined the road between the two houses of worship with welcoming messages as members of the mosque showed up for Friday night prayers. Ibrahim Ezghair, associate imam at the mosque, called the event “a really nice gesture.”



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