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First came a 60-foot wheelchair-accessible catamaran called Impossible Dream. Then came Josh Basile, a C4-5 quad with his own dream: a Cuba sailing adventure harking back to the 1950s involving two friends with SCIs, an ESPN film crew, a Pulitzer Prize-winning photographer and his fiancée-to-be. BOB VOGEL takes us on their journey.

Cover and Contents Photos by Carol Guzy
I celebrated my 51st anniversary of the day I became a paraplegic just two days ago as I write this.

It started with a big breakfast — three eggs, three pieces of Canadian bacon and two slices of Dave’s Killer Bread — knowing it would be my last meal of the day. An outpatient surgical suite was waiting for me at Providence Portland Medical Center. I would be getting my first Botox injections in my bladder, and the urologist, a new one for me, insisted that I be anesthetized.

Words that end that way creep me out (hospitalized, anesthetized, euthanized, cannibalized).

My daughter drove me to the joint and they incarcerated me, poked me, sucked my blood, started an IV. A green-suited gnome did an EKG that took all of 3 seconds. I will be charged about $300 for that, if I’m lucky. If you count the time it took the gnome to patch me with electrodes, flick the switch, then rip the electrodes and hair from my chest, it came to 20 seconds, which calculates to $54,000 per hour.

I spent the next two hours waiting in my cell, growing increasingly agitated. My new urologist was, sadly, not on my good guy list. When he first requested my Botox pre-authorization, it was denied. I think he made a poor case for it. So I sent him an official letter asking that he do an expedited appeal, which means a simple phone call to the insurance company doctor who decides these things. They messed up, missed the call appointment and had to schedule it all over again. Weeks later, they finally spoke. I had emailed my urologist my reasons for the appeal. He never responded so I asked his assistant to hand-deliver them. She did, the call happened, and my appeal was approved.

So they scheduled my Botox procedure for another four weeks down the road. I was to go in on the anniversary of my plane crash and be there at 1 p.m. The procedure would take place at 3 p.m. A week before the big day arrived, I received a call. The procedure had been moved back to 5 p.m.

So there I was, waiting in my cell at 5 p.m., and no one had checked on me for over an hour. Finally a nurse entered and told me the doctor had not arrived at the hospital yet and “No,” I said. “I will not stay and I will not wait another minute. I am out of here.” I called my wife, told her to pick me up and discharged myself.

We went directly to a favorite restaurant, drank some good wine, reminisced about the good old days and feasted on a gourmet meal that was both healthy and delicious. I got a little tipsy and felt grateful to be alive — an annual ritual I have grown to honor. Finally, I was properly anniversarized.

— Tim Gilmer
Lilly Longshore became quadriplegic in 2002 from a freak fall at home. She is a mother, a wife and an environmental engineer-turned writer/speaker/advocate for those with physical disabilities and vision impairments. She is a Washington state governor’s appointee to the Governor’s Committee for Disability Issues and Employment and follows her passions by traveling and writing about wheelchair accessible travel, sharing the world of possibilities. Longshore has recently completed her memoir, Crazy, Blind Unmovable Love, and hopes to publish it this year. You can learn more about her at www.lillylongshore.com.

Two years post-spinal cord injury, Richard Holicky got his start with NM in 1991 following a chance encounter with Barry Corbet, and he has contributed stories every year since. He wrote for Craig Rehabilitation Hospital’s research department, at first full-time, and as a consultant from 1997 until 2014. In 2010 he was instrumental in creating, then facilitating the three-part Reinventing Yourself study, which focuses on wheelers new and old, and family caregivers. Holicky has also penned an SCI caregiver’s manual and Roll Models, a “survivor’s manual” for people with new spinal cord injuries.

When she’s not freelancing, Paula Larson does marketing for the Tacoma Nature Center and leads recreation activities for people with intellectual disabilities and developmental delay. She has lived a wide-ranging career life, having worked as a wildlife biologist, an orthotist, a stand-up comic, a prune picker and a kennel worker, among other things. She likes to garden, play basketball and tennis, kayak, bird watch, camp and generally enjoy things. Larson lives in Tacoma, Washington, with her spouse, Julie, and their elderly but always feisty cat, Ursula.

Sonny Ali founded the Sacramento Spinal Foundation in 2015, just months after he was paralyzed in December 2014. Prior to his injury, Ali was given the Community Values Award by Mayor Christopher Cabaldon for his commitment to the City of West Sacramento, and for creating an online community dedicated to improving neighborhoods, parks and open spaces for the residents and businesses within the city. Ali has always had a passion for mentoring, coaching (sports), and leveraging innovative technologies to improve lives, and he has continued to do so after his injury.
Praise for Atlantis
I strongly disagree with a reader’s comment — “Sounds like my trip to Mexico, no accessibility anywhere” — on the NM website regarding my article (“Discovering the (Mostly) Accessible Atlantis Resort,” June 2016): On the contrary, Atlantis was incredibly accessible. The management and staff not only listened to my concerns but actually changed policies and incorporated suggestions to improve access. They exceeded standard ADA accommodations by assisting with transfers, having beach and water wheelchairs, accommodating my needs at the snorkeling and dolphin swim adventures, and propelling my raft through slow areas of their uber-accessible water ride, The Current. Once on this ride, guests never have to leave the water and are propelled in an endless loop of whitewater fun or up a slide tower via water conveyors where they can access two four-story waterslides. I hadn’t been on a water slide since my injury. Their can-do attitude provided access above and beyond any theme park or resort in the United States.

Ellen Stohl
Northridge, California

China Trials
I have long been a fan of the China study efforts (“China Trials Result in Walking,” June 2016). I do think the [trial] design suffers significantly for not having one control group that only gets intensive exercise treatment, yet there probably are some studies of that at this point with chronic SCIs, so perhaps comparing to those is adequate. … Having 55 percent cease use of catheters is astounding — cannot be argued with on any level! But why did none of the Hong Kong participants enjoy similar bowel and bladder improvement? It is puzzling.

Patricia Woodruff
via newmobility.com

Disability ‘Snuff’ Films
(EDITOR: The following exchange on newmobility.com was spurred by Bob Vogel’s blog, “The Inaccurate and Dangerous Message of Me Before You”)

Responsible suicide prevention needs to be an integral part of the larger society. Paralysis, poverty, loneliness, emotional abandonment by others are integral issues of a larger society. Thus we need to be proactive and struggle against the taking of human life!

Elisabeth Alice Ellebogen

However, it is just as important that an individual have control of their own destiny, regardless of the outcome.

Noel Chrzanowski

[Yes], it is important that people have control of their destiny. The problem with movies like this is that they tell society that people with disabilities can’t have control or anything else in their lives to make them worthwhile, so they should spare their loved ones and kill themselves, and that’s a lie. Tim Bowers didn’t even get a chance to see if he could have had a great life; one can’t make an informed choice if you have no idea about what you’re deciding. Most likely what he decided was that he didn’t want to be pathetic and a burden, because that’s what movies show us to be, over and over. But that’s not reality, especially if we have equal rights! We can only control our own destiny if we chose to live … There is no destiny if you’re dead, you’re just dead!

Michelle Steger
via newmobility.com

Stem Cell Hopes
I would just say tread carefully. People can get better on their own (“Stem Cell Trials Show Improved Hand Function, Sensation and Bladder Awareness,” June 2016). I was a quadriplegic from the nose down but within a month or two, I was a T5 paraplegic. Never rely on a significant other for disability-related needs (“Breakup Wakeup” June 2016). Like it or not, no matter how trusting and close you are with your partner, it’s just a bad idea for the relationship. Period.

Linda Ilene Dolphin
via newmobility.com

Partner-Caregivers: A Bad Idea
From many friends I have who rely on attendants, I have learned this: Never rely on a significant other for disability-related needs (“Breakup Wakeup” June 2016). Like it or not, no matter how trusting and close you are with your partner, it’s just a bad idea for the relationship. Period.

Linda Ilene Dolphin
via newmobility.com

Mobility Service Woes
Even so much as a cushion cover can take over a month to get … [and] private paying doesn’t have any effect on the vendors. Being a double above-knee amputee, my power chair is my means of getting around. Let one of these vendors or insurance reps have to depend on a chair and see how their attitude changes. Until you’ve been in our chair, you really don’t get it.

Brian Dalesandro
via newmobility.com

LETTERS

The Atlantis Resort exceeded standard ADA accommodations.
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Chicago Gets Taxi Upgrade
Although Chicago is already a very accessible destination, it is getting ready to ramp up that access a notch with the coming influx of even more accessible taxis to the Windy City.

The city will add 50 MV-1 wheelchair-accessible taxis to its fleet over the next several weeks, which will put the number of accessible Chicago taxis from 160 to 210. And in case you’re not familiar with the MV-1, it’s that same vehicle that’s getting the big thumbs-up from disability advocates in New York City.

These vehicles aren’t retrofitted — they are purpose-built at the factory to be accessible. And that means fewer mechanical problems. It also comes with a ramp that has two options — manual or automatic — which also means fewer service failures. And last but not least, they are huge, with plenty of room for multiple passengers and a mountain of luggage.

The addition of these vehicles puts the city well on the way to its goal of doubling the number of wheelchair-accessible taxis by the end of 2018. To meet that goal taxi companies who have a least 10 medallions are now required to have at least 10 percent of their fleet composed of wheelchair-accessible vehicles. Previously, the requirement was 5 percent of the fleet for companies with 20 medallions.

All this means we’re going to see even more accessible taxis in Chicago in the coming years.

But there’s more news on the access front in Chicago. The folks at Open Doors Organization are working hard to update their online Easy Access Chicago guide. They are busy inspecting properties and compiling information this summer, so look for a new website with updated access information sometime this fall.

— Candy Harrington

ABLE Savings Accounts Available for Some on SSI and/or SSDI
People who are on SSI and/or SSDI who acquired their disabilities before the age of 26 are eligible to open tax-exempt ABLE Accounts under the Stephen Beck Jr. Achieving a Better Life Experience Act, which was passed on Dec. 3, 2014.

An ABLE Account allows savings of up to $14,000 per year, and allows SSI recipients to save up to $100,000 and keep their benefits. In many states, ABLE Account holders can save $300,000 or more and still keep their Medicaid. Money saved in an ABLE Account may be used on such things as education, housing, transportation, employment training and support, assistive technology, personal assistance, and health.

Not every state has rolled out an ABLE Account program, but Ohio’s STABLE program and Nebraska’s ENABLE program are up and running, and are open to anyone eligible for ABLE who lives anywhere in the United States. Visit the below links for more information.

• ABLE National Resource Center, www.ablenrc.org/about/what-are-able-accounts
• Ohio’s STABLE program, www.stableaccount.com
• Nebraska’s ENABLE program, www.enablesavings.com

TRAVELING WITH FREEDOM
I am a quadriplegic that loves to travel and participate in tourism, cultural and gastronomy activities. I get around in a motorized wheelchair and have very little upper limb movement. I depend on others for many activities in my life, including getting in and out of bed, personal hygiene, getting dressed, cooking, etc.

Now with the help of the robotic arm Jaco, I get some of my independence back! It doesn’t matter if I am at home or travelling in a new environment, I can now serve myself something to drink, pick up things when I drop them on the floor, press buttons no matter how high or low they are located, etc.

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Orlando, FL

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Houston, TX
Greg Smith — “the wheelchair dude with attitude” — passed away on June 2 at age 52. He dedicated his life and career to increasing disability awareness through the media and public speaking.

Smith’s Encyclopedia.com entry reads, “As one of two children, Gregory Allen Smith was born to Jim and Adelia Barnes Smith on March 25, 1964 in Bay Springs, Mississippi. His mother was a language arts teacher; his father had been an All-America quarterback at Alcorn University and later coached high school sports and became a business executive. When Smith was 3 years old, the family moved to upstate New York after his father completed his master’s degree and went to work for Corning Glassworks. When Smith was in the fourth grade his father was transferred to Chicago, and Smith spent the rest of his childhood and teen years there.”

Smith was a pioneering disabled broadcaster who discovered his love for radio in high school while working as a play-by-play announcer for football, basketball and baseball games on the student radio station. Smith later attended Arizona State University, where he earned a bachelor of arts in broadcasting and became the sports director on the campus radio station. After graduation, Smith worked as the research and sales promotion director for KTAR/K-Lite Radio in Phoenix, and hosted Cardinal Talk, a call-in show that aired after NFL Cardinals games.

In 1992, Smith started “On A Roll,” which began as a local AM radio show in Phoenix and despite significant obstacles — and, at times, blatant resistance from mainstream media — expanded to air on more than 70 national stations over the next 11 years. In 1999, Smith spoke at the Congressional Black Caucus on disability issues for African Americans and started a web-based discussion group to discuss unique issues facing “double minority” groups. Smith was actively engaging in intersectional advocacy before most people were aware of the concept.

In June 1998, Smith caused a stir among the disability community by having Christopher Reeve, who had just been named vice chairman of the National Organization on Disability, on as a guest. Reeve, who had been paralyzed in a horse riding accident just three years earlier, was a controversial figure in the disability community at the time for his emphasis on curing paralysis rather than giving attention to larger societal and systemic concerns.

Smith told Ragged Edge that representatives for Reeve, who had made the request for Smith to conduct the interview, were concerned that “activists would call in and blast Chris. I assured him that I wanted this to be a bridge-building opportunity. … Activists ‘flamed’ me on the internet for even having Reeve on the show, but I think some people are too impatient. He’s only been a cripple for three years.” If given a chance to evolve, Smith surmised, “I think he’ll shift some of that media spotlight on the true disability experience, on disability rights, legislative issues and things that matter to the lives of all people with disabilities.”

Smith’s instincts were correct.

His public radio commentaries — which aired biweekly on WYSO in Yellow Springs, Ohio, for a year — won second place in the Public Radio News Director’s National Award competition, for Smith’s December 1999 commentary about the animated film Toy Story 2, in which a broken toy is rejected by the child who had previously adored it.

Smith later authored two books, his bestselling memoir, On A Roll: Reflections from America’s Wheelchair Dude with the Winning Attitude and Shut Up! Silencing the Negative Voice Within. A candid documentary detailing his life as a broadcaster, advocate and parent, “On a Roll: Family, Disability & The American Dream” aired on PBS stations around the nation in conjunction with Black History Month in 2005.

During celebrations of the 25th anniversary of the Americans with Disabilities Act on July 26, 2015, Major League Baseball requested that all broadcasts of games that day highlight fans with disabilities in the stands, a campaign initiated by Smith.

“I have been watching baseball on TV my whole life and I have never seen one shot of a fan with a discernible disability,” Smith told The Washington Post. “This gesture by MLB is being celebrated by the disability community as a key milestone. TV time and acknowledgement of our community are important for us to develop disability pride and … put our spin on pop culture.”

On October 6, 2015 Smith had a stroke followed by two cardiac arrests that literally killed him. After resuscitation via CPR, the Mississippi Medicaid Waiver program rejected his request for financial assistance to fund 35 hours per week of personal care assistance (because Smith once helped pay for his daughter’s tuition). While in intensive care, Smith was unable to respond to queries from the Social Security Administration about income he earned as a speaker, and the SSA suspended his benefits.

At the time of his passing, Smith was working on establishing a nonprofit organization in Phoenix to serve as his production facility and residence. He wanted to leave a legacy that would continue producing disability-centered media and be made available to people with disabilities in need of transitional housing upon his death.

Greg Smith’s commitment to helping others develop their own disability pride and his trailblazing efforts as a disabled broadcaster and radio host have earned him a unique place in disability history — a history that he played a valuable role in both chronicling and shaping. He is survived by his parents, Jim and Adelia, two sons, Gregory Allen Smith, Jr., and Donovan James Smith, and a daughter, Berkeley Renee Smith.

— Lawrence Carter-Long

In Memoriam: ‘The Strength Coach’ Greg Smith (1964-2016)
“The world did not have access or expectations for persons with disabilities.”

Accessibility Pioneer

The world that existed before the ADA is still fresh in the mind of J.R. Harding. Paralyzed in a 1982 schoolyard fight, Harding, a C5 quadriplegic, had to work hard for the life he wanted. A friend of high-profile politicians, a speaker, an advocate and an author, Harding has gone on to become one of the most passionate disability advocates in the country.

Harding was a military brat growing up and loved sports, specifically football and rowing. After his injury, he was lost. “All of a sudden the scholarships were gone, and now academics and test scores would play a role,” he says. He ended up being the first person with a significant disability to attend Western Kentucky University.

“Harding eventually transferred to Wright University, where he received an English degree and then his master’s of education. After graduation, he became heavily involved in disability advocacy and policy shaping.

Harding, now 49 and married, has helped contribute to several bills in Florida, where he now lives in Tallahassee. He was a contributing author to the Florida State System University Master Plan and is a two-time U.S. presidential appointee and seven-time Florida gubernatorial appointee. Helping to make voting places, public transportation and other aspects of life more accessible has been his life’s work.

“The world in the 1980s was not very accessible. Leaving the house took a team of friends. Going to the movies, or on a date, only happened through double dating, and then you had to sit in the aisle,” he says. “The world did not have access or expectations for persons with disabilities.”

Pop ‘n Drop — A New Way to Cruise

After 25 years of being paralyzed, Sergio Scognamiglio, a C6 quadriplegic from Crystal Beach, Florida, needed a faster way to get around.

“I needed to keep up with my teenage son when he went out on bike rides,” says Scognamiglio, who also was feeling the inevitable shoulder pain all longtime wheelchair users experience. As a manual wheelchair user, he knew he needed power assistance for long rides.

Since he wasn’t interested in paying an exorbitant amount of money, he invented his own device — a bracket/scooter system that attaches to any manual wheelchair — that he calls the Pop ‘n Drop for the easy way it attaches to a wheelchair. And the biggest selling point? It’s hundreds of dollars cheaper than any competitor.

Scognamiglio created a customized bracket for which he charges $325. Once you have the bracket, you can attach it to an electric scooter, instantly transforming your manual wheelchair into a power chair.

See more: myfastchair.com

Game Fish From Your Chair

Robert, a quadriplegic from Australia, injured 20 years ago, has created a powerful fishing rod holder that enables quadriplegics to enjoy the thrill of fishing by allowing them to reel in their catch seamlessly. Dubbed Reel Keen, this game-fishing rod holder has caught fish up to 15 pounds in weight. Check it out: reelkeen.com.
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Scotland is known for the verdant beauty of its Highlands, its historic stone castles dotting cliffs and countryside — and Nessie, of course. Scotland also offers some of the warmest, friendliest hospitality found in Europe. Its unique geography includes the northern one-third of the Island of Great Britain as well as 790 additional surrounding islands, totaling a land mass roughly the size of the state of South Carolina. Many worthwhile tourist sights are packed into this relatively small area, a good thing for travelers.

Andrea Reaves, a disability advocate in her home state of Arkansas and the mother of a 2-year-old, is the wife of a native Scotsman. She is also a C6-7 quadriplegic due to a car accident as a teenager. Last year she traveled to Scotland with her family using a rigid frame manual chair.

“I wanted to go and see for myself all the things my husband has told me about from his childhood,” Reaves says. “And after having my daughter, I wanted her to meet her family.”

Reaves flew into Glasgow and stayed at the wheelchair-friendly Glasgow Holiday Inn. Only 47 miles east in the capital city of Edinburgh is the most visited tourist destination in Scotland, Edinburgh Castle. “I was amazed at how much they try to accommodate people with disabilities. I thought the wheelchair accessibility was wonderful,” Reaves says. “Many areas throughout the castle were accessible.

Considering we spent eight hours there, I was perfectly fine with the few areas that were not accessible.”

Paul Ralph agrees with Reaves. Ralph is the founder of the United Kingdom’s Disabled Access Day and an affiliate of Euan’s Guide, the fabulous tourist review website for people with disabilities. He is also a native Scotsman who resides in Edinburgh and uses a power chair for mobility. “Edinburgh castle is a really good attraction to visit,” says Ralph, “particularly as it has an excellent mobility vehicle that will take you personally around the site, as and when you need it.”

When Reaves arrived at Edinburgh Castle, staff took her via the accessible van from the parking area to the top of the volcano where the 384,000 square foot castle is sited. She toured gardens, trails and grounds around the castle. Nine sites on the grounds are wheelchair-friendly, including the Crown Room, St. Margaret’s Chapel and the Museum of the Royal Scots.

Located opposite of Edinburgh Castle along the Royal Mile is Holyrood Palace, the main residence of the Kings and Queens of Scots since the 16th century. “Holyrood Palace really goes the extra mile,” says Ralph, “little things like being invited to use the Queen’s private lift to access the upper floors, and discovering with the help of friendly staff that there was a different route leading out of the Abbey that gave ramp access into the building.”

Of the hundreds of castles throughout Scotland, Cawdor Castle, made famous as the setting of Shakespeare’s Macbeth, was also a must-see for Reaves. It is located in the beautiful Scottish Highlands near Inverness.

“I wanted to go there basically because of its history,” says Reaves. “It’s quite accessible … the gardens are full of beautiful flower beds, there’s nature trails. Those areas are all easily wheelchair accessible. There are many areas within the castle that are.”

Near Inverness, Reaves made sure to visit Clava Cairns, an ancient Bronze Age burial mound. The site is located near the town of Inverness and is one of the most important prehistoric sites in Scotland.

Andrea Reaves and her husband pose in front of the famous Greyfriars Bobby statue.

Andrea Reaves and her husband pose in front of the famous Greyfriars Bobby statue.

Andrea Reaves and her husband pose in front of the famous Greyfriars Bobby statue.
Age burial grounds. She needed some help to navigate around tree stumps and across grass, but where there’s a will, there’s a way. “My favorite, favorite TV series is Outlander,” Reaves explains. “I wanted to go to where it was filmed and to some of the sites, like Clava Cairns, where the character Claire touches one of the stones.”

In the TV series, Claire is mysteriously transported from the 1940s to the 1700s by touching a stone at Clava Cairns. “I’m not sure if I touched the exact stone as Claire did, but at least I got to go and touch them.”

HOSPITALITY RULES
Kindness and warm hospitality is a theme that runs through stories from those who have traveled Scotland.

Barry Long, an inspirational speaker and president of Talk and Roll Enterprises, traveled the United Kingdom for five months in 1995. Long, a T5 paraplegic from a motorcycle accident, backpacked in his manual wheelchair re-fitted with common, easy-to-replace bike tires.

“Hospitality overcame inaccessibility,” Long affirms. “I was trying to get from Carlisle, England, to Inverness, Scotland. This Scottish guy saw me along the road and stopped in his Austin Mini — the smallest car in the world,” Long laughs. When Long’s chair wouldn’t fit into the Austin Mini, the man asked Long to wait in a nearby pub and he would send someone back for him. Forty-five minutes and a pint of ale later, in walked the man’s brother — a tree farmer with a truck — who paid Long’s tab and took him all the way to Inverness, a 254-mile ride.

“When I got to the hostel in Inverness, it was up four flights of stairs,” Long remembers. Since the hostel wouldn’t work, the tree farmer took Long to a four-star hotel in Inverness. He even negotiated a lower backpackers’ rate so Long could stay with comfortable accommodations for the next three weeks.

“The hospitality was absolutely fantastic!” His enthusiasm is still strong. “The constable of the town came and took me to distilleries, and to privately owned castles. None of them had ever seen anyone backpacking in a wheelchair before.”

Reaves was also touched by the warm hospitality. “The people — as much as the scenery, beauty, and history of the country — really made the trip great,” Reaves exclaims. “They are a very gift-oriented people. Family and friends would pop into our hotel. Every time, they had chocolates or wine. Everyone that met my daughter brought a gift for her … it’s just a tradition.”

SCOTTISH HERITAGE AND HIGHLIGHTS
The Scottish people are proud of their heritage, which was influenced by a variety of cultures. From invasions by Vikings to wars with England, Scottish history is rich. Six miles east of Inverness, Culloden Battlefield provides an award-winning accessible visitors center where tourists can learn about the last battle fought on British soil. It is where supporters of the House of Stuart, or Jacobites, were defeated in a bloody battle by troops from the House of Hanover in a
fight over the British throne.

“Culloden has a fantastic visitors center,” says Ralph, “and you can wheel out onto the battlefield!”

The battle lines have been redrawn for an accurate depiction of the historic encounter in an interactive display. Films are presented and audio devices are available in multiple languages. Live reenactments take place daily.

After the Battle of Culloden ended, the English banned the wearing of traditional kilts and tartans from 1745 to 1782, as well as the speaking of Scottish Gaelic. But the Highlands culture has survived and Scottish Gaelic is spoken throughout the Culloden Visitors Center displays as well as throughout the Highlands today.

Heading 80 miles southwest of Inverness, past 23-mile-long Loch Ness, reported home of Nessie, is Glencoe. This village resides at the mouth of a glacial valley beside towering volcanoes of the Lochaber Geopark. A Geopark is an area set aside by the United Nations Educational, Scientific and Cultural Organization with the purposes of protecting and promoting the use of geologic heritage in a responsible and sustainable manner. The Locheber Geopark is known as the Outdoor Capitol of the UK.

“The most beautiful area in the world that I’ve seen thus far is Glencoe,” says Reaves. “The mountain peaks, the rivers, the ridges — the whole region was beautiful!” Formed by glacial and volcanic activity, it is truly a unique and picturesque region.

ON THE EDGE OF THE NORTH SEA

Leaving the west coast and heading 170 miles east and slightly north, the town of Aberdeen is situated on Scotland’s east shoreline, on the North Sea. With a population of 197,000, Aberdeen is the third largest city in Scotland. Its tall granite buildings, museums, shops, art galleries and gardens create a mix of great shopping and entertainment, yet it is still one of the best places in Scotland for nature lovers to spot dolphins and other wildlife. According to Ralph, Aberdeen is one of the most accessible towns in Scotland.

“Aberdeen is very good,” says Ralph. “The buses there are accessible, the train station also has good access, and everything is close to Union Street. Union Square shopping center also has a Changing Places toilet [a very large accessible bathroom, which includes a sling lift], which is fantastic. The Aberdeen Maritime Museum is also really impressive and has great access!”

The Maritime Museum displays thousands of years of shipbuilding history with paintings and clipper ship replicas. The history of fishing, sailing and oil and gas drilling in the North Sea is presented. A model of an authentic oil platform is on the third floor, offering outstanding views of the busy harbor and North Sea.

Long made use of public transit — the train — to visit Aberdeen. However, he accidentally got off at the wrong station, landing in a nearby small town. At nightfall, with nowhere else to go and the train pulling away, he went to the nearest business, a pub just closing.

“I knocked on the door and asked if there was a hotel around. The lady just laughed and said, ‘There’s no hotel in this town. But we’ve got a couch. Do you want to stay here?’” Long laughs at the memory. “So I stayed the night in this pub.” The owner opened up the bathroom by taking the door off the hinges, left the taps on and pointed the way to munchies and a fireplace. “I didn’t even know their names and they had absolutely given me their pub.”

Now, that’s hospitality!

Long was also given a key to a McDonald’s in one small Scottish town so he could use the accessible facilities whenever he needed. So his recommendation after traveling through 19 countries? When you get to a new town, look for McDonald’s, Starbucks or other American restaurants. Worldwide, these places almost always have accessible restrooms and even accessible employee showers.

With awe-inspiring sights, welcoming hospitality and more facilities being constructed with accessibility in mind, Scotland truly is a fabulous wheelchair-friendly destination. “I felt they were 20 years ahead of us when it came to wheelchair accessibility,” Reaves says.

And on the occasion that a helping hand is needed, it seems there is always one extended, with sincere Scottish warmth.

RESOURCES

- General tourism in Scotland, www.visitscotland.com

Photo by Disabled Access Day

The kelpies keep watch over Andrea Reaves and her family.

Carlton Hill in central Edinburgh is one of the city’s most iconic locations, site for many photographs, such as this one featuring Paul Ralph.
The Battery Matters

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Peer groups can be great. They can increase life expectancy, decrease depression and improve quality of life. People who have peer support tend to feel less isolated, have more confidence and are more likely to actively participate in the communities we live in.

Those are all great things. The problem is that many of us don’t live in a place where we have access to a peer group that will let us experience all these wonderful benefits. United Spinal Association currently lists 182 support groups in the United States, and while that is a significant number, considering there are millions of wheelers, and support groups are not evenly spread throughout the country, there are still many areas that are unserved.

So when Lynn Murray, Kenny Salvini and Mark Bender each realized there was no peer group for them in their respective communities, they each decided to go for it and start a group that was what they wanted to see in their own community.

None of these men had experience starting (or leading) a peer group, but they didn’t let that stop them. Today these men lead three very different, thriving peer groups in their communities, and they couldn’t be happier about it.

THE PLACERVILLE MOBILITY GROUP

“It became glaringly apparent that there was no way in hell I was going to realize full recovery without having a support group,” says Lynn Murray, founder of Placerville Mobility Support Group in Placerville, California. Murray has a T6 incomplete and T10-11 complete injury from falling off a roof in 2004. There were no peer support groups in the town where he lived, and after attending a few meetings about 30 miles from his home, he concluded that was just too far to travel regularly.

“So I decided to hell with it, I’d get my own game going

Kenny Salvini (right) started a support group near his eastern Washington home when he realized how much there was to learn from other people with spinal cord injuries.
Here,“chuckles Murray, a 69-year-old active retiree who started his group in 2007. “I have found that travel of any kind is one of the challenges that people in wheelchairs and with ambulation challenges face, so the more you can minimize that, the better.”

Murray’s Placerville group started as an SCI support group, but quickly widened focus to be inclusive for everyone with mobility issues. The group is largely focused on doing, with monthly meetings for folks with mobility impairments and their supporters. The group also has a loosely affiliated group of peer supporters who visit hospitals and homes of people new to their injuries.

The Placerville Mobility Support Group has several fundraisers each year, including an annual bike and handcycle ride called “The Hangtown Cranker Classic.” The funds they raise go toward giving financial assistance to wheelers for purchase of durable medical equipment, retrofitting homes for accessibility, and more. They focus on getting people what they need to live the group’s motto: “Get up. Get out. Get Better.”

“One of the things we believe in is to get over yourself and get moving,” explains Murray. “In other words, you have a choice — you can lie in bed and stay in the house all day long and ruin your life and the lives of those around you, or you can get past yourself.”

Members of Murray’s group do what they can to help kick-start lives. He recounts the story of a young man who became a quad as the result of an auto accident. Members of the group did several home visits, but it was a long process before the young man really got his life back on track.

“It took a while, but now he and his mom meet with us monthly,” says Murray. “More importantly, he wants me to go with him to visit high schools in the area and make a presentation about the consequences of poor choices.”

Several years post-injury this man is not only an active participant in the support group, but is also active in the greater community and trying to help others. Murray says this is the embodiment of their motto, and he’s proud to be part of a group that helps people find their way.

“It’s hard to overcome injury. When depression sets in, people need tools to overcome that. It’s almost like AA — you need to have people you can call and say, ‘I’m in a hole, I need a rope.’”

THE HERE AND NOW PROJECT

Thirty-six-year-old Kenny Salvini is a quad who experienced a C3-4 complete injury in a skiing accident in 2004. His closest peer group option was over half an hour away from his home in Sumner, Washington, and he was discouraged to find that it was filled with only paras and “no one that looked like me.”

His opportunities to meet people in the wheeler community were further hampered by non-healing pressure sores. He was a self-described “shut-in” for the first six years post-injury. Then a chance meeting at a fundraiser transformed his life. Salvini met a fellow quad who told him about a chair cushion that was a game changer for his pressure sores.

“I realized then that I needed to connect with as many people as possible because I was obviously not going to learn hands-on...
He and some friends co-founded the Here and Now Project in 2014 to provide a “fellowship of support” for people experiencing paralysis and the people who support them. He suspected that he wasn’t the only person who needed the wisdom and company of peers, and he quickly found that there was a community out there, ready to go.

“The reason the Project works is that the whole community has rallied around this idea,” says Salvini. “We just tapped into something.”

Today Salvini’s Here and Now Project has monthly meetings for folks with mobility issues and their supporters in five different locations, separate caregiver meetings, an annual barbecue and other activities out in the community for fun and public awareness.

“Experience is paramount,” continues Salvini. “You can have talks and lectures and books and all that stuff, but you are not going to take it to heart until you see someone who can say, ‘I know exactly where you’ve been, and it gets better.’”

One of the main goals of the Here and Now Project is to simply allow people the space and time to connect and learn from one another. The group is focused on getting people “wheel to wheel” with other wheelers and to live their motto: “Do Life in the Here and Now.”

“The goal has been to get people under one roof and let the sparks fly,” says Salvini. Here and Now Project members have used those sparks to help one another for everything from day-to-day moral support to advice on how to get benefits that people need to survive. More than one member has come to the group struggling with serious care issues, from unresolved pressure sores to insufficient personal care, and they found that the collective experience of the group has helped guide them and find solutions for their issues.

The Here and Now Project doesn’t require anyone to sign up or officially join. It is a network of peers coming together for each other. Ultimately Salvini views the group as a tool to be used by individuals looking to improve their own lives:

“We are focused on ‘one.’ If we can even have one person make one connection that’s anywhere close to the experiences that I’ve had meeting people, then it’s all worth it.”

**FINDING HUP**

Mark Bender, founder of the group Finding HUP, in Duvall, Washington, had a slightly different reason for starting his peer group. He wanted to play.

The 41-year-old husband and father of four was an avid cyclist and outdoor enthusiast prior to his 2013 body surfing injury. His accident resulted in what he thinks was a C5-6 dislocation and he believes that he’s currently considered a functional C7 — but he’s not positive.

“I know I should know,” laughs Bender, “but I’ve never wanted to focus on the level of injury because it instantly assigns limitations to you.”

As someone who has never been defined by limitations, during his rehab at Craig Hospital in Denver, Bender took full advantage of Craig’s wealth of adaptive recreational equipment.
Kenny Salvini: Stay patient. Sometimes his group’s monthly meetings have consisted of just Salvini and his family, but he committed to meeting monthly regardless. Over time more and more people started coming. “If you can commit to just finding a room, doing it once a month, and show up and advertise it,” he says, “you never know who’s going to come through the door.”

Mark Bender (left): Involve successful people with a broad range of experiences as early as possible. “Getting a board with some outside influences has been very, very helpful,” he says.

Lynn Murray (whose group started out completely on its own before becoming a chapter of United Spinal): Turn to an already established resource. “I would take advantage of an umbrella organization at the early stage.”

But when he returned home to Washington, he quickly became frustrated by his lack of access to the equipment he needed to resume an active life. He also realized that he was not the only one in this predicament.

“It hit me,” says Bender. “There was a problem, a gap, and I had a feeling that I wasn’t the only one in that situation having a problem.”

So in 2014 he founded Finding HUP, a group committed to providing free opportunities and equipment for people with mobility impairments to “get back in the mix” and participate in outdoor recreational activities.

“The concept of Finding HUP is finding encouragement,” says Bender. The group name comes from the term “HUP!” — a word used to encourage cyclists and other racers. “It’s a way to say … you can do this. Being a quadriplegic it seems like [the challenges of] that group can be harder and more discouraging. One of the things that we like to say is ‘Get back in the mix and off the sidelines.’ I want to help people get there. I want to help people find new passions or rekindle something they never thought they’d be able to do again.”

Finding HUP isn’t a traditional peer group. They don’t have meetings — they have experiences, from a weekly handcycle meet-up at a local racetrack to getting together to try out a Mountain Trike. Beyond that, there is peer support and friendship in the midst of all that play.

“When you are doing an activity, I think it helps to pull the focus off the injury,” explains Bender. “When you are
doing the activity and socializing, you forget that you got hurt. A community tied around an activity is very strong, regardless of what that activity is.”

Something else that sets this group apart is that everything is free. Most adaptive recreation activities cost money that participants often cannot afford. Finding HUP has had fundraisers to raise money for equipment and is currently crowdsourcing in an attempt to buy adaptive stand-up paddle boards to share with the community.

“One of my key convictions is that when we do an activity, it is free to the individual,” says Bender. “Being injured I understand the financial strain.”

Through its focus on activity and recreation, the group’s participants are having some life-changing experiences. One member wrote a Facebook post explaining what it meant to him to get to ride bikes with his children for the first time. Another member recently borrowed the group’s Mountain Trike to take his kids to the beach. It was the first time ever that he was able to take his kids out on the sand and share in the fun.

“It literally brought me to tears just to think that I’m helping somebody get out with his two kids for the first time to the beach,” says Bender. “It’s so much bigger than me. It’s helping people live.”

FRINGE BENEFITS

Murray, Salvini and Bender are putting a lot of their time and energy into leading their respective groups, but each of them feels like the experience has given them back much more than they have given. “I get everything from managing The Here and Now Project,” says Salvini. “That’s my joke — everyone thanks me for doing this, but I’m doing it for myself. Every time I meet somebody I learn something new.”

“When you’re out there trying to help other people and not focused on yourself, I think it’s very, very healthy,” says Bender. “It’s what life should be about. The more I reach out to help someone, the further along it helps me in my journey.”

“I’m so damn lucky … I’m just doing what I’m supposed to do,” sums up Murray. “Whatever’s your thing, whatever you’re supposed to do, just do it.”

RESOURCES

- Placerville Mobility Support Group, placervillemobilitysupportgroup.org
- Here and Now Project, hereandnowproject.org
- Finding HUP, findinghup.org
- Wheel Life Peer Support Resources (all wheelchair users), wheel-life.org/connecting-peer-support-group-community/
- Christopher and Dana Reeve Foundation Resources (people with paralysis), www.christopherreeve.org/get-support
- Backbones connections, backbonesonline.com/?page_id=74
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SPOTLIGHT: SACRAMENTO

PLACES TO GO
Sacramento is America’s “farm-to-fork” capital, so eating healthy food is more than a lifestyle choice for most residents. Some of the highest rated restaurants in Northern California are located in Sacramento, and there are plenty of choices between high-end eats or casual dining for pizzas or burgers. My family loves trying new restaurants, and we’re amazed at how accessible the vast majority of restaurants are. There are a few exceptions in historic Old Town, but even there the addition of ramps has made many of the elevated wooden boardwalks accessible. To help facilitate this process, my wife, Jeanette, and I started the Sacramento Spinal Foundation. By raising awareness and advocating for positive change for wheelchair users, we believe the Sacramento Spinal Foundation can be an integral part of legislative and social improvements that will help the large population of people with SCI/D.

HEALTH CARE
Since my injury less than two years ago, finding the right health care was absolutely critical. UC Davis Medical Group is the premiere hospital rehab center in the region. Shriners Northern California is located adjacent to the Davis campus and serves as the Shriners west coast hub for SCI/D. Dr. Holly Zhao, physiatrist and acupuncturist, is well known for her SCI experience, compassion, and dedication in assisting those she works with to make the most gains. For private pay SCI fitness centers, it doesn’t get any better than SCI-FIT Sacramento. The owners, Kayla Robertson and Mike Terrell, have a thorough understanding of how people with spinal cord injuries can achieve personal gains through exercise and movement.

GETTING AROUND
For the most part, public transportation in Sacramento includes buses and light rail, and both are very accessible. What needs significant improvement is traveling across county lines. Sacramento County and Yolo County are separated by the American River. Wheelchair users residing in Yolo County do not have accessible public transit options to get into Sacramento County, even though it’s just across the river. Paratransit doesn’t cross county lines, so other forms of transportation are required. Sacramento Spinal Foundation is partnering with Yellow Cab and other local taxi companies to provide affordable solutions to allow wheelchair users to safely traverse counties for medical appointments or leisure.

MY TAKE
My wife and I left Silicon Valley and moved to Sacramento 15 years ago, well before I sustained an SCI. With all the accessibility improvements the city has made, there’s still room for improvement. Historic buildings and landmarks typically lack wheelchair access, but many of those businesses are starting to listen to the concerns of wheelchair users, and improvements are being made. To help facilitate this process, my wife, Jeanette, and I started the Sacramento Spinal Foundation. By raising awareness and advocating for positive change for wheelchair users, we believe the Sacramento Spinal Foundation can be an integral part of legislative and social improvements that will help the large population of people with SCI/D.

SKINNY ON THE CITY
As the capital of California, Sacramento offers a range of exciting attractions for locals and visitors. Sacramento is known for the capital building, but it also features bike trails, rivers, parks, performing arts, restaurants, shops in historic Old Sacramento and museums like Crocker Art Museum, Governor’s Mansion, Railroad Museum, and California Automobile Museum. Centrally located between Silicon Valley, San Francisco, the Napa vineyards, and the Sierra Mountains, there’s no shortage of things to do. Thankfully, most of Sacramento is very accessible.

MUST SEE, MUST DO
Raley Field is home to the Sacramento River Cats, the Triple-A affiliate of the San Francisco Giants. The stadium is one of the best in Triple-A baseball, and with beautiful views of the city, easy access and a boisterous crowd, you are sure to have a good time.
Sacramento: Networking Is Key to Quality of Life

Sacramento, California, is the largest city in California's Central Valley, but listening to Sonny and Jeanette Ali, founders of the Sacramento Spinal Foundation, talk about their vision for the organization, you would be forgiven for thinking they were in the heart of another famous California valley — Silicon Valley. The husband and wife team have big plans for their nascent organization and are focusing on innovation and networking to ensure their vision becomes a reality.

“We’re trying to network the SCI community with manufacturers and products that can enable them to do more in their daily lives,” explains Sonny.

“I’m trying to get in the hospitals and make inside connections,” adds Jeanette. “It all comes down to outreach awareness and fundraising to be able to give back to the SCI community.”

Like the start-up companies in the valley to the south, Sonny and Jeanette have wasted little time getting things going. Sonny sustained a T5 injury in 2015. Just about a year later, the two founded the Sacramento Spinal Foundation.

“When Sonny was in rehab there was very little information available in the hospital for newly injured people and very little awareness,” says Jeanette. “The rehab here didn’t see providing information about what comes next as a value as it would for someone with MS or who had a stroke.”

The Alis set out to fill that gap by raising awareness and connecting the members of the local SCI community with the abundance of resources around them. Among their plans are efforts to work with local hospitals to improve the discharge process by compiling better listings of appropriate caregivers and more complete listings of local accessible housing options. They are also aggressively pursuing grants from the many California corporations headquartered nearby.

The power couple is relying in part on the connections they built prior to Sonny’s accident while also working to enmesh themselves in the power structure of the state capital. Prior to his injury, Sonny received the Community Values award from the mayor of West Sacramento, and he and Jeanette ran a successful neighborhood website.

The Foundation held its first chapter meeting, focusing on wellness, earlier this summer at a local Round Table Pizza and had a good turnout. “A lot of good information was shared,” says Sonny. The next meeting is focused on independence and is scheduled for Aug. 10 at SCI-Fit Sacramento, a local SCI gym.

The Alis would like to eventually expand their offerings to adaptive sports and get the SCI community more involved in advocating at the state level, but right now Sonny says the chapter’s early success is a little overwhelming.

“It’s got a life of its own and is moving a little faster than we anticipated,” he says. “We didn’t know what we didn’t know. We started it based on a need, and now people are reaching out to us. The calls are coming in and the emails are coming in and the grants are coming in, and we’re just trying to keep up.”
Tribute

Former Executive Director
Gerard ‘Jerry’ Kelly

Gerard “Jerry” Kelly, United Spinal’s executive director from 2002-2005, passed away June 18. Kelly was 70. He waged a brave fight against brain cancer for the past three years. He is survived by his wife Lynn, his daughter Carolyn, son-in-law Mike, and granddaughters Trinity and Faith.

Kelly was a paraplegic veteran who worked as deputy executive director to James J. Peters from 1971-2002. In that role, Kelly managed direct mail fundraising programs, worked closely with our board of directors and with PVA’s board of directors, and lent his mature, thoughtful and gentlemanly nature to all EPVA/United Spinal endeavors. Kelly was a go-to-guy for staff members with problems, and for members with problems, and led the organization through two very difficult transitions: first as Peters’ replacement when he died, and second when the organization transitioned to become United Spinal.

Kelly lived the model that we hope is achievable by all of our members. He was well adjusted to living with a disability, integrated and active in his community, and a good boss. He was a real New Yorker, raised in Queens and educated in Brooklyn. He was committed to making the world a better place for people with spinal cord injury/disease and wheelchair users everywhere.

Those of us who knew Jerry have suffered a great loss. He was a friend, a leader, and a role model.

A memorial mass followed by interment with honors at a military cemetery in the Denver, Colorado, area was held. In lieu of flowers, donations can be made to Porter Hospice, Denver, Colorado (www.porterhospital.org/POH/Home/), or to the charity of your choice.

Midwest Ability Summit

Seven years ago, the Greater Kansas City Spinal Cord Injury Association hosted its first abilities fair in the small lobby of one of the local rehab facilities. As board member Erin Brown remembers, about 25-30 people showed up to interact with a handful of exhibitors. From those humble beginnings it would have been hard for even the biggest optimist to imagine how the event would evolve and grow.

The second year the chapter moved the event to a larger facility, arranged for some demonstrations, put together a panel on consumer education and more than doubled the number of exhibitors. “Around that time, several of our exhibitors commented that there were a number of smaller groups in the area holding similar awareness expos, drawing the same exhibitors and different fragments of the disability crowd,” says Brown. “They asked why we didn’t get together, so we did.” Those unions led to the Kansas City Ability Expo, held at a local mall, and an continued on page 54
EDITOR: In June, 150 members from 33 states — 85 of them wheelchair users — stormed Washington, D.C., to advocate for legislation that improves the quality of life for people with spinal cord injuries and disorders. The event was a huge success, but you don’t have to take our word for it. Here is one member’s experience.

After being paralyzed in a car accident at age 15, I didn’t quite know where my life was headed. At that time, about to be a junior in high school and now paralyzed, I have to admit that I thought my life was just about over. Although I wasn’t sure of what the rest of my life would consist of, I was pretty adamant about the fact that I would never end up doing anything that involved politics or public speaking. That is, until I was introduced to three very important organizations that would change my life forever: Ms. Wheelchair Louisiana, Toastmasters, and United Spinal Association. These organizations made me more aware of my voice, introduced me to politics in a completely different way, and gave me confidence in what I was doing as an individual in order to advocate for the larger disability population.

Growing up I’d heard so many people talk about how our legislators don’t listen and they don’t care, which is part of why I never really wanted to deal with politics as a whole, not to mention, I always found the subject rather boring. My trip to Washington, D.C., for the Roll on Capitol Hill June 26-29 changed my mind completely about politicians.

For the last year, I have been emailing Sen. David Vitter (R-LA) about two Complex Rehab Technology (CRT) bills, asking him to co-sponsor them because it is important to me as a wheelchair user with a C4-5 SCI to maintain and enhance my quality of life. With every email, it seemed, came a negative response. But when I received my schedule for the visits I had during Roll on Capitol Hill, I was pleased to see the word “senator” next to his name — because it meant that I was going to meet with Sen. Vitter instead of his staffers.

When I arrived at his office, two of his staffers stepped into the lobby, and one said, “The senator has been called down to a Judiciary Committee meeting; however, we are going to go downstairs because he is going to step out of the meeting and meet you outside.” Wow! Not only is he taking time out of his day to see me and listen to the concerns and issues I’m bringing to him, but he is going to step out of the meeting and meet me in the hallway?! I think my heart went down to my toes and left me overwhelmed with many different emotions, but I never lost my confidence.

As we were walking out of the door to Sen. Vitter’s office, one of the staffers looked directly into my eyes and said, “You are Jamie.” I almost didn’t know what to say … I was stunned for a second, and then I replied, “Yes sir, that is me.” We conversed back and forth a little bit, and as we were getting off of the elevator, he said to me, “So we know you have been doing quite a bit of work in the state.”

Just a few minutes later, the staffer went to get Sen. Vitter out of his meeting. As the senator walked out the door, it seemed as though he was looking directly at me and headed straight for me because he knew exactly who I was. He said his hellos and I started the conversation by making sure I let him know that a mutual friend said to tell him hello. He just kind of giggled and awaited my conversation. I began talking of the importance of eliminating competitive bidding for CRT and urological supplies, and what it would mean if he would acknowledge the Disability Integration Act.

He seemed to be engaged throughout the whole conversation and expressed how grateful he was for us coming out to meet with him. He said how involved he was with the Steve Gleason Act. He communicated to me that, now seeing the extent of my disability, he can better focus on the literature he has based on the bills we need co-sponsored. This experience made me realize that throughout the time I thought I was being rejected, he was reading my email and looking into what I was asking, who I am and what I’m doing.

Even when it seems as though you are being told no, keep pushing, because you never know what’s going on behind the scenes. At the end of the day, it is always the squeaky wheel that gets the oil.

— JAMIE DUPLECHINE, LOUISIANA

Meeting advocates from around the nation is a highlight of ROCH.

Sen. Vitter discusses the CRT legislation with Jamie Duplechine, right.
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*ROCH 2016 Sponsor Expo Participants*
Josh Basile has a knack for dreaming big and turning his dreams into reality. Case in point, his plan to visit Havana, Cuba, with two friends who are also wheelchair users, to introduce Sling-shot Golf — an adaptive game he invented that enables quadriplegics to play. Getting there took a 90-mile voyage from Key West aboard a chartered 60-foot wheelchair accessible catamaran sailboat aptly named Impossible Dream. Basile planned to propose to his girlfriend while there, and the entire adventure would be documented by an ESPN film crew and photographed by four-time Pulitzer Prize winning photojournalist Carol Guzy.

What they found is that visiting Havana is like wheeling into a 1950s time warp replete with classic cars and beautiful architecture. On the downside, they also found ’50s style communications, outdated architecture and other barriers.
Josh Basile has a knack for dreaming big and turning his dreams into reality. Case in point, his plan to visit Havana, Cuba, with two friends who are also wheelchair users, to introduce Slingshot Golf — an adaptive game he invented that enables quadriplegics to play. Getting there took a 90-mile voyage from Key West aboard a chartered 60-foot wheelchair accessible catamaran sailboat aptly named Impossible Dream. Basile planned to propose to his girlfriend while there, and the entire adventure would be documented by an ESPN film crew and photographed by four-time Pulitzer Prize winning photojournalist Carol Guzy.

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The plan for the trip started fitting together last fall when Chesapeake Region Accessible Boating challenged Basile’s non-profit foundation Determined2Heal and his SCI video mentoring platform SPINALpedia.com to recruit participants for a sail on a fully wheelchair accessible catamaran built with universal design. During the sail the captain mentioned to Basile that he was excited that Cuba would be opening up its borders for sailing. This would be his next destination, and if Basile ever wanted to go, there would be a subsequent opportunity.

The pieces of the puzzle popped into place when Guzy talked with Basile about doing a human interest story for ESPN. She had first met Basile in 2005 while working for the Washington Post on a story about struggling through SCI rehab ("The Spirit the Waves Couldn’t Break"), which led to a follow-up story 10 years later on Basile ("The Way Forward"). The idea of sailing to Cuba to demonstrate Slingshot Golf and
get a view of Cuba from a wheelchair user’s perspective fit perfectly. The marriage proposal to Gabrielle “Gabby” Ahrens was a surprise bonus. However, Ahrens suspected something might be up when Basile scheduled an unexpected meeting with her dad to ask permission for her hand in marriage.

Basile invited two close friends to go on the adventure — Robby Beckman and Colin Buchanan — all of whom shared a bond formed at various stages of rehab. Basile met Beckman when he was first injured. Beckman, 32, a C5-6 incomplete quad from Chesapeake Beach, Maryland, is a quad rugby player and civilian logistics specialist for the F-35 fighter jet. “I was going through a really dark time, lost and scared,” recalls Basile. “I was 19, a new C4-5 quad with no movement in my arms, still in my hospital bed,” he says. “And Robby came wheeling into my room, smiling and joking with the nurse. It hit me — here is a quad who’s happy and loves life. It really changed my spirit. And we have been friends ever since.” Basile thrived in rehab, finished college and now, at 30, is a medical malpractice attorney in Washington, D.C.

Basile met Buchanan — a project manager for ReWalk Robotics from Chicago, Illinois — when Buchanan was doing outpatient rehab at Kennedy Krieger Institute in Baltimore. “We became close friends and spent the entire summer hanging out together,” says Basile. As a plus, Buchanan, 27, in his 10th year as a T4 complete para, would bring serious travel cred to the group, having done several extended journeys throughout Europe with nothing more than his wheelchair, backpack and a thirst for adventure.

Basile also felt the combination of an upper-level quad in a power chair, a low quad pushing a manual chair, and a para would give unique perspectives to the trip.

However, after months of planning, communications, paperwork and arranging journalist visas, the group, now only a little more than a week from departure, was unexpectedly confronted with a weirdly ironic dilemma: Guzy, nondisabled up to this point, was struck with Guillain-Barré syndrome.
Barré, a rare, serious syndrome that attacks the nerves and causes paralysis. “It freaked me out because everything was going numb, I couldn’t walk,” recalls Guzy. “My throat started closing up and my face started to go numb, and I was worried I was going to be one of the people who ended up on a ventilator.”

Fortunately, she started to recover unusually fast. After a week and several rounds of IV immunoglobulin therapy, she was released from the hospital just days before departure. With a warrior’s spirit, Guzy decided to photograph the trip. “I’ve known Josh for 10 years and covered his story for all that time. Plus this story was my pitch to ESPN, so there was no way I was going to miss it. Josh brought his spare power wheelchair for times when I couldn’t walk, and I figured it would give me a unique look at the trip.”

Havana, Circa 1950

On Sunday afternoon, May 29, the three wheelers, along with Guzy, Ahrens, captain William Rey, first mate Evan Duffy, and Basile’s attendant Kingsley Ndasi, cast the dock lines and set sail riding gentle winds into a brilliant Key West sunset on the start of the 90-mile passage to Havana.

After a smooth overnight crossing, the rising sun illuminated Cuba coming into view as they glided over brilliant turquoise waters. The boat docked at Earnest Hemingway Marina, near Havana, around 9 a.m. to clear customs. “The customs folks were polite, but all business,” says Basile. “They boarded us, checked all of our documentation, took our temperature to check for sickness, went through all of our stuff, and signed affidavits of what we were bringing.”

During the tour, although the streets were bustling and alive with people, few other wheelchair users were visible, something that would become more evident during their stay. “I don’t think I saw more than three wheelchair users on the streets the entire time we were there,” says Basile. “And the ones I did see were in old banged-up hospital-type chairs, most missing cushions and one or both foot rests.”

They stayed at Casa Camilo, a wheelchair accessible Spanish colonial style villa owned and operated by Camilo Finlay, 49, a Cuban born in Sweden and a graphic artist and chef in his 17th year as a T6 paraplegic. The house was handed down from his grandfather, Carlos Finlay, a famous Cuban doctor and scientist who discovered the disease vector for yellow fever. Camilo’s father was a Cuban ambassador to Sweden in the ’60s, and his sister Carla is assistant director of engineering at Columbia University in New York. With his background, Camilo could live anywhere in the world; however, his love of Cuba and the Cuban people drew him here, and he started renting out rooms in his house in

“I FELT LIKE I WENT THROUGH A TIME WARP.”

Photo courtesy of Kennedy Krieger Institute
Meeting Camilo Finlay and staying at his accessible villa was a highlight for everyone. After ascending to the roof in the outdoor elevator, the guys enjoyed amazing meals and conversations about life for wheelchair users in Cuba — and the occasional cigar.

1994. Current room rates are $50 a night. He modified the house to be accessible after his injury.

Basile, knowing that wheelchairs and accessories are difficult to come by in Cuba, and having heard that Finlay’s cushion was in bad shape, brought a ROHO cushion as a gift.

Finlay and his wife, Terre, were wonderful hosts, says Buchanan. “There is a bar and restaurant on the roof where he prepared amazing feasts, including a lobster dinner with many side dishes one night, and a roast pig another,” he says. “To get to the roof you ride a unique, three-story elevator located on the outside of the building, which seemed bare-bones comparable to the sheet metal-type lifts you would see in the states. It wasn’t enclosed, just railings to hold you in, but it got the job done.”

During evenings there were conversations about life for wheelers in Cuba. For mobility Finlay has a three-wheel power scooter and an old lightweight folding chair. “His sister brought the wheelchair down to him [from the States] after buying it off eBay,” says Beckman. In the United States, his two chairs would be considered basic wheels, but in Cuba they are more like a Porsche and a Ferrari.

Finlay explained that in Cuba there isn’t an institution that provides wheelchairs. People who are fortunate to have relatives in other countries have them send chairs. He also said there are workshops that provide wheelchair maintenance, but they don’t have essential parts like brakes and tires and can only do simple repairs.

Jorge Gutierrez, a Cuban-American translator who works at Shake-A-Leg adaptive sailing in Miami, added further details about wheelchairs. “There are no wheelchair manufacturers in Cuba,” he says. Manual wheelchairs are received through nonprofits from other countries and distributed through government hospitals and Cuban nonprofits like the Cuban Association of People with Physical and Mobility Impairments. “Most of the wheelchairs are used and lots of times not in good shape. Power wheelchairs are very difficult to get. You need to know the right people and pull the right strings.”

According to “Cuba Needs Wheelchairs,” a 2014 article in the Havana Times, the number of people who need wheelchairs far exceeds the amount that are donated.
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The Cuban Economy: A Puzzle of Opposites

Communications in Cuba is also caught in a ‘50s time warp. Basile had planned to file daily blogs on his websites as well as stay in touch via cell phone but found that cell coverage was nonexistent and internet access was rare and spotty. "It was tough at first, but after a while it was great to have a break from constant information overload," says Beckman.

"Cuban communication happens by word of mouth. You tell your friends where you are going to meet. I grew to really appreciate speaking with people to find out where to go, and having to pay attention to where you are."

One of the things that really shocked the group was low Cuban wages. According to Best Cuba Guide, the average monthly wage in Cuba is $30/month, possibly because living in the communist/socialist country is highly subsidized — including free education, medical care, food allowances, subsidized utilities, stores, and rent control. Ironically, there is a high rate of homeownership. Most family homes are passed down for generations, and people live in the neighborhood where they grew up. The World Health Organization rates Cuba’s water quality, nutrition levels, health and life expectancy among the best in the world. But the standard of living is just enough to get by and nothing more.

“I’m kind of at a loss trying to wrap my head around the wages of the average Cuban,” says Buchanan. "We went to an amazing show at the Tropicana, which was a riot of color, dancing and music, another throwback to the ‘50s. But it cost $75 a person. And another day we had a phenomenal lunch overlooking Havana Harbor at the famous Hotel Nacional, a Havana landmark since 1930 that once hosted Winston Churchill and Frank Sinatra, where rooms start at $250 a night. I found the prices for meals and daily living to be on par with the United States or Europe.”

If this is not sufficiently confusing, articles on the Cuban economy say that cab drivers, bartenders and people that receive tips in the hotel industry make as much as 10 times the $60/month salary of the average Cuban physician.

Buchanan wonders if the best way to make money would be to open a business and make and sell handmade goods. He and Beckman visited a flea market in Old Havana. "It was really big, with all kinds of cool local crafts," says Buchanan.
At the market Buchanan struck up a conversation, through an interpreter, with a 72-year-old amputee in a beat-up hospital type wheelchair with hard rubber wheels run down to the rims. “I saw a couple other wheelchair users in similar beat-up old chairs, using folded up towels for cushions — stuff I’ve seen in other developing countries,” says Buchanan. “One of the cool things about travel in a wheelchair is it instantly breaks down barriers. We had a 10-minute talk and it was clear he enjoyed the conversation. As an afterthought I gave him $20 as a nice gesture and he broke down crying. It drove home how fortunate we are to have access to so many things, including great wheelchairs and cushions.”

Buchanan found an interesting mix of architecture in Old Havana. “One row of buildings would be kept up and painted and the next would be trashed and falling down. It is like a lot of other places I’ve been in the world where poverty is right next to wealth.”

They also found architectural barriers to be similar to the ’50s. No curb cuts or ramps (with the exception of the Hotel Nacional) or accessible rest rooms. “I can’t tell you how many times I discreetly cathed in public when we were down there,” says Beckman. “And there were curbs everywhere, but fortunately the people were really helpful and happy to help us up and down them.”

Accessibility for Basile in his heavy power chair was another matter. In Havana, Gutierrez arranged the rental of an ambulance with a lift on the back — for $25 an hour — from an expensive upscale hospital that caters to wealthy Cubans or international patients who pay cash, called Centro Internacional de Salud, La Pradera. Basile brought a folding 7-foot ramp. “I also brought custom 16-inch long ramps that fit on the back of my wheelchair for the seemingly endless number of curbs.”

Basile’s ramps came in handy on a visit to an “accessible” cigar factory.

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Proposing With Style

Josh Basile and Gabby Ahrens started dating in October 2015. The couple met through eHarmony.com, exchanging messages for about a week and a half until Basile mustered the courage to ask for an in-person date. “She is the love of my life, and I wanted the proposal to be just right, starting with asking her dad permission to marry her,” says Basile.

The proposal went into play Wednesday afternoon. The plan included everybody on the trip and numerous details, including where to mount cameras (the proposal was filmed by ESPN). The ruse involved hiring a sketch artist who would draw each person sitting on the sea wall in front of Impossible Dream. Gabby would be sketched last, and everybody would be onboard the sailboat.

“In her sketch, I was sitting [in the background, unknown to her] on the front of the boat holding a sign that read ‘Will You Marry Me?’” says Basile, who also had an engagement ring in its box held between his legs. “She got the sketch, looked at it, smiled and cried all at once, then ran around the back of the boat with everybody cheering and clapping, and when she got around to the front, there I was, just like in the sketch. She said yes and gave me a big kiss!”

The wedding is planned for winter of 2017.

“There were five stairs going into the factory, so we put both my ramps together to create a dangerously steep ramp,” says Basile. “A bunch of Cuban men hanging outside the cigar factory pushed me and my 400-pound wheelchair up the ramp.” After a very cool tour of the factory, Basile realized going down would be perilous. “After feeling like I might spend the rest of my life in a cigar factory, the ambulance driver backed up to the stairs and extended the lift, which reached the top of the steps and saved the day.”

Highlights of the Trip

Two of the trip’s highlights for Basile were, in order, proposing to Gabby and teaching Slingshot Golf to Finlay (see sidebars). “I love golf and invented the Slingshot Golf game so I could compete like an athlete again,” says Basile. “I’ve taught over 25 paraplegics and quadriplegics how to play but never through a translator. He caught on quickly and was making extremely long drives with the slingshot and sinking very difficult putts in no time.”

Unfortunately, the ESPN film crew wasn’t able to capture the game. The crew and Guzy had journalist visas, but they also need a specific permit to shoot at each government facility, and the ministry wouldn’t issue permits for the golf course or cigar factory which, like many things in Cuba, are owned by the government. However, they did use “stealth GoPro cameras” to capture the footage. “At the golf course they let me shoot stills, though it may have been because I was using a power chair,” says Guzy. “And any type of photography was strictly forbidden inside the cigar factory, not even smart phone photos. I have a journalist friend that was recently arrested in Cuba for taking a photo of a building she wasn’t supposed to. The Cuban people were fabulous, but it is going to take some time for the bureaucracy to catch up with the changes that are taking place.”

Other highlights included sailing up the Cuban coast, one time at sunset with everybody out of their chairs lying on the nets between the hulls. “It was like flying over the water,” says Beckman. On another sail they were propelled by a stiff breeze, the hulls slicing through 4-foot seas at 10 knots. “We were getting blasted with spray — a
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Slingshot Golf — A New Game

Josh Basile loved playing golf before his injury. Early on after his injury he would go out with his dad, but it was frustrating not being able to play. Now Basile is back on the links with a new version of the game he invented — “Slingshot Golf.” A quadriplegic, with the help of a caddie or friend, or a paraplegic, uses a slingshot to hit the long shots and get the ball on the green. The pendulum putter is then used by all players to put the ball in the hole. In February 2014 and March 2015 Basile received two separate patents for the pendulum device. You can watch a detailed introduction video on how to play the sport at www.slingshotgolf.org.

Finlay, using his scooter for the golf course, tries a long “drive” with the slingshot. The pendulum putter can be seen to the right.
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The Impossible Dream is a 60-foot catamaran that is universally designed so every area of the boat is wheelchair accessible, including wheelchair lifts that descend into the sleeping quarters and accessible bathrooms located in each hull. Designed and built for Mike Brown, a paraplegic who wanted to be able to sail independently, the Impossible Dream has push button hydraulic controls that hoist and control the sails. In 2010 Geoff Holt, a sailor and quadriplegic, made history when he sailed the boat solo across the Atlantic Ocean.

After sailing Impossible Dream for 10 years, Brown sold it to Deborah Mellen, 62, a gem dealer, jewelry designer and L1 para 27 years post-injury. Mellen made the purchase when she fell in love with sailing through Shake-A-Leg Miami. “My dream is to have as many wheelchair users sail aboard her as possible,” says Mellon, the boat’s owner for three years. She runs it as a nonprofit organization whose purpose is to introduce sailing and accessible design to as many people as possible. “This summer we will be sailing up to Maine and back, stopping at ports and taking people with disabilities sailing for the day.”

In January 2016, Mellen and two other wheelchair users, Harry Horgan, a paraplegic and founder of Shake-A-Leg, and David McCauley, a quadriplegic, along with three non-disabled crew members, raced Impossible Dream in competition with 50 other sailboats in the Conch Republic Sailboat race from Key West to Varadero, Cuba. They finished third place in their 11-sailboat division. “It was a great race, and we were the only boat with sailors with disabilities,” says Mellen.

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FREE ADMISSION
Even though his bladder cancer wasn’t caught early, Kevin Smith has hopes that the excellent care he currently receives means he will have years to spend with his granddaughter.

Smith happened to mention his nonhealing wound problem to a neighbor of his who coincidentally happens to be a surgeon. “He recommended I see a urologist who was experienced treating people with spinal cord injuries from Craig Hospital and was with a clinic staffed solely by urologists.”

The urologist Smith’s neighbor recommended was Dr. Richard Augspurger of The Urology Center of Colorado, in Denver. By the time Smith saw him in mid-December, it was nearly eight months after he had begun noticing symptoms. The punch biopsy revealed a fast growing squamous cell tumor in the stoma canal leading to the bladder. “I don’t know why they didn’t do this at Kaiser,” Smith says.

The Kaiser physicians didn’t do a biopsy most likely because they were unaware of the elevated risk for bladder cancer that people with SCIs face. Given the often aggressive nature of bladder cancer and the scope of treatment involved, it’s logical to ask about risk factors. This type of cancer is quite rare in the general population, affecting about 3 percent of all men and about 1 percent of women. And when it does occur, it’s normally what’s called transitional cell carcinoma and usually takes up residence in the lining of the bladder.

“The risk of bladder cancer for people with SCI is about 15 times higher than that of the general population,” says Augspurger. “People who have been using indwelling catheters are at even greater risk, especially if they’ve used an indwelling catheter for more than 10 years. When
bladder cancer does occur in people with SCI, it’s just as likely to be squamous cell carcinoma, a fast growing and more dangerous form of cancer.”

But even factoring in the elevated risks, the number of wheelers who develop squamous cell bladder cancer is actually fairly low, according to Craig Hospital. Still, I can name four people I’ve known who’ve died of squamous cell bladder cancer in the last 15 years or so, including Barry Corbet, past editor of New Mobility.

BLADDER CANCER CAUSES AND RISKS

Augspurger speculates that bladder problems most likely begin due to irritation, either from an indwelling catheter, repeated UTIs or bladder stones. All are quite common with a neurogenic bladder. Another problem is that bladder cancers — especially squamous type cancers — exhibit few early symptoms other than blood in the urine, which is also quite common. “Squamous cell cancer doesn’t look like other cancers, and when it is biopsied, the results can show something entirely different,” Augspurger says.

Dr. Donald May, a colleague of Augspurger, explained it this way: “It mimics other symptoms. In the bladder, it often looks like simple irritation or normal thickening of the bladder tissue rather than a growth or tumor until it gets larger. In addition, it can develop anywhere in the canal from the abdomen to the bladder. We usually spot it during a cystogram. For people who use suprapubic tubes, it’s important for physicians to go in through the stoma canal rather than the urethra so they can inspect the entire canal thoroughly as well as the bladder. Most doctors may be unaware of the elevated risks of bladder cancer with SCI.”

May says that physicians should employ a “high index of suspicion” concerning the bladders of SCI survivors.

Bladder irritation — both chronic and repeated — poses the greatest risk of fostering bladder cancer. And for wheelers, the risks of irritation are many, beginning with UTIs. In addition to the irritations repeated infections cause, some researchers speculate that UTIs also cause the release of nitrosamine, which may foster the development of cancer in the way cigarette smoke promotes lung cancer.

Bladder stones seem to form around some foreign object in the bladder — a strand of hair, some sediment or grit. Once they’re formed, they can be quite painful and damaging to the bladder. If not removed, the stones can also precipitate a UTI and even more irritation.

But the generally accepted biggest risk for irritation appears to be an indwelling
catheter, either Foley or suprapubic. The irritation can be where the catheter tip rests on the bladder wall, at the neck where the catheter enters the bladder, or as in Smith’s case, anywhere along the ostomy canal through the abdominal wall leading to the bladder. That risk with indwelling catheters increases significantly after eight to 10 years. But don’t think you’re immune just because you don’t use an indwelling catheter. Fully half of all wheelers who develop bladder cancer use some other method of bladder management.

The literature also suggests that the “era of care” at the time of injury may also play a role, especially for those injuries predating modern antibiotics, anticholinergics and non-rubber catheters. In the ’60s, ’70s, ’80s and into the ’90s, suprapubic tubes were seen as a way for quadriplegics without the necessary hand function to do an intermittent catheterization program to lead more independent lives. Many paras also opted for suprapubics out of convenience.

Tobacco use and job type also contribute to the likelihood of bladder cancer. According to the American Bladder Cancer Society, smokers are two to three times more likely to develop bladder cancer than non-smokers. Different occupations can also pose risks, as truck drivers, hairdressers, printers, painters, textile workers and many who work in the chemical or leather industries may all be exposed to unhealthy levels of carcinogens. Diets high in fat and nitrates have also been linked to cancer.

THE TREATMENT

Diagnosed in mid-December, Smith began wide field radiation and chemotherapy treatments in the middle of January, followed by surgery in May. “I tolerated the radiation therapy very well,” Smith says, “but the chemo was very painful. I almost stopped treatment. If I hadn’t been retired, I probably would have stopped.”

The surgery Smith faced in May was major and extensive, normally taking between four to six hours. Smith’s took eight hours and required three surgeons. They removed his bladder, prostate and stoma, then did an “ileal loop urinary diversion,” which brings a piece of small bowel — ileum — to the skin. The procedure is similar to a colostomy and requires the person to wear an external collection appliance. For women, in addition to the bladder removal, surgery also takes the uterus, possibly the ovaries, and maybe even sections of the vagina — essentially anything that comes in contact with the bladder is removed. Another surgeon removed a large tumor, along with affected lymph nodes and a large mass of necrotic tissue around the stoma canal. Throughout the surgery, surgeons sent tissue samples to be analyzed and confirm tumor boundaries for safety’s sake. Then a large piece of Smith’s thigh skin and muscle tissue was grafted to close the wound. Smith spent 15 days in the hospital.

By September, only four months later, the cancer was back and Smith was once again in the OR, this time to remove a small tumor in the surgical suture line. He also received two skin grafts. That surgery was followed by an additional round of chemo. Smith will now be scanned every three months. His January scan was clear, but the April scan revealed yet another tumor, which was treated with stereotac-
tic body radiation therapy (limited but highly precise radiation fields). “That’s the nature of squamous cell cancer,” Smith says. “It’s aggressive and tends to spread.”

**IMPORpREVENTION**

Regardless of how you manage your bladder, there are steps you can take to decrease your risk of contracting bladder cancer. First and foremost, be diligent in all aspects of your management program. That means following all health care professional recommendations regarding medications, fluid intake, annual check-ups/exams, and above all cleanliness, including good hygiene to maintain a sterile environment when changing catheters or doing an intermittent cath. (For IC, “clean technique,” according to some studies, can also be effective, but not when frequent UTIs are a problem.)

Good hygiene also includes daily cleaning of leg and night bags using a solution of chlorine bleach to flush the bags and kill off any potential infection threats.

People using indwelling catheters should alternate the leg on which they wear their collection bag. The thinking is that doing so will change the location where the catheter end and balloon rest in the bladder. Also, try alternating the side of the bed where the night bag hangs.

Don’t ignore different physical indicators that something is amiss: feeling run down, experiencing increased spasticity, more aches and pains than usual — all can be indicators of UTIs. If irritation is a problem, try using hydrophilic catheters, which are lubricated and cause less irritation. Change catheters monthly or more often if recommended.

Follow other recommendations as well, especially those regarding any anticholinergic drugs, such as Ditropan, Vesicare, or Detrol. These drugs relax the bladder and help control bladder spasms, yet another source of significant irritation. [See important related news about the use of anticholinergics in this month’s Para/Medic column on page 50.]

Don’t ignore different physical indicators that something is amiss: feeling run down, experiencing increased spasticity, more aches and pains than usual — all can be indicators of UTIs. While they are part of the SCI package and so fairly common, more than two or three UTIs a year should be cause for some concern and should be discussed with your urologist.

Many centers recommend annual visits to a urologist. May and Augspurger recommend not only yearly urological exams, but annual cystoscopies (a simple outpatient procedure in which a catheter with a tiny camera allows the urologist to examine either the urethra or the stoma canal, as well as the bladder for stones, unusual growths or other abnormalities).

Why yearly cystoscopies? “If I wait two years to spot something,” says May, “it’s often too late. Bladder cancer’s not...
very common, but it’s quite lethal. If we catch it early, we have a good possibility for a positive outcome. Unfortunately, the people I see often come from somewhere else and haven’t seen a urologist in some time because everything has been fine. They often don’t know the warning signs or risks and usually are not following a recommended protocol.”

Part of the yearly urology check-up should include an ultrasound and kidney-ureters-bladder X-ray to check for kidney and bladder stones, irritants known to be risks for bladder cancer.

Another important preventative behavior is staying adequately hydrated. While it’s hard to make accurate recommendations, intake should be sufficient to generate an output of three to four quarts of clear to straw-colored urine a day. Doing so helps keep the plumbing well flushed out and operating properly. A wise educator’s mantra for people with new injuries is: “The solution to pollution is dilution.”

Those doing intermittent catheterization should be sure to cath often enough to keep bladder volume at no more than 400 cc (about 12 oz.) so as not to over-stretch, irritate and scar the bladder. When doing an IC, be sure to use adequate lubricant to avoid irritating the urethra and sphincter. Consult with a urologist concerning any ongoing problems with an IC regimen.

And the obvious bears reiteration: Don’t smoke or use any other tobacco product, including chew. As previously mentioned, smoking can increase the risk of bladder cancer threefold.

For his part, Smith remains hopeful. But having lived so long with SCI, he’s also a realist. “It is what it is. After 37 years of being a quad, cancer seems like just another barrier. Something’s gonna kill me,” he says. “I practiced law for 23 years, put two sons through college and now have an 8-month-old granddaughter. I’ve had a good life. I was upset with how long it took for a diagnosis, but since then I’ve had good care. I could go into long remission.”

Smith’s reason for optimism comes from the recent fast-track status given to the cancer drug Opdivo to treat a similar cancer. “With this new drug, I’m hoping for another few years. A similar drug is helping keep Jimmy Carter’s brain tumor in remission.” Smith began treatment in late June. At $9,000 a treatment — not covered by insurance — he’s hoping for drug company assistance so he can watch that granddaughter grow up.

RESOURCES
- Craig Hospital, craighospital.org/resources/bladder-cancer
- National Rehabilitation Hospital, sci-health.org/RRTC/publications/PDF/Bladder_Cancer.pdf
- New Mobility, “Bladder Cancer: Increased Risk?” www.newmobility.com/2012/02/bladder-cancer-increased-risk
- New Mobility, “Suprapubic Revisited;” www.newmobility.com/2010/06/suprapubic-revisited

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Owning a vehicle, even if you are unable to drive personally, can make a big difference in quality of life. Driving allows flexibility for attending school, work or social functions without advance reservations or worrying about bus schedules.

The number of people with disabilities who drive or own vehicles, especially those of us who use hand controls, is small when compared to the number of cars, trucks and vans that are sold each year. Despite that, there are many manufacturers that realize the value of our customer base and have continued to introduce new products or improve what is already on the market.

Automobile companies do whatever is necessary to keep ahead of their competition. The beginning of every new model year includes announcements about new models or, at the very least, some styling changes to set their latest vehicles apart from what they sold in the past. Consumers often prefer to buy something new rather than a vehicle that remains unchanged for years. While it sounds good, such changes can pose problems for those companies that modify vehicles for our use.

Mobility conversion companies rely on the availability of vehicles from domestic and foreign vehicle manufacturers in order to modify them for our use. Vehicles being converted for the first time require extensive engineering and testing, which can require a significant investment of time and expense. This can create challenges unknown to other businesses, as the continuing availability of the vehicles that mobility conversion companies need is beyond their control. That impacts the larger conversion companies like BraunAbility and Vantage Mobility, as well as smaller companies that modify only a few vehicles a year. The main focus of their efforts has been the modification of minivans, but there is a surprising variety of other vehicles available today.

Buyers seeking larger vehicles or more interior room can choose between the Mercedes Sprinter, Dodge ProMaster or Ford Transit, as well as a few of the minivans. Those seeking more rugged vehicles might consider one of the converted pickup trucks or full-sized SUVs from companies such as Mobility SVM or All Terrain Conversions. Mobility SVM claims that the seven-passenger seating capacity of their larger vehicles results in them having “the largest seating capacity of any consumer wheelchair accessible vehicle.”

ATC, a company that normally completes GM Truck conversions, now performs conversions on some of the new “crossover” SUVs: the Chevy Traverse, GMC Acadia (pictured) and Buick Enclave.
lowered floors and removable front seats. Some of the larger SUVs, pickup trucks and vans can even retain their four-wheel drive capabilities.

**New Models Being Converted**

BraunAbility has teamed up with Ford to offer the BraunAbility Ford Explorer MXV. This accessible SUV has several features that will interest wheelchair users, including a lighted under-floor ramp, a movable shifter unit and a seat base design that provides toe clearance for maneuvering. The BraunAbility engineering staff are currently working on the latest model of the Chrysler Pacifica for those who are seeking a hybrid minivan. While the BraunAbility version of that particular vehicle has not been released to the public yet, it will be coming to market very soon.

Mercedes recently unveiled their new "Metris" minivan in both passenger and cargo editions. They are not conversion vans, but what sets these minivans apart is that both are capable of having a full-sized Braun Lift installed. Before the introduction of the Metris, it was necessary to have a larger vehicle like the Sprinter or Ford Transit in order to accommodate a large wheelchair lift. Mobility equipment dealers are hoping to have the first Metris equipped with a Braun lift system and Q’Straint restraints available by the summer.

While the vehicles that those companies convert for our use usually begin as standard models off the production lines of mainstream car companies, there is an exception to that pattern. The Mobility Ventures MV-1 is touted by the company as “the first mobility vehicle built specifically for wheelchair accessibility and not an after-market conversion.” The MV-1 is not an entirely new concept, as it originally debuted as the Standard Taxi but was discontinued. The latest versions are equipped with new features such as an automatic ramp and are being marketed to taxi companies, which will improve the accessibility of taxi fleets worldwide. They should also be durable, as the parent company of the MV-1 is AM General — the same company that built the first Jeep vehicles over 70 years ago.

The best means of finding a vehicle that fits your situation is to visit a local mobility equipment dealer and work with their staff to discuss needs and learn what is available. Head clearance, maneuvering space and legroom are features that can make a real difference in the ability to use a particular model of car, truck or van. Boarding a vehicle at a dealer’s showroom or checking out one owned by a friend can reveal more information than any amount of time spent reading brochures or doing internet searches.

The “ideal” vehicle is an individual preference based on the characteristics of drivers or passengers and their mobility devices. Finding and purchasing the ideal vehicle is a time consuming process, but readers who check out the Resources List that follows should be able to find much of the information they need before visiting a mobility equipment dealer. Additional news about vehicles can be found periodically in the pages of *New Mobility*, especially in our November Consumer Guide. The Motorvation column in that issue will discuss the assistive technology and peripherals that make a conversion vehicle accessible: hand controls, wheelchair lifts, securement systems, and more.

**Resources**

- ATC, 855/324-3085; www.atconversions.com/atc-crossover-suv-conversions
- BraunAbility, 800/488-0359; www.braunability.com
- Mercedes Metris, 877/762-8267; www.mbvans.com/sprinter/commercial-vans/metris-passenger-van
- Mobility SVM, 877/659-1512; www.mobilitysvm.com
- Mobility Ventures MV-1, 877/681-3678; www.mv-1.us
- NMEDA, 866/948-8341; www.nmeda.com
- Vantage Mobility International, 855/864-8267; www.vantagemobility.com
Anticholinergic Medications and Dementia: Clarification, Perspective, Options

By Bob Vogel

Q. I’m 49, in my 10th year as a T7 complete para. I take VESIcare to manage my bladder spasms. For me it has minimal side effects, mainly dry mouth and drowsiness, but it’s difficult to tell if the tired feeling is from the drug or life as a para. The side effects are way less than when I was taking Ditropan, which seemed to turn my thinking to mush. However, when I read “Anticholinergic Meds May Cause Brain Damage” [May 4, 2016] on the New Mobility website, it freaked me out! Especially when I read the linked study in JAMA Neurology that concludes that the use of these medications was associated with brain atrophy and brain dysfunction. Is this information new? Are taking these meds damaging my brain at my age? Can the effects on the brain be reversed if I stop taking the drug? And finally, are there alternatives that don’t affect the brain?

— Stacy

Although the title of the JAMA article is scary on face value, it is important to keep in mind that this is still a gray area. Here is some information that should put this study in perspective.

Perhaps the most important thing to consider is that the average age of the people in the study was 73. Also, the study had nothing to do with spinal cord injury. Also, urinary dysfunction used to be the leading cause of death among people with SCI. These days, thanks to multiple advances in the way we manage bladder — including drugs to quiet spasms — it doesn’t even make the top three.

As the NM article explains, studies suggesting a link between anticholinergics and cognitive decline in older people have been around for quite a while. A PubMed search on “anticholinergics and dementia” pulls up pages of studies suggesting a link between anticholinergics and mental decline in older people going back at least as far as 2005.

Anticholinergics work by blocking acetylcholine, which stimulates muscle contractions, including the detrusor (bladder) muscle. When acetylcholine is blocked by a medication, it can’t stimulate the bladder and cause it to contract (spasm), which is a good thing. Anticholinergic medications used to treat neurogenic bladder include: Ditropan and Ditropan XL extended release tablets, Oxytrol Patch, Gelnique topical gel, Detrol and Detrol LA, Sanctura and Sanctura XR tablets, Enablex, Toviaz, and VESIcare.

A good overview of the recent anticholinergics and dementia study can be found in the May 9, 2016 article on WebMD by Kathleen Doheny (see resources). She writes that acetylcholine is also an important chemical in brain function, especially crucial for memory. This would explain why these medications often produce a foggy “brain-haze” side effect. Conversely, drugs used to treat Alzheimer’s and improve memory do the opposite. They act to increase the amount of acetylcholine.

It is important to note that of the 451 subjects in the study, only 60 were taking one or more anticholinergic meds. Although the study found a strong “link” between the drugs and dementia, it did not show that the drugs cause dementia. “There could be other things that explain the decline,” writes Doheny. Researchers she interviews echo the fact that multiple studies have suggested this link for quite a while.

In this latest article, Shannon Risacher, Ph.D, explains that there is no way to figure out an absolute risk for a single person. This is because among many variables, drug metabolism is unique to each person and has different effects on different people. She says there haven’t been any studies done that focus on a link to anticholinergics and cognitive decline in younger people, so it is difficult to know if the findings of this study apply. If the link to anticholinergic use in elderly people turns out to be cause and effect of dementia or Alzheimer’s, it’s likely because acetylcholine naturally declines with age, and older people are likely more sensitive to anticholinergics, she says.

The recent study did not look at whether or not the risk of developing cognitive problems disappears if you quit taking anticholinergics. Risacher says other studies have looked at this, but there is no consensus.

As for how this applies to managing spasms in a neurogenic bladder (bladder compromised by SCI or other nerve dysfunction), Dr. Michael Kennelly, director of urology at Carolinas Rehab in Charlotte, North Carolina, who has a specialty in SCI medicine, says, “At this point the level of evidence is not strong to make guideline changes or radical changes in bladder management. So far the evidence that using anticholinergics leads to dementia or Alzheimer’s is pretty thin, but it is gaining traction.”

Kennelly’s practice guidelines focus...
on how anticholinergics affect his patients’ cognition in the here and now. “We always try to minimize the use of anticholinergics, especially in at-risk groups, including children, elderly and patients with some cognitive impairment, such as MS, Parkinson’s Disease, stroke, etc.” he says. “We have known for quite some time that these drugs affect cognition, and we know that a lot of them cross the blood brain barrier.”

In addition to cognitive dysfunction, the side effect of dry mouth can lead to serious tooth decay, and blocking acetylcholine also causes muscles in the bowel to relax, causing constipation. At the present time, Kennelly says, there are two non-anticholinergic medication options to quiet the bladder — Mirabegron, sold in the United States as Myrbetriq, and Botox injections in the bladder.

Myrbetriq is a once daily pill that mellows bladder spasms but doesn’t affect acetylcholine; instead it quiets the bladder by stimulating Beta 3 receptors in the bladder’s muscle cells and doesn’t cause cognitive or other severe side effects that often accompany anticholinergics. It received approval by the FDA for treating overactive bladder in 2012. The downside? “Myrbetriq is expensive and not all insurance covers it yet, or there may be a high co-pay,” says Kennelly. According to GoodRx.com, Mybertriq is covered by 91 percent of Medicare part D and Medicare managed plans. However, co-pays for a month’s supply range widely, from as low as $15 a month to $341 a month. Cash price for a month’s supply is around $303. Price-wise, Botox has become a bargain. GoodRx.com lists the Medicare co-pay for Botox at $172, and the procedure generally lasts four to six months or more.

Unfortunately, most insurers, including Medicare, won’t let you simply switch to Myrbetriq or Botox. The usual requirement is that you have tried to manage your bladder with an anticholinergic drug and it isn’t working for you. That may mean that you can’t tolerate the side effects or it doesn’t keep you dry at the maximum prescribed dose, says Kennelly.

“The most important thing to take away from this is you have to manage bladder spasticity, because if you don’t, you will likely ruin your urinary system, which can prematurely end your life,” says Kennelly. “The bottom line is, if you are worried about your memory or are having memory issues, avoid anticholinergics as best as possible. Ask your urologist about other options like Botox and Myterniq.”

Resources
• Anticholinergic Meds May Cause Brain Damage, www.newmobility.com/2016/05/anticholinergic-brain-damage/
• Anticholinergic Study in JAMA Neurology, archneur.jamanetwork.com/article.aspx?articleid=2514553
I’m sorry if I’ve seemed preoccupied lately. There’s a lot on my mind. I’m trying to word my appeal. Actually, I’m trying to word my appeal of the denial of my appeal. My first appeal was denied so my next recourse is to appeal for the right to appeal the denial of my appeal. If that’s successful, I will go back and appeal the denial of my appeal. But if my appeal to appeal the denial of my appeal is denied, I will appeal for the right to appeal the denial of my appeal for the right to appeal the denial of my original appeal. This is very high stakes for me because I really need a new wheelchair and that’s what this is all about. Once upon a time, if a guy like me needed the state to buy him a new wheelchair, he went to a state office and did six tons of paperwork and jumped through a bunch of degrading hoops, only to be denied in the end. But things have changed. The state now contracts with private managed care corporations. So now, if a guy like me needs the state to buy him a new wheelchair, he goes to the office of a managed care corporation and does six tons of paperwork and jumps through a bunch of degrading hoops, only to be denied in the end.

I’m not sure how this saves the beleaguered taxpayers money. I guess managed care corporations pay their employees to not do anything. The state swears that turning everything over to managed care corporations will “improve the level of customer satisfaction” for guys like me. So when it came time for me to apply for a new wheelchair, I told myself what the hell, I’m going for broke! I saw an internet video that was an ad for this cool new motorized wheelchair. I know they’re making wheelchairs cooler and cooler these days, but this is the coolest chair ever!

They call it the Seduction wheelchair. Apparently if a guy drives it down the street, women throw themselves at him. They can’t resist. It must emit a powerful invisible pheromone or something because in the video this badass quad wearing wraparound sunglasses was cruising in his Seduction wheelchair through the Hot Babe District, which is that section of the city where every woman is knockout gorgeous and wears a tight dress. And every last one of these women was jonesing to get their hands on this sexy quad. He had two women sitting on his lap and another riding on the back of his chair. He had women all over him like pigeons on a statue. Women stomped over each other for a chance to get next to him. Cat fights broke out all around.

So I decided I’d get the managed care corporation to approve me for a brand new Seduction wheelchair. That would sure as hell improve my level of customer satisfaction. I went to the office of a managed care corporation and did six tons of paperwork and jumped through a bunch of degrading hoops.

Six months later, my request was denied due to lack of “medical necessity.” However, the notice said the managed care corporation approved me for the purchase of a different mobility device, listed as DME Code 046. So I consulted the Big Book of DME Codes (a must-have item for every cripple survival kit) and discovered that DME Code 046 is a shopping cart.

Of course I immediately appealed. In order to make my case that a Seduction wheelchair is a medical necessity, I threw the words of the managed care corporation right back at them. They say their mission is to “promote long term health and wellbeing.” Well, I wrote, what could promote a man’s long term health and wellbeing more than having knockout gorgeous women in tight dresses stomping over each other for a chance to get next to him? If that’s not a medical necessity, what is?

I was still denied. But I won’t give up! My long term health and wellbeing is at stake! I don’t want to look like a real dork cruising through the Hot Babe District in a shopping cart.
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attendees, according to Brown. “It’s definitely evolved quite nicely,” she said.

Despite all the growth, and the chapter’s significant investment of time and money, the expos have stayed in the black. “It’s been a self-sustaining entity,” says Brown. “We’ve made enough money to cover all of our expenses, usually with some left over.”

The chapter takes great satisfaction in seeing all of the attendees who have used the event to get connected with dealers, artists, businesses and resources as a great source of pride. Brown said the expos have also helped raise community awareness about how involved and capable the local SCI/D community is.

In fact, the event grew so big that national competitors started to notice. Just as last year’s flyer was going to print, the Expo committee received a certified letter from the legal team behind a nationally known organization asking them to change their name so as to avoid confusion. And so was born the Midwest Ability Summit.

This year’s Summit is scheduled for August 27, back at the Overland Park Convention Center. Brown, who serves as the membership chair for the event, anticipates the biggest turnout yet, and credits the planners’ efforts to reach out beyond state borders as one of the key reasons. Looking back, she said the decision to grow the event beyond just SCI/D and tap into the broader disability community proved invaluable, and she encouraged others to consider doing the same.
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"Yes I can," croons wheelchair user Tony Dee, while he rolls through scenes of wheelchair racers, amputee dancers, murderball players and big band extravaganzas in an infectious new ad for the Rio 2016 Paralympics.

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The ad is being run in the United Kingdom by Channel 4 to lure viewers for the 2016 Rio Paralympics and was seen by over 200,000 people on YouTube the very first day it was uploaded. View it at youtu.be/IocLkk3aylk.

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**XBOX TWEETS IMAGES OF AVATARS USING WHEELCHAIRS**

Xboxers who use wheelchairs have been frustrated that the game has no wheels their avatars can use ingame, but recently Mike Ybarra of Xbox tweeted a sneak peek of a work in progress. Xboxers responded joyfully, but questioned why the chairs look so dorky. “Hopefully a second version with a light titanium chair, not the hospital kind,” tweeted Xbox_Addict.

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