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For further questions, call Coloplast Corp. at 1-866-226-6362 and/or consult the company website at www.coloplast.us.



FEATURES

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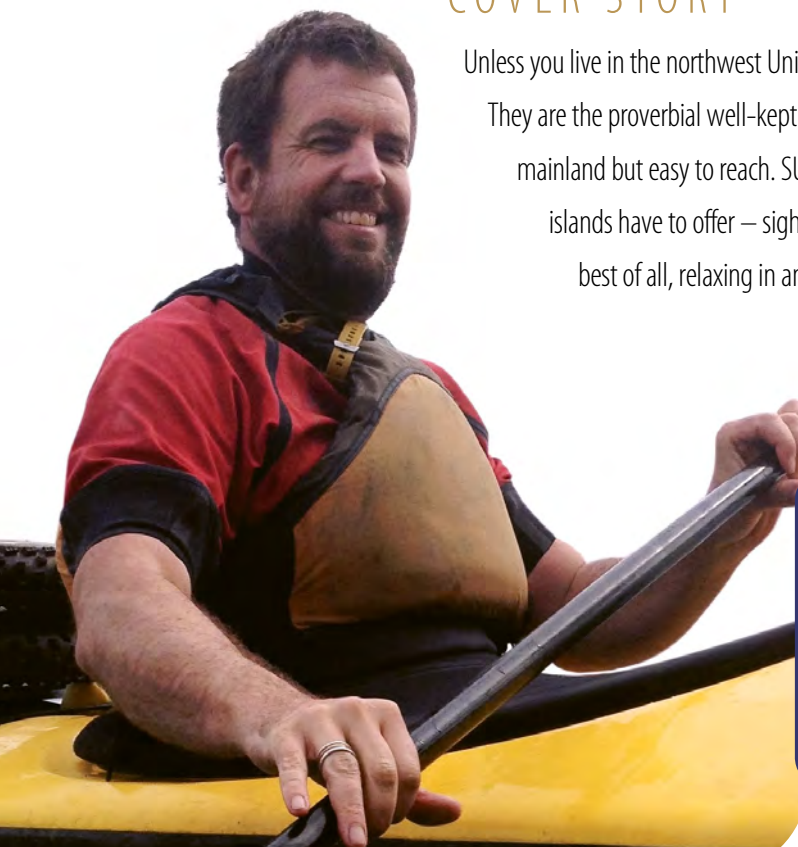


Remember when para Gretchen Schaper crawled around campus all day as performance art? (Page 16)

COVER STORY **DISCOVER THE SAN JUANS** 32

Unless you live in the northwest United States, you may have never heard of the San Juan Islands. They are the proverbial well-kept secret — beautiful, serene, unspoiled, set apart from the mainland but easy to reach. SUSAN M. LOTEMPIO gives us a guided tour of the best the islands have to offer — sightseeing, hiking, kayaking, whale watching, crabbing — and best of all, relaxing in an unhurried haven of natural wonders.

Cover and Contents photos by Cheyenne Black



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(BULLY PULPIT)



That was the night the elders retired the Golden Zucchini.

Poor Players

Churchgoers are often expected to be contrite, especially those of us with obvious disabilities, but I stumbled across a congregation with a contingent of souls who liked to laugh, especially in their annual Untalent Night. It was a dedicated event each year when I could play the part of Crazo on Wheels and know my behavior was duly sanctioned.

Untalent Night had only one rule: absolutely no authentic talent allowed. Maybe you always wanted to sing or play an instrument or perform Shakespeare or put on a skit. You could do it on this one night of the year as long as you were truly untalented. A panel of peers would judge you, and if you were really really bad, you just might win.

I had always wanted to be a ventriloquist, so I cajoled my 8-year-old daughter into dressing like a doll. My wife drew freckles on her nose and vertical lines on either side of her jaw to make her into a dummy, we stuffed her into an old trunk

and stashed her on stage. I wheeled up a homemade ramp, the curtain opened, and there I sat next to the trunk.

I opened the trunk, took my dummy out and placed her on my knee. I squeezed the back of her neck to signal her to open her mouth and I supplied a silly high-pitched voice, making weird jokes about well-known people in the church. I had written a script fit for adolescents, so my dummy daughter ended up pouring water on my head and slapping a whipped cream pie in my face. We were bad, but just talented enough not to win.

The next year I organized Rubberdance, a group of clompers clad in fluffy clothing and rubber boots. I chose the clumsiest people I knew and choreographed ridiculous routines. We rehearsed only once, just enough for them to get the idea but perform terribly. I slapped out a snappy Irish beat on my forehead while wearing a bright green bathing cap. The Rubberdancers stumbled around and kept time, sort of,

to my beat. The crowd loved it. We came in second. Just a wee bit too good to win the Golden Zucchini.

The next year I went all out. I conned the pastor and the youth pastor into dressing like The Supremes. I was Diana. We were Diana Gross and the Testosterones. A bit much for some in attendance, especially when the pastor's dress tore off above his thighs and revealed his jockey shorts in the middle of our lip-synching "You Keep Me Hanging On." That was the night the elders retired the Golden Zucchini.

Next morning at Sunday service our pastor endeared himself forever (to me, at least) when he apologized with a straight face for the length of his dress the night before. At least half the congregation hadn't even been there. They looked around, aghast. Our pastor in a dress? Too short!?

Alas, Untalent Night. We are all but poor players, strutting and fretting our hour upon the stage.

—TIM GILMER



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CONTRIBUTORS



JUNE 2014

A North Dakota native who calls the majestic mountains of Western Montana home, MARK J. BOATMAN joined *NEW MOBILITY* in 2012 as a news columnist and freelance features writer after graduating from the University of Montana with a bachelor's in journalism. Besides being an ardent disability rights advocate, researcher and writer, Boatman enjoys spending time in the great outdoors, digital photography and doting on his frisky pug, Frankie.



A former newspaper features editor, SUSAN M. LOTEMPIO has published articles on the disability experience in *NEW MOBILITY*, *The New York Times*, *Dallas Morning News* and the *Buffalo News*. Currently she writes the SpokeSpeak blog for *newmobility.com* and contributes freelance features and cover stories. As a wheelchair user after having polio at the age of 8 months, she plans to spend her retirement years on as many cruise ships as possible searching the world for accessible vacation spots.

Injured in a motorcycle accident in 1976, RICK HAYDEN went back to school and received a bachelor's degree from Springfield College and Westfield State College — both located in Massachusetts. In 1987 he went to work for Everest & Jennings in Los Angeles and has worked in the rehab equipment industry for almost 28 years. He is currently employed by Icon Wheelchairs. Married, he has five children, four grandchildren, loves collecting music and is a die-hard New England sports fan.



Since a C5-7 spinal cord injury in 1988, MICHAEL C. COLLINS has become known as a "boundary spanner" for bringing information about disability and accessibility to the attention of those who may have never considered the subjects. Collins began writing for *NEW MOBILITY* (when it was known as *Spinal Network Extra*) in 1991, covering the challenges and rewards of daily life from a wheeler's perspective. He attributes much of his success to an ability to convert frustration into actions necessary to achieve change, and he strives to share that information in his writing.

CALL FOR DECEMBER STORIES

As part of our series celebrating 25 years of *NEW MOBILITY*, our December 2014 issue will feature stories written by readers who want to share their personal experiences detailing how NM made a difference in their lives. We have received anecdotes and messages from many of you over the years about how you discovered *NEW MOBILITY* at a critical time in your life. Perhaps you were new to the world of disability and were encouraged when you found out there was such a thing as disability culture. Or maybe you were no stranger to life on wheels but found a specific story, personality or product in these pages that in some way changed your life for the better. Whatever it was or is, this is your chance to craft your experience into a first-person narrative of 500 to 1,500 words that will communicate to tens of thousands of readers. Send your submissions, along with appropriate contact info, to tgilmer@newmobility.com by September 1. Your story may be one that we'll select to run in our December issue. Good luck!

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I do think there needs to be further training with TSA.

First-Time Flyer

I flew for the first time last year, and while it was not the worst experience, it did have its ups and downs ["Taming Our Fear of Flying," April 2014]. I do think there needs to be further training with TSA, the crew that helps with transferring people into and out of their wheelchairs, and the ground crew that handles storing the wheelchairs. I do like all the tips in the story, some of which I used when I flew and some I did not know about. I do hope to travel again.

Tiffany Poland

Via newmobility.com

Tips From Frequent Flyer

Good article ["Taming Our Fear of Flying"], but as a C6 quad who takes about 30 flights a year for my work, the information provided is incomplete in terms of helping those who do not fly or are afraid to fly. Here are some tips I have found to be helpful:

Your airline choice matters, but often you will not have a choice of carriers unless you are going from one major airport to another. Your wheelchair will not fit on 95 percent of planes. Even if it fits, it will only get to a few seats that are emergency row seats by

the cabin door. You may not be allowed to sit there. Bathrooms are not accessible on planes. I've never seen one in over 200 flights. Bring two empty Tropicana orange juice jars in a plastic shopping bag on your carry-on. Empty your leg bag into it. No

one will notice or care. Tie it up in the plastic bag and have your friend throw it out or just leave it on the floor tied up.

Always check in at curbside. Remove

everything from your wheelchair (pouches, bags) and body (jackets). Every U.S. airport has a line for wheelchairs to make your wait shorter at security. It varies by airport how much time you'll save, but find that line.

Once you clear security, head to your gate to arrive about one hour before boarding time. If you have more than one hour, buy bottled water and food. The plane may serve beverages, but not enough to keep you hydrated. Also, if your flight lands at night, your destination airport may not have food stores open.

Wait in front of the gate agent counter. You want to be first in line to talk to the gate agent, especially if you were not given the bulkhead aisle seat and your helper/friend/spouse was not given the bulkhead middle seat when you booked

your flight. Check SeatGuru.com to find out details on any seat on any flight.

David Birnbaum

Via newmobility.com

Viva Pazzo Pazzo!

Wild! I recognized the name Pazzo Pazzo, but when I read further ["Ashley Lauren Fisher: Full Force, Non-Stop," April 2014], I realized that I frequented it when I used to live there [Morristown, N.J.] years ago and wasn't in the mood for fish and chips at the Dublin Pub. There are many good places to eat in MO Town, and Pazzo Pazzo was always at the top of the list. It's been many years since I moved to Georgia, but I always recommended ya'll to others as a

Flying: not a breeze but doable with insider tips.

great place to dine. I'm glad to see that a disabled person is behind much of the operation and inspiration. I was not disabled back in 2005 when I moved. I admire your conviction, Ashley, and those who support(ed) you!

Grant Brown
Via Facebook

Kudos for Tackling This

I'm a para with 40 years experience. Your article on having a colostomy was very good ["Colostomy Pros and Cons," April 2014]. A friend injured in the same auto accident that paralyzed me had a colostomy for 15 to 20 years before I got mine. There are advantages and disadvantages. The odor and mess of a failed colostomy appliance is less than the social stigma that accompanies the same problem without the procedure. Kudos for tackling this important issue.

Arvin Post
Via Facebook

All Professional

As far as I can tell I am accepted at work ["At Work, Are You Just One of the Workers — or Special?" April 22 blog by Sue LoTempio]. I try to keep an iron skin, project confidence and competence. I am an attorney working as an administrative law judge for a state agency. I manage three other attorneys and five paralegals. My interactions with co-workers, staff and parties appearing in front of the agency are all very professional. The couple of site visits to not terribly accessible construction sites and power generation plants have been very matter-of-fact in how they are handled (as far as what is reachable by wheelchair and what isn't). Travel has been very professionally handled as well. All in all, work has been about being able to do the job and not about being "special."

JP
Via newmobility.com

Editorial Submissions

Please send letters to the editor or story ideas to tgilmer@unitedspinal.org



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Accessible Taxi Policy Becomes Official

On May 1, the New York City Taxi & Limousine Commission unanimously voted to increase the number of wheelchair accessible taxis to 50 percent of the entire fleet by 2020. Beginning in January 2015, a 30-cent per ride surcharge will be applied to the 13,000-plus yellow cabs and street-hail borough taxis, eventually increasing the number of yellow wheelchair accessible taxis from the current 405 cabs to at least 7,500.

"This victory is the result of 15 years of litigation by United Spinal Association and other disability advocates," said James Weisman, general counsel for United Spinal Association. "The increase of access to all modes of transportation to the public will enhance the employability and lifestyle of wheelchair users or people with mobility impairments who wish to live, work and travel in New York City," he added.

"Reliable accessible transportation changes my life," testified Ronnie Raymond, a United Spinal board mem-

ber and wheelchair user who spoke during the TLC hearing just prior to the vote. "I want to have a life that is meaningful, affordable and achievable," she said, echoing the views of the many disability advocates who had gathered at the TLC headquarters to support the historic vote.

Weisman added, "The measure adopted by the TLC will create sufficient funds to purchase and maintain accessible taxis as well as to create a dispatch for accessible borough taxis."

The plan also has the potential to dramatically reduce the city's Access-A-Ride costs (\$500 million this year) and exorbitant Medicaid ambulette costs (\$200 million this year), noted Weisman.

People in the News: Marilyn Saviola

Getting routine medical screenings can be a stressful challenge for women with physical disabilities, but it's also a matter of life and death. Women with mobility impairments aren't at a higher risk for breast cancer, but they are one-third more likely to die from it. This sobering statistic has motivated Marilyn Saviola — who runs the Women's Health Access Program for Independence Care System in New York City — to fight for care that every woman deserves.

In seven years, Saviola has greatly increased the accessibility of breast and gynecological care for many women who haven't been to a doctor in years because of past bad experiences. The women's health project launched in 2008 with a grant from Susan G. Komen Greater NYC. It was a difficult and slow beginning, but Saviola found a local partner to provide mammography services to her clients. Soon three other partner sites were added along with gynecology services. The New York City Council also budgeted \$5 million to purchase accessible medical equipment for the program's partners.

Education has been a core component of the program. Often medical professionals haven't received any training on disability and aren't aware of their responsibilities to the patient. "Many times they think they can't transfer someone because if they get hurt, it's a liability," she says. "They don't realize there's a greater liability if you refuse people services." The program notifies medical professionals about their legal responsibilities in providing care to patients with disabilities.

It's been a long, rewarding journey for Saviola, but there is much that is left to do. "It's late in the health care game to finally address these crucial issues, but the health of people with disabilities has suffered for far too long," she says. "It's time to make health care accessible throughout New York City."



ADA Legacy Project Bus Tour Kicks Off in July

It may be another year until the Americans with Disabilities Act turns 25, but the ADA Legacy Project is launching a cross-country bus tour this summer to celebrate and raise awareness of the historic civil rights law.

The yearlong tour begins July 25, 2014 in Houston, the home of President George H.W. Bush, who signed the ADA into law. During the tour, visitors in each city will be able to view displays featuring historic

\$164K AVERAGE COST OF A NEW DIGITAL MAMMOGRAPHY MACHINE

\$120K COST OF TREATMENT FOR ONE STAGE 3 OR 4 BREAST CANCER PATIENT

67% PERCENT OF CLINIC ADMINISTRATORS CLAIMING DISABLED PATIENT NUMBERS ARE TOO LOW TO JUSTIFY BUYING ACCESSIBLE MEDICAL EQUIPMENT

Sources: BlockImaging.com; Susan G. Komen Foundation; UNLV study

photos and documents.

Raising ADA awareness is important, especially in light of the initial failure to include the disability community in the Civil Rights Summit recently held at the Lyndon B. Johnson Presidential Library. "For people not to value our rights and the ADA at the same level as other people's rights and their civil rights laws says there's a lot of need for awareness," says Mark Johnson, chairperson of the ADA Legacy Project. The oversight was corrected as Lex Frieden was belatedly included in the celebration, but it reminds Johnson of the ground yet to be gained. "Social and systemic change takes a long time even when you have civil rights laws," he says.

The tour ends in Washington, D.C., in July 2015, as part of the ADA 25 Gala, March and Rally, hosted by the National Council on Independent Living. For more information on the tour please visit adalegacy.com.

ADA Penalties Get Stiffer

As of April 27, those who fail to provide public accommodations under Title III of the Americans with Disabilities Act now face heavier civil penalties from the U.S. Department of Justice. This is the first time these penalties have been raised in over 10 years.

Even though the increased penalties are good news, James Weisman, general counsel for United Spinal Association, suggests this isn't really something to get excited about. "It's clearly beneficial to people with disabilities because it makes the penalty more significant, but in fact it's not an enormous development or some new commitment by the federal government," he says.

According to the DOJ, the maximum civil penalty for ADA violations will increase from \$55,000 to \$75,000. All subsequent offenses will rise from \$110,000 to \$150,000. The increases were announced in the March edition of the Federal Register. The penalties were last adjusted for inflation in 1999.



19,765,514

POPULATION OF EIGHT MAJOR CITIES LISTED ON ADA BUS TOUR

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— U.S. CENSUS BUREAU

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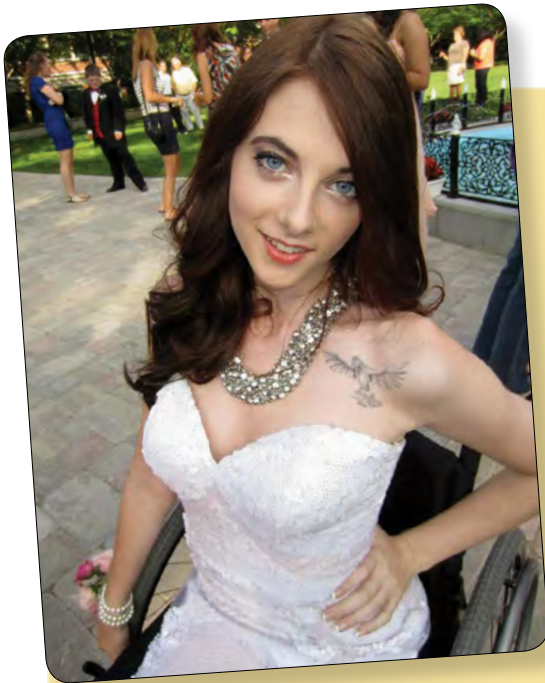
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By Tiffany Carlson



“I never wanted to be that person in a wheelchair who wore sweat pants because it was easier.”

Fashionista on Wheels

Sometimes we are blessed with a beautiful face, but for whatever reason we can't see it ourselves. This is exactly what happened to Brianna Scalesse, a T12 paraplegic and Trinity College sophomore from Hartford, Conn.

Injured when she was just 6 years old in a car accident that killed her mother and left her in her grandmother's care, Scalesse had a hard time being different growing up. "I constantly day-dreamed about waking up one day and being able to walk," she says. But she didn't let that unfulfilled daydream stop her.

As a little girl she had parties at her house for her and her girlfriends, creating her own social circle. She also embraced how she looked in her teens, skinny legs and all. "I thought that if I could walk, more boys would be interested in me and I would feel more beautiful," she says. "But in college

I realized confidence is 10 times more important than how you actually look."

Much of her confidence comes from her experience with fashion. "All of the women in my family have a great sense of style, and I learned from them. I never wanted to be that person in a wheelchair who wore sweat pants because it was easier," says Scalesse. "I've been picking out my next day's outfit and jewelry the night before for as long as I can remember. When I'm wearing the perfect outfit, I just feel right."

For women who use wheelchairs, Scalesse recommends dressing boldly. "Wear what you want to wear, and don't let the chair stop you. Wise beyond her years at only 19 years old, she has already figured out how to love who she is — something that can take many people with disabilities much longer to figure out.

The Ultimate Wheelchair Home Gym

Over the years there have been several universal gyms created for wheelchair users. While some were definitely better than others, there has been nothing like the Wheelchair Fitness Solution — a training system designed exclusively for wheelchair users that offers 30 different exercises.

Featuring a central stackable weight unit, various extensions for training your upper body, as well as a harness that helps you achieve maximum resistance, this training system can replace most free-weight sessions. It also offers much more than just free weights; resistance training is possible.

The Wheelchair Fitness Solution includes additional features like a pulley system, a punching bag, hand-pedaling, parallel bars, chin-up bar and quick release harness clips for transitioning between exercises. Your arms, shoulders, chest, back and abdomen can also get a traditional workout on this machine.

With so many exercise possibilities, you may be able to cancel that gym membership. See for yourself: www.wheelchairfitnesssolution.com.



Quad's New Band Drops First Video

Injured nearly five years ago in a diving accident, former music student Gabe Roderick, 20, a C5-6 quad from Minneapolis, Minn., has gone on to start his own band, Treading North. Their single, "Dunes," from their album *Beautifully Gone Wrong*, is one of the coolest music videos you'll ever see featuring a wheelchair user: www.youtube.com/watch?v=H0drw3ITMdl
Learn more: www.treadingnorth.bandcamp.com

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1997-2000: Our Bodies, Ourselves



Perhaps there was something about the closing of a millennium that led us to reflect on ourselves and our place in culture. Whatever it was, 1997-2000 was a time of focusing on issues that affected us deeply. NM began publishing an annual women's issue in 1997 — powerful voices speaking not only from unique perspectives but also from a shared sisterhood. Acclaimed essayist Nancy Mairs reflects on body image from the viewpoint of a woman coping with advancing MS. Harriet McBryde Johnson captures how her appeal as an attorney is inextricably bonded to her lifelong disability in the eyes of a curious jury. And Gretchen Schaper (now Ryan) fearlessly leaves her wheelchair and crawls on campus, exposing not only her bodily weakness, but her invincible character. Our vulnerability came into uncomfortable focus with another issue — assisted suicide. Richard Holicky touches all the bases in his “My Dinner with Death.” And Jean Dobbs sheds light on what humbled and motivated one of our most beloved activists, Justin Dart.

NEW MOBILITY, OCTOBER 1997

The Body in Trouble

Here is my troubled body, dreaming myself into life: a guttering candle in a mound of melted wax, or a bruised pear, ripe beyond palatability, ready for the compost heap. The images, though they vary, always bear the whiff of spoliation. If there ever was a time of unalloyed love, I have long forgotten it, though I had hopes in early adolescence: that my breasts would grow magically larger and my mouth magically smaller; that I would become a strong swimmer and sailor and cyclist; that men, irresistibly drawn, would touch me and I'd burst into flame. Mostly I was, as I was trained to be, disappointed in myself. Even in the '50s, before the dazzle of shopping malls and the soft pornography of advertising for every product from fragrance to bed linen, a girl learned to compare herself unfavorably to an ideal flashed at her on glossy magazine covers and cinema screens, and then to take measures to rectify her all-too-glaring deficiencies. I started painting my lips with Tangee when I was 11, polishing my fingernails as soon as I stopped biting them, and, for my first great love at 13, plucking my eyebrows. At 16, it was green eye shadow. I strapped on padded bras and squeezed into panty girdles to accentuate the positive and eliminate the negative. I could

not imagine a body that didn't require at least minor structural modification.

I still can't, and neither can any other woman I know. Not long ago, my mother and I shared a mirror as we put on faces for a festive evening. “I hate these,” she said, drawing her fingers down the lines from the corners of her mouth, “and this,” patting the soft sag of flesh under her chin. I didn't protest, though she is a pretty woman, because I hate the same features now developing in my own face. One sister's breasts hang down, she laments, and the other's hips are too broad; my mother-in-law's bosom is too ample; even my daughter, possessed of a body too shapely for complaint, rues her small round nose. All these women, ranging in age from 30 to 84, are active and fit, and fortunately they are too absorbed by their demanding lives to dwell upon whatever defects they perceive themselves to display. None could be considered vain. Not one has mutilated herself with rhinoplas-



BY NANCY MAIRS

ty or liposuction or any of the other measures cosmetic surgeons have developed for emptying women's pockets into their own. Their dissatisfaction with their bodies seems as natural to them as their menses or hot flashes, simply an element of womanly existence.

Even if I hadn't developed MS, then, I'd probably view myself with some distaste. Now, in

my 50s, I divide my time between wheelchair and bed, my belly and feet are swollen from forced inactivity, my shoulders slump, and one of my arms is falling out of its socket.

The other day, when my husband, George, opened a closet door, I glimpsed myself in a mirror recently installed there. “Eek,” I squealed, “a cripple!” I was laughing, but as is usually the case, my humor betrayed a deeper, darker reaction.

Reprinted from Waist-High in the World: A Life Among the Nondisabled, 1996. By permission of Beacon Press.

NEW MOBILITY, OCTOBER 1999

A Disability in Full

BY BARRY CORBET

The car door opens. A young woman places her feet outside, then drops to the ground. She begins to crawl, alone, along a sidewalk. A skateboarder rattles past, then people appear. Students. It's a long sidewalk, a big university.

It's not an able-bodied crawl. Gretchen Schaper crawls like the para she is, doing all the work with her arms, feet splayed behind her. More students. They can't seem to see her. There's a groundskeeper. He can't see her. She's invisible, untouchable. A cyclist glides past. People flow by.

Once I got the idea of going to school like everyone else, wheelchair-free, how could I resist? The piece was an experiment and an opening for discussion — not about Gretchen crawling like a pre-toddler to college but about the unexpected, about speed, height, disability, endurance, strangers, pain and the human condition.

In crawling, I was exhibiting my disability in full.

— Honors thesis

There's a crowd now. As Gretchen crawls along an arched courtyard, the students act simultaneously as if she's nonex-

istent (they glance but pretend they didn't) and as if she's contagious (they give her the widest possible berth).

She lowers herself down three steps, sits momentarily in the blown-in trash at the bottom, then resumes her crawl. Nobody speaks to her. Twenty minutes into this journey, nobody has spoken to her directly.

She crawls up a short ramp, through an automatic door, and into the fine arts building. She crawls past a drinking fountain and the sound of toilets flushing. Nobody talks to her. She's there, but she's not.

That's the video. This is me: This is amazing to watch. How can anyone withstand such brutal isolation.

Hostile reactions? I don't know. I don't think so. Part of it's who I am — I'm a girl, I'm young, I've got a pretty face, so I think other people could be more capable of evoking more hostile reactions. I have a sweet look, you know?

— Interview the day before

I did feel hostility. I really did. A lot of scoffing. Like four people addressed me all day. It was amazing how many people

pretended they didn't see me. And a lot of, "Oh, she just wants attention."

— Interview, the day after

She crawls into a classroom and hoists herself on to a hard plastic chair. Later, she transfers to an upholstered chair with casters. Wheels! After class, a man pushes her into the john. Then it's back to the floor and on to another class.

At last someone calls her by name and embraces her. It's a friend, one who uses a wheelchair. Gretchen transfers onto the wheeler's lap and they visit the restroom together. Human contact, girl talk with someone who understands. Gretchen's on the floor now, washing her hands at the sink above her head. She's sitting in splashed water and wadded-up paper towels. Then she heads out the bathroom door and down the hallway.

I'm curious about people's reactions. In my chair, I fit in so well because I can move as fast as a walking person. When people sit down, I'm at the same height. But on the ground — I'm interested that it's acceptable to be at a certain height, but it's not acceptable to be on the floor.

And I think about how many people in the world don't have the wheelchairs we do. Technology has made it so much easier for me to be amongst nondisabled society. Sometimes people have to make do.

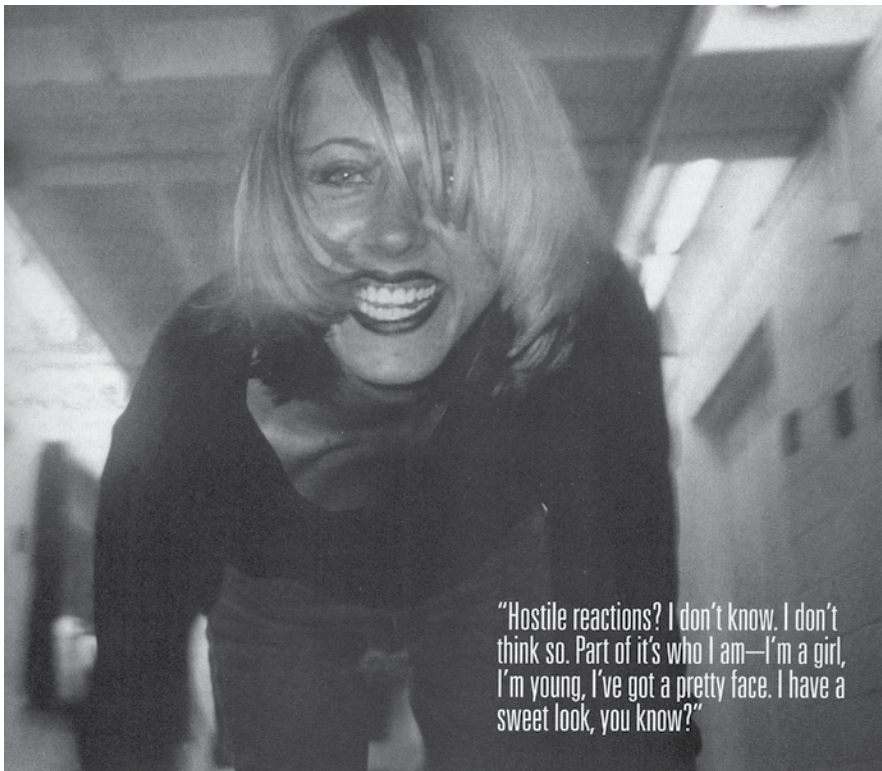
— Interview, the day before

She crawls across the courtyard to the student union and into the cafeteria. There's a mob, and it acts as if a woman crawling on the floor with obvious difficulty is ordinary, not worthy of note. How can this be ordinary?

She crawls through the food line. From the floor, she hands her money to the cashier. Omigod, is she going to eat off the floor? I hope not. I don't want to watch that.

It takes so much strength to be in such a vulnerable position. It's such a juxtaposition for me — I'm in really good shape and I'm healthy, but to the outside world I often appear sick and vulnerable. And without my chair, I really will be.

— Interview, the day before



"Hostile reactions? I don't know. I don't think so. Part of it's who I am—I'm a girl, I'm young, I've got a pretty face. I have a sweet look, you know?"



NEW MOBILITY, OCTOBER 1997

Self-Esteem: What Helps? What Hurts?

GET REAL

Now my self-esteem is very high, but if you had asked these questions a few years ago, the answer would be totally opposite. The media does not present a true image of any woman in society, disabled or not. And the people with disabilities that they present to the public are only the “good-looking ones” — they’re never overweight and never, ever have more than one impairment at a time. The thing that helps is remembering who I am and what is really important.

*Kathy Hoell, 42, quadriplegic
Graduate student, Omaha, Nebraska*

IGNORE IRRELEVANCE

For some reason I feel just fine about my body. Mass media has little impact on me, except for the harm I see it doing to my female students. I try to make them aware, as I am, of the manipulation going on there, and of its total irrelevance. What helps? Being busy, happy, having children and good friends, a satisfying job — all those make appearance a lot less important than it might otherwise be.

*Anne Kelly, 49, T9 para
High school counselor,
Nacogdoches, Texas*

IN TV HELL

My disability has affected my self-esteem a great deal. Actually, not so much the wheelchair, but the fact that I’m a quad and can’t get enough exercise to lose the fat I’ve gained since my injury. I look in the mirror and I hardly recognize myself. I know a lot of my low self-esteem comes from society’s expectations of what a beautiful woman should look like, and even though I disagree, I can’t fight the negative feelings I have about my body. I yearn to look like the thin, muscular women in commercials and TV shows. But this envy did not come from being disabled — I had the same feeling before — but it has gotten stronger since my disability.

*Corie Jones, 26, C5 quad
Student, Redding, California*

ADAPTIVE THINKING

My self-esteem has changed. People react differently. But when the wind changes, all you can do is adjust your sails. Knowing that helped a great deal. I had to adjust how I feel about myself.

*Deborah McCreath, 30, C7-8 quad
Ms. Wheelchair Ohio, Cleveland, Ohio*



Vote each month on your favorite cover from the featured time period, this month at www.surveymonkey.com/s/NMcovers3. In October, we’ll share the seven most popular covers from 25 years — vote again, and see NM’s best cover of all time in the December issue.

NEW MOBILITY, DECEMBER 1998

Power Dressing

By power chair, I zoom toward the Four Corners of Law, the old heart of Charleston's legal community. It's the first day of a federal jury trial, and I'm a lawyer for the plaintiff.

I'm nervous, but I've suited up for the occasion. I can't wear those women-lawyer suits you see on television, but my raw silk turquoise dress drapes nicely around the curves of my back. I'm wearing my best black shoes. They're velvet, and cost \$6 at the local hippie store. And, of course, serious jewelry — a simple gold bracelet, pearl earrings, a sapphire ring. It's my kind of power dressing. They'll know I'm a force to be reckoned with.

There's a lot riding on the opening. Research shows that most jurors are convinced — or not — during opening statements. I've heard hints that I'm the wrong person for this job. It's an ADA case, and my client was fired, she says, because she told her boss she'd need back surgery. The problem is that, compared to me, she doesn't look like she has a disability. In fact, she looks great in a suit. The company lawyer will surely tell the jury there's no way this plaintiff can file an ADA lawsuit when there's nothing wrong with her. How do I convince them otherwise?

I stop obsessing and enjoy the ride. I know every bump in the slate sidewalks, every gap in the old bricks. I know when to slam full speed ahead, when to slow down, when to dodge. As I get closer, I merge with a stream of lawyers and clients striding on legs from downtown offices to court. I flawlessly navigate the challenging terrain without clipping any of them. I'm good. I belong in this world. Nobody can mess with me.

I stop for a line of cars. Beside me an elderly black lady waits at the bus stop and looks me over. I'm used to being gawked at, but this is different. She's looking at my clothes, my jewelry, my "look," and

BY HARRIET MCBRYDE JOHNSON

her smile is openly appreciative.

I nod at her the way we nod at one another in downtown Charleston.

"You look so beautiful," she says.

I give her the classic aw-shucks smile.

"You look just like a Doll Baby!"

A Doll Baby? Not a tough, terrifying litigator?

My smile freezes and I say, "Thank you, ma'am." She means well. And in a flash I know there is a certain Doll Baby factor at work. My body is undeniably small and rag-doll floppy. And, against the vivid turquoise dress, the extreme whiteness of my face and hands must look like — well, porcelain.

The traffic clears and I cross the street. I have one short block to get focused.

I'm jumpy when the judge calls for plaintiff's opening, but I find the spot where I

can meet the eyes of all 12 jurors. As I begin the expected formalities, I find the rituals restore a sense of confidence. Echoed on marble and mahogany, my voice comes back strong, clear, and just genteel enough. I'm ready to confront the issues. I explain about invisible disabilities. I review the evidence. Formality gives way to folksiness. One by one the faces show understanding, acceptance.

As I thank them for their attention, I'm conscious of 12 faces looking at nothing but me. Clearly, they're responding not only to my words, but also to my visible persona — to the tiny woman in a wheelchair, wearing gorgeous fabrics and precious metals and stones. A different kind of lawyer.

I turn back to the plaintiff's table and I know those two dozen eyes are watching the arc I make, like a skater, as my tires etch the plush carpeting. For a moment, I wish appearances didn't matter. I wish I could simply master the law and the evidence and do my job. But then I look back at the jury. They're still with me, and I'm glad.

The Doll Baby has spoken.

**'YOU LOOK
JUST LIKE A
DOLL BABY!
A DOLL BABY?
NOT A TOUGH,
TERRIFYING
LITIGATOR?'**

UPDATES

Since 2000, Nancy Mairs has published two more books of essays as well as her uniquely personal reflection, *A Dynamic God: Living an Unconventional Catholic Faith*, her ninth book — which a *Los Angeles Times* book reviewer tagged "a stunning collection."

Gretchen Ryan earned a second art degree in 2005 and has made a life for herself as a respected artist. Her work has shown in galleries in New York, Paris, Singapore, Brussels and Los Angeles. She is currently working on new paintings as well as portraits commissioned by Pamela Anderson of her husband's daughters and dog, to be given as gifts.

Harriet McBryde Johnson's account of her debates with Princeton bioethicist Peter Singer, "Unspeakable Conversations," caused



Johnson

a sensation in *The New York Times Magazine* while educating the mainstream public on how life with a disability can be as rewarding and fulfilling as any.

She wrote two well-received books before her death in 2008.

For 10 years, NM highlighted the work of great women wheelchair users such as Mairs, Ryan and Johnson in an annual Women's Issue. At a time when men with SCI dominated the landscape, we wanted to connect women with true peers around the topics of body image, domestic abuse, fashion, health, self-esteem and empowerment. (You can find a collection of articles on these topics and more at www.newmobility.com/2011/05/womens-issues.) In 2008, NM editors decided that women's concerns had been successfully integrated into the publication and that a dedicated Women's Issue was no longer necessary. Let us know if you agree by emailing jbyzek@unitedspinal.org.

NEW MOBILITY, MARCH 1998

And Justin for All

BY JEAN DOBBS



Justin Dart dreams big: Love, empowerment, truth, freedom and justice for all. But the great orator of the disability rights movement also has struggled with his own pettiness. “When I was a businessman and athlete in the ’50s,” he says, “I thought that disability rights activists were a bunch of old ladies talking about infirmities, while I was out doing important, macho things.”

Now Dart, 67, a full-time independent advocate in Washington, D.C., admits his faults like a fallen evangelist. “I made every fashionable mistake — alcohol, prescription drugs, womanizing, divorces, bad mouthing, big mouthing, bad parenting and outrageous self-advertising.”

His turnaround couldn’t be more dramatic. On Martin Luther King, Jr. Day, Bill Clinton presented Dart the Presidential Medal of Freedom, the highest civilian award for service to the country. The award honors Dart as a leading architect of the Americans With Disabilities Act and a driving force behind its passage.

“Justin Dart,” declares the certificate, “has earned our thanks for helping us to realize the possibility within each individual and for tenaciously advocating equal access to the American Dream for all our people.”

* * *

Justin Dart Jr. spent his youth playing the rotten little rich boy — hurling insults at anyone who would listen, and, among other accomplishments, breaking Humphrey Bogart’s demerit record at Andover prep school. He abandoned his obnoxious antics — but not his basic

rebelliousness — only after a near-fatal bout with polio in 1948. He emerged from the hospital humbled by the kindness he received there and by his new status as a wheelchair user in a land of conformity.

Dart was 20 years old and lost. He felt pressured by his father to continue on the elite track, but he needed to assert his independence. “I was searching for something to believe in,” he says. What he found was Gandhi’s book, *My Experiments With Truth*. “It gave me a vision, a passionate vision that permeated my whole consciousness and still does. It’s a pretty simple idea — to find your own personal truth and live it — but it takes a lifetime of experimentation.” ...

Dart’s father soon tapped him for a risky venture overseas: launching Japan Tupperware. Dart made good in two short years, growing the company from four employees to 25,000. But the corporate life led him astray.

“I got off the Gandhi track and got on the Donald Trump track,” Dart says. “I told myself that this was my truth, so I’m going to go along with the system and infiltrate it with a more profound truth. But I found that I was conning myself and I was just doing the ordinary thing: being flamboyant and doing photo ops, making money by any means, drinking and chasing women.”

When he resigned from Japan Tupperware, he started a greeting card company that benefited people with disabilities. Still, the flashy lifestyle was at odds with his humanitarian urges. The press called him St. Justin in a Wheelchair, but Dart knew he was a fake. And after a 1966 media event at a Saigon “institution” for children with polio — a 15,000-square foot pavilion with a tin roof and a concrete floor — his self-disgust became intolerable.

“The floor of the whole place was covered with children ages 4 to 10, with bloated stomachs and matchstick limbs,” he recalls. “They were starving to death and lying in their own urine and feces,

covered with flies. A little girl reached up to me and looked into my eyes. I automatically took her hand and my photographer took pictures. She had the most serene look I have ever seen — and it penetrated to the deepest part of my consciousness. I thought, here is a person almost dead, and she knows it. She’s reaching out for God and has found a counterfeit saint doing a photo op. I was engulfed by the devastating perception that I have met real evil, and I am part of it. The way I’m living and dealing with disability is killing this little girl. I’m going to go to my hotel, drink Johnnie Walker, eat a steak, and this picture is going to be in some magazine. I told [my fiancée] Yoshiko, “We cannot go on as we have been. Our lives have got to mean something. We have got to get into this fight and stop this evil.”

Dart was a quick study, and he spent the 1980s as a government appointee in posts that included vice chair of the National Council on Disability, head of the Rehabilitation Services Administration and chair of the President’s Committee on Employment of People With Disabilities. All tallied, Dart held five gubernatorial, one congressional and five presidential appointments in the area of disability policy.

Predictably, he aspired to be more than a policy wonk. Many of his reports and recommendations helped shape the ADA, but he poured his real energy into ensuring its passage. Wearing his now-famous ADA cowboy hat, he visited every state several times, spoke at every possible forum and haunted the halls of Capitol Hill. He became a nagging conscience to the nation.

His relentless advocacy — along with the work of many others — finally paid off with the signing of the ADA in 1990. Afterwards, members of Congress are said to have joked, “We had to pass the ADA to get that hat out of the halls.”

NEW MOBILITY, SEPTEMBER 1999

My Dinner With Death

BY RICHARD HOLICKY

What's wrong with assisted suicide?" my friends asked. "If people want to die, who are we to stop them?"

Over an appetizer, I reminded one of how quickly he had intervened when his daughter expressed suicidal desires.

"She was a teenager. She didn't know what she wanted."

"What makes you so sure that most people who commit suicide know what they want?"

"Look," he said, "I know I don't want to die in a hospital filled with tubes and needles and on a machine. I know I don't want to die in a nursing home. I know I don't want to die in a lot of pain."

"Who does? Is killing them the best solution?"

"So you're against assisted suicide."

"It scares me," I said. "I'm not sure it's a genie we can put back in the bottle. And I think there are better ways to put people out of their misery than by killing them. It sounds like one of those wacko epitaphs from Vietnam — 'We had to destroy the village to liberate it.'"

"Well, what's your answer?" they all asked.

"Making it easier for people to off themselves implies that terminal illness or permanent disability are just inconveniences, something to be avoided or eliminated or aborted. What's to stop us from eliminating defective humans? The Nazis did it."

"The Hemlock Society wearing swastikas? Government death squads? HMOs using Jonestown cocktails for cost containment? Did you forget your anti-paranoia medication?"

They were crowing by the time the main course arrived, and I tried again.

"Assisted suicide without universal health care coverage is ludicrous. Do our choices have to be between death or pain, death or the nursing home, death or life support? Can't we address the real-life problems instead of just pulling the plug?"

"You're talking about a personal world that doesn't exist," one said. "We're saying that when quality of life is gone, we should have the right to say 'enough.'"

"How do you know what's enough? I

didn't know for a couple of years after my injury what my quality of life could be. All I thought paralysis meant was burdensome and expensive and something I didn't want. I still don't want paralysis, but my quality of life's not bad."

They turned cynical: "You mean people should have to live in pain or isolation or without their dignity for years just to make sure they won't — perhaps — come to like it? You sound like the Nazi now."

"But it's more complicated than that. What if your care is bankrupting your family, what if your pain isn't treated or prescription drugs are too expensive or going to a Medicaid nursing home is too scary? What if you'll be forced to live way below the poverty level? Then assisted suicide might look pretty good. Assisted suicide may be a real choice if you approach the end of life in a rational state of mind and you're supported by a loving family with adequate finances. How many of us does that describe? It shouldn't be a financial decision or a pain decision or a living-situation decision. It should be a quality-of-life decision. Death shouldn't be the only option."

My friends remained unconvinced. Time for coffee and dessert.

"Are you saying that life under any circumstances is preferable to dying? You can't imagine reaching a point where life's just too tough?"

Snag.

"I wish I could," I said. "I'm incredibly ambivalent and fearful about death. I'm paranoid enough to think some people look at me and think, 'Take him out, he's too expensive,' but I don't know if I'm tough enough to look the Reaper in the eye and say 'Bring it on.' I'm not real comfy in bed with Jack [Kevorkian], but the Right to Lifers and Not Dead Yet people make me sort of nervous, too. I've watched friends die some pretty ugly deaths. I can think of situations where I'd probably go for the full Kevorkian. Without legalized assisted suicide, I won't have to make the decision."

Imagine my surprise when closing time arrived and nothing had been resolved and all our opinions remained unchanged.

SIGNS OF THE TIMES

WORTH FIGHTING FOR: WOMEN'S RIGHTS; FREEDOM FROM PRESURE TO DIE; PRISONERS' RIGHTS

SPORT WITH GROWING STREET CRED: WOMEN'S WHEELCHAIR BASKETBALL

ON THE EMPLOYMENT FRONTIER: ARTISTS WITH DISABILITIES



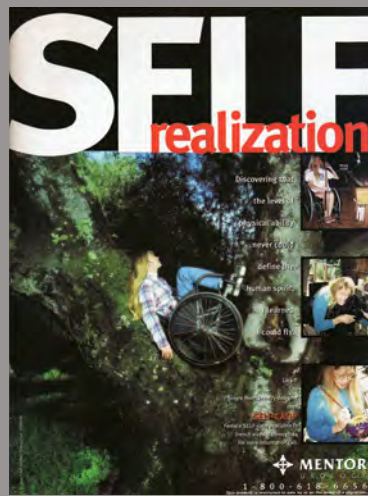
"The Big Wedding Dilemma" was part of Elisa Terranova's stunning "Up from the Ashes" series, painted post-quadruplegia.

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MEDIA MILESTONE: BREATHING LESSONS: THE LIFE AND WORK OF MARK O'BRIEN

HOT TOPIC ON THE NEW MOBILITY.COM MESSAGE BOARD: SEX SURROGATES

PROGRESSIVE AD IMAGES: MENTOR'S SELF (CATH) CAMPAIGN



On Assisted Suicide

Satisfactory safeguards cannot be established in the context of society's current health-care system and anti-disability bias."

— DIANE COLEMAN

"You do not need to be pro-abortion to support the rights of a woman to determine what happens to her own body. Nor do you need to be in favor of suicide to support physician-assisted suicide. You simply must realize these are personal issues."

— LARRY KOHOUT

"Activists in the disability community have for years complained that doctors have too much power over their lives. Why then would we consider giving additional life-and-death power to physicians?"

— JULIE MADORSKY, M.D.

"To believe that economic demands will force the medical profession to start murdering us in our beds by withholding life-saving medications and medical help is paranoia of the highest order."

— LORENZO MILAM

"I worry that others may be self-righteous and do what is best for others and not for me. I don't believe anyone has the right to play God with my life."

— THOMAS MATOLA

"I will protest anyone being forced to 'choose' suicide; that is murder. But to forbid someone who wishes to die a physician or anyone else to assist is no choice at all."

— SUE PENDLETON

"Death with dignity is an oxymoron."

— CARLOS AMANTEA

On Jack Kevorkian:

"He seemed to take such glee in knocking people off. I thought that all many of his patients needed was some Prozac and therapy."

— ROBERT SAMUELS

"Most of those he killed were not terminal. Many had MS, which I have lived with for years, and some were less symptomatic than I am."

— LAURA R. MITCHELL

"Kevorkian did not stalk disabled people and kill them in alleys. Every individual he assisted came looking for him."

— CHRIS STEINBERG

"He is the wrong guy doing the right work."

— DANIEL BARNES

THE 'DEATH-WITH-DIGNITY' LAWS BEING PROPOSED IN SEVERAL STATES ARE SEEN AS EITHER ENLIGHTENED LEGISLATION OR PENDING GENOCIDE. TO BOTH SIDES, YOU'RE EITHER A TRUE BELIEVER OR A TRUE JERK. WHY ARE WE SO BEACHED ON OUR DOGMA? — BARRY CORBET

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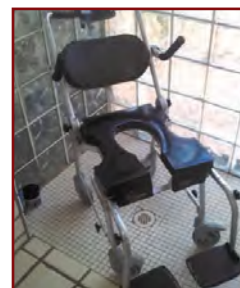
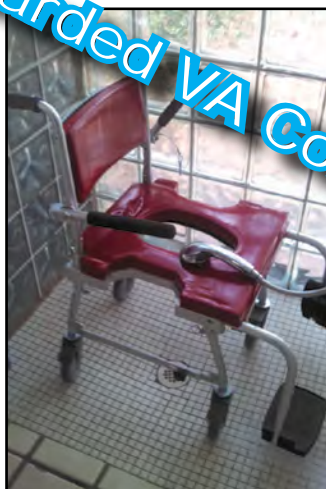
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Accessible Electric Cars: Soon?

BY IAN RUDER



The Kenguru

In 2012 some pictures of a bright yellow mini-hatchback vehicle designed specifically so a wheelchair user could roll in via a ramp and drive from the comfort of their own wheelchair went viral. There weren't many details available, but the vehicle, called the Kenguru, looked slick and seemed to fill a need by providing an easy-to-use option for wheelchair users who didn't want a modified van or the hassle of transferring in and out of a car.

Viral fame didn't translate to immediate success for the vehicle. Funding issues and logistics problems have slowed the Kenguru's roll to market. That delay has provided time for two new companies — Chairiot and EcoCentre — to come on board with their own hopes of carving out a new niche in the mobility market. Based on the prototypes each company has been showing and information from their websites, all three aim to offer aesthetically similar takes on a small electric low-speed vehicle just big enough for a manual wheelchair user to roll in the back. Their amenities and technical specs differ, but they all promise the ability to drive for five to eight hours at speeds of up to 25 mph on a single charge.

Whether any or all of them will actually deliver a vehicle to market remains to be seen. No one has actually purchased and driven any of the companies' current models. Kenguru built 15 vehicles a year ago and sold them to European dealers but has not made any of a since-retooled model. At press time, Chairiot executives were meeting with their manufacturer in China and optimistic the first Chairiot solos would be shipped stateside in May. EcoCentre president Ramon Alvarez says his company is in the process of finalizing documentation and agreements for the Eco Mobility. He hopes to start taking orders in two to three months. But with expected prices ranging from \$18,000-\$25,000, top speeds of 25 mph and limited interior space, will the companies be able to rekindle the enthusiasm those original pictures generated, and will they be able to find a market to sustain this new vehicle-type?

The Issue: Price and Practicality

The two biggest questions wheelchair users I spoke with had when asked about

Actor Regan Linton demonstrates how the Chairiot can back up to a sidewalk for easy access.



their interest in these new low-speed vehicles centered around their price and practicality. Specifically, why would I spend \$18,000-25,000 on a vehicle that can't go above 25 mph and can't go on all roads? And, is there enough space inside the vehicle for it to serve as anything more than a shuttle? For instance, can I go to the store or take bags with me?

Stacy Zoern, the founder and CEO of Kenguru, has heard those questions countless times. Zoern got involved and helped raise the funding to bring the Kenguru to America after inquiring about buying one for herself, only to discover that the Hungarian company behind it had run out of money. As a power chair user, Zoern wouldn't be able to use the current model of her own product, but she still sees a market for her product, even at the \$25,000 price level.

"I definitely realize that a lot of people in manual chairs can drive a regular car with less expensive modifications, and I recognize that for those people this current model is really more of a secondary vehicle — it's a moped for them," she says. "It's something that's a lot easier to get in and out of and is especially great when there is bad weather. You can open it from the remote while you're inside the building and then just zip out and roll in."

Ralph Megna, the president and CEO of Chairiot, says the choice between a low-speed vehicle and a car with hand controls is not mutually exclusive.

"The Chairiot is best suited for someone who finds transferring themselves to a conventional vehicle difficult or time-

consuming or tiresome," he says. "After that, the Solo works as a primary vehicle for those who cannot afford a modified van and for whom the exceptionally low cost of operation and the relatively low initial purchase cost is attractive. Or, as a second vehicle for somebody who enjoys the spontaneous freedom of a vehicle they can enter and drive off in less than 40 seconds."

Megna has been working to bring an accessible low-speed vehicle to the States since 2010. Until last spring, Megna was vice president of operations for EcoCentre, working to bring the Eco M to market. He left the company and started Chairiot, focusing on the Chairiot Solo. Megna downplays the importance of the obvious physical similarities between the three low-speed vehicles, saying that there are many differences in details and specs.

"If you put a Camaro and a Mustang next to each other, they're both two-door cars with long front hoods and short rear decks and an unusable rear seat," he says. "The basic concepts are very much the same, but they use different approaches."

Where is the Market?

Each company also has a different approach to selling their vehicles, based on different assessments of the market.

Alvarez has been demoing three Eco M prototypes throughout southern California for the last six to nine months and sounds confident the vehicle will sell itself if he can get it to consumers.

"The reaction and response has been phenomenal," he says. "Customers are wanting to order the vehicles right then and there." He shared the story of one customer who came to his warehouse to see one of the three prototypes he is cur-

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rently demoing and was “too overwhelmed” by the vehicle’s potential to actually drive.

“It’s almost overwhelming the acceptance of the vehicle within the mobility industry. We haven’t even begun to scratch the surface of what this car could represent to the mobility sector.”

At \$18,000-19,000, he is hopeful disabled veterans will use the one-time automotive grant available to them to pay for the vehicle. Low-speed vehicles could also qualify for state and federal tax exemptions. That said, Alvarez said making money isn’t his priority.

“Eco Mobility is not about the profitability of the company, because it’s a subsidiary of EcoCentre and the four other electric models we have are making money and sustaining themselves,” he says. “We just feel that if we put our grain of salt in the mobility industry, we can better the lives of some veterans and some civilians who had nowhere to go.”

Megna is looking at a similar price point for the Chairiot Solo, but says he has every intention of his venture being profitable.

“We did the math and we were still left with the belief that there is a market here in the United States for several thousand of these vehicles a year,” says Megna.

While Megna and Alvarez are primarily focused on domestic sales, Zoern



is also hoping to infiltrate Europe by taking advantage of the fact most European countries don’t let teens drive cars until they are 18, but do let them drive mopeds at 16. “The whole initial idea was let’s get a moped for teenagers,” she says. She acknowledges that \$25,000 is a lot, and says she hopes to bring the cost down, but doesn’t think it is unreasonable for the added freedom the vehicle provides.

All three business owners point out that the ability to avoid paying for gas will save owners a great deal in the long run.

When it comes to the vehicles’ lack of storage space, everyone knows it is an issue, but no one views it as a deal breaker. All three say they are working on ways to increase storage space, including racks and other design tweaks. Megna alluded to the fact the vehicle is named the Solo, suggesting a future product might add space or the ability for a passenger.

“If you are in a manual wheelchair and you go to the store, you’re probably not going to push a shopping cart full of grocer-

ies through the store,” says Megna. “You’re going to do a modest amount of shopping, which probably will lead to four to five bags of groceries. Four or five grocery bags will fit just fine.”

Despite all the answers and optimism coming from each of the companies, it will all be for naught if the vehicles don’t resonate with the customers in the mobility market. Dave Hubbard, the executive director and CEO of the National Mobility Equipment Dealer’s Association, has followed the industry for the last 13 years and says he can’t remember any other instances where three companies were trying to carve out a new niche in the market at the same time. He did not question the need for the accessible low-speed vehicles but did wonder about the demand. “I have not gotten any calls in here and that’s usually telling,” he says. **MM**

What’s your take? What intrigues you about these vehicles? What would you like to see? Respond to tgilmer@unitedspinal.org.

Resources

- Kenguru, 512/994-2634; info@kenguru.com, www.kenguru.com
- Eco M, 951/653-1200; info@ecocentre.us, www.ecocentre.us/eco_m.html
- Chairiot Solo, 888/642-8806; www.chairiot-mobility.com

The Tangled History of the Accessible LSV

In 2005, Istvan Kissaroslaki had just started working for Rehab Corp., a Hungarian medical supplier, when the emails started trickling in. Email after email kept asking about a vehicle his company allegedly built called the Kenguru. The emails described a small, low-speed electric vehicle that would allow its owner to roll in via a back hatch using a wheelchair and drive away without ever transferring. Kissaroslaki couldn’t find the vehicle in any of the company’s catalogs, so he trudged down to the basement with the head of research and development. In the corner of the basement, covered up and buried under two years of dust, sat two yellow Kengurus.

The head of research and development

explained that the prototypes had been showed off around Europe after winning a design award in 2002 and then returned to Budapest and consigned to a dusty death in the basement. Kissaroslaki saw problems with the prototypes — the driver had to use a special manual chair to drive, and there was not enough space for the casters to turn — but he was intrigued enough by the potential to ask the board for funding so he could keep looking into the Kenguru’s viability.

Rehab Corp. eventually partnered with Changzhou Greenland Vehicle Company, a Chinese company, to manufacture the vehicles. But three years later Rehab Corp. terminated the contract and ended its involvement with the Kenguru. Kissaroslaki

persevered and formed Kenguru Service LLC to pursue bringing the car to market on his own, eventually partnering with Stacy Zoern in 2010 to form Community Cars (now Kenguru).

Kissaroslaki and Zoern are now working with an Alabama company to manufacture a fourth generation Kenguru. In a strange game of business musical chairs, Changzhou Greenland Vehicle Company now shows a vehicle resembling the Kenguru on its website called the Kangaroo and has since partnered with Chairiot and EcoCentre to develop the Chairiot Solo and Eco Mobility.

- Kangaroo, Greenland Vehicle Company, www.gl-ev.com/en/main.php

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Discovering THE SAN JUAN IS

If the vacation you're craving this year calls for a mellow place that's an escape from stress, and also offers beautiful scenery and accessible adventures under bright blue and sunny skies, then set your sights on the San Juan Islands.

It's not Puerto Rico you'll be headed to, but an archipelago located between the state of Washington and Vancouver Island, British Columbia, Canada. At high tide, the San Juan Islands, officially part of Washington, have more than 400 islands and rocks, 172 of which are named. Four of the islands have become popular destinations for tourists and are accessible only by ferry, boat and airplane.

San Juan, Orcas, Lopez and Shaw islands feature unlimited opportunities to hike, kayak, whale watch and experience the spectacular scenery of ocean, mountains and pasture lands. There's also bountiful shopping, museums, arts

and crafts exhibits, as well as fine dining and casual eateries, and plenty of places to relax and soak up the sun.

For those who worry about rain in the Pacific Northwest, the islands are drier than most areas of Western Washington, with the last two weeks of July through the first week of August usually the driest period.

Can wheelers enjoy the scenery and participate in the adventures and tourist activities that the San Juan Islands offer? The islands can be hilly, and not all places are up to ADA standards, but Barbara Marrett, communications manager for the San Juan Islands Visitors Bureau, says there are ways to get around obstacles. "I'd say that most folks in the islands will go the extra mile to help those with disabilities get around or accommodate them," she says.

"The main issue to remember is that

the San Juans are islands that have a lot of rock bases and hills, so even in town and along the waterfronts there can be issues with running slope and cross slope when they have sidewalks," explains Rory D. Calhoun, a T12 para who lives in Graham, Wash. "Go there expecting some wheelchair access challenges, roll with the flow and you'll do fine."

Calhoun is familiar with the San Juan Islands both for his job (he's a recreation accessibility specialist for the state's Recreation and Conservation Office) and in his personal life (he's an avid boater and fisherman).

"When vacationing there, we just eat, drink and enjoy touring by car, stopping at different places and seeing the views by different spots on the islands," he says. That is, when he's not fishing or crabbing somewhere on the islands.

Calhoun advises visitors who use



Photo by Carl Silvernail

Photo by Cheyenne Black

ISLANDS

BY SUSAN M. LOTEMPIO

wheelchairs to consider taking their cars over to the islands on the ferries (see accompanying story for details) “for more physical access. The freedom of having your own vehicle is worth the hassle of long wait lines in summer and holiday weekends.”

To discover what vacation fun awaits, let’s do some island-hopping:

San Juan Island

This island, with 8,000 year-round residents, has much to offer: an alpaca ranch, valley dotted with cows or sheep, lavender farm, vineyards with a tasting room, and a forest that leads to the sea marked by two iconic lighthouses.

The one-square-mile seaside village of Friday Harbor is where the ferries arrive, and while “in the past it’s not been easy for those in wheelchairs to cover these

short distances and negotiate some of the steep sidewalks, that’s been changing for the better,” explains Marrett. The town has retrofitted four intersections with ramps and built new sidewalks with access to the airport, marina and grocery store, she says. Later this year, more new sidewalks with ADA ramps on one of the busiest streets will be added.

“Friday Harbor is the best island without a car because right at the ferry landing there are some shops and the marina,” says Calhoun. “Parts of the waterfront and town have steep hills but with help, sometimes I can navigate it. Power chairs would do OK.”

To go whale watching, particularly for orcas, Calhoun suggests heading to the west side of San Juan Island to Lime Kiln State Park, which, he says, has good parking and a very useable trail from the parking lot down to a viewpoint near the

water. The park also has an accessible picnic site, restrooms, .2 miles of hiking trails for bird watching and wildlife viewing and a lighthouse that’s described as “very photogenic.”

Also on the west side is San Juan County Park, which is another good spot to view whales from the day use area near the boat launch, Calhoun points out.

Other places to see on San Juan Island, with access information provided by Marrett of the Visitors Bureau:

San Juan Vineyards: There are ramps to all areas and tasting rooms are accessible, as are the chapel, pavilion and restroom.

Whale Museum in Friday Harbor: Only the downstairs is accessible with a few exhibits and a souvenir shop.

San Juan Island National Historical Park: This marks the sites of the U.S. and British encampments — the two coun-

GETTING TO THE SAN JUANS

The San Juan Island Ferry is free for people staying on one of the larger islands who want to visit the smaller islands.

By air: Kenmore Air has several daily flights to Friday Harbor or Eastsound airports from various Seattle-area locations. Free shuttle service is offered to and from their terminals and Sea-Tac airport.

Northwest Sky Ferry flies from Bellingham, and San Juan Airlines flies from Anacortes and Bellingham to the San Juans.

By ferry: The passengers-only Victoria Clipper leaves downtown Seattle for Friday Harbor on San Juan Island. It's about a three-and-a-half hour trip.

The Washington State Ferry accommodates cars and leaves from Anacortes to the San Juans. Anacortes is about an hour's drive northwest of Seattle. For information on access for passengers with disabilities and ferry schedules, go to: www.wsdot.wa.gov/Ferries

Rory Calhoun's Helpful Ferry Trip Suggestions:

- Washington State Ferries will park cars with access placards near the elevators on the ferries if you let them know in advance of boarding the ferry. Go here for more info: www.wsdot.wa.gov/ferries/commuterupdates/ada/
- You can apply for a disability travel permit.

If you need to have an attendant with you, the attendant rides for free in the vehicle.

- Owners of vans with lifts should be very clear on the need for room for the ramp to be deployed. They usually direct you to a specific spot in the traffic lanes for boarding.
- The first stop is at least a 45-minute boat ride with great views from the decks. Most of the bigger ferries leaving Anacortes have elevators, and you can get around the decks with ease.
- If you stay in the car, ask to be loaded in the front for a view.
- Be aware that ferry schedules are approximate and it's best to get in line at least an hour before leaving an island, especially on Sundays when returning to Anacortes. Try to be two hours early on Fridays when leaving Anacortes for the islands during the busy season — from end of May to September.



Photo by Jim Maya

Getting up close and personal with pods of orcas is one good reason to take the trip to the beautiful San Juan Islands.

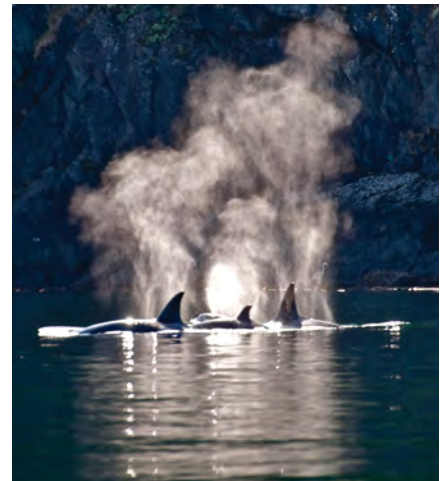


Photo by Jim Maya

tries settled ownership of the islands through peaceful arbitration. Its visitor center and restrooms at American Camp are accessible. American Camp includes the island's longest stretch of beach. At English Camp, a motorized vehicle helps bring visitors from the parking area to the parade grounds.

Calhoun suggests going to Cattle Point, which is past the American Camp, "where there is an accessible trail to the old lighthouse and good beach and water views. There's also an accessible vault toilet on the site," he adds. The trail is compacted gravel.

San Juan Community Theatre: Both of its theaters are accessible via ramps and have designated wheelchair seating.

Orcas Island

This horseshoe-shaped island, known as "the gem of the San Juans," boasts Mount Constitution, which is the highest moun-

tain in the islands, as well as charming hamlets and beautiful shoreline — all of which can be viewed on the Scenic Byway driving tour. The two-to-three-hour long drive meanders past spots designated for their unique beauty or historical significance, including the 75-year-old Orcas Island Pottery, which sits on a 100-foot-high bluff overlooking President's Channel.

At Moran State Park, visitors can drive the 2,409 feet to the top of Mount Constitution for a wheelchair accessible view of the islands below, Marrett says. That view includes snow-capped Mount Baker, part of the Cascades Range on the mainland, and the island-dotted sea around Orcas Island.

Calhoun adds the park also has an accessible day use picnic site, one campsite and a vacation house rental.

Other things to do and see on Orcas Island:

Deer Harbor Marina: Located on the

southwest side of the island, or the Sunny Side as it's commonly called, this is the place to go if you're interested in fishing, crabbing, kayaking and whale watching. The marina and the shops along it are accessible.

Eastsound: This historic village nestled above Fishing Bay is considered Orcas Island's "downtown." Strolling along its accessible streets, visitors will find restaurants, shops and art galleries that exhibit paintings, ceramics, photography and more. About half the stores are considered ADA compliant, according to Marrett. During summer Saturdays, there's a farmers market and live music on the village green.

Orcas Center, the performing arts center in Eastsound, is wheelchair accessible and schedules dance, music, theater and visual arts performances.

LUMMI ISLAND: HIDDEN GEM

BY TIM GILMER

Mike Passo, founder of Elakah Expeditions, a company that specializes in providing kayaking experiences for people of all abilities, has a special appreciation for Lummi Island. "I lived for about two-and-half years on Lummi, and they were some of the best years of my life. It is truly a hidden gem. Hardly anyone knows about it," says Passo, a para.

Lucky for kayakers with disabilities interested in exploring the San Juan Islands, Passo still takes expeditions to Lummi. It is less than a 10-minute ferry ride to the island from Bellingham, Wash., where Passo now lives. "I'm fortunate to be able to keep my fleet of kayaks on a private beach in Lummi."

The Lummi expeditions are educationally focused around natural elements, says Passo. "We forage for wild edibles and explore intertidal life. We show people how to make use of seaweed, invertebrates and we get to look down on a wide variety of life in vertical tidepools. Most of the wild foods we gather we use to add in and spice up more traditional dishes."

Who goes on these expeditions? "We focus on people who have almost no experience kayaking. The routes we take are very sheltered from rough water and good for beginners. We'll spend three days on one of the lesser-known, undeveloped islands, two nights camping." Elakah has about 10-12 experienced guides who specialize in a specific area of interest. Besides foraging on Lummi, Passo takes small groups of kayakers to explore James, Jones and Sucia Islands, all of which are uninhabited but have state park campgrounds with privies. Volunteers are available to help those who need assistance.

Sucia Island, far from light pollution, is the perfect natural venue for an astronomy trip that takes place during the Perseid Meteor Showers (August 11-13). A special expedition for women usually happens during the summer solstice and is organized around learning about the native history of the coastal Salish people. Women learn about wild foraging and native crafts. "There is a special camaraderie about this trip," says Passo.

For those who don't want to commit to a three-day trip, family-oriented day trips happen on Lopez Island, which is more developed, yet still unspoiled by commercialization. Hiking and camping and kayaking around the coast are relaxed, easy activities for people of all ages.

For more about Elakah Expeditions and the full slate of kayaking activities, visit Elakah Expeditions at elakah.com. For a recent article on Mike Passo, visit: outdoorsnw.com/2013/profile-mike-passo/



Let Mike Passo be your guide to Lummi Island.

Photo by Cheyenne Black



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Lopez Island

Known as the “Friendly Isle,” Lopez is 15 miles long with forests, rolling farmlands, quiet bays and 63 miles of shoreline. Bald eagles and a variety of water birds can be spotted here.

Arriving at Lopez on his 24-foot aluminum fishing boat, Calhoun likes to spend time at **Fisherman Bay**, “because it’s close to my crabbing and fishing spots.”

Overall, Calhoun says Lopez Island has a lot of useable and some very accessible venues, especially the newer businesses and building areas.

He suggests driving from Fisherman Bay to **Fisherman Bay Reserve**, which has a gravel parking lot with gravel trail to an overlook at the bay. Other hiking trails take you to a sandy beach at the entrance of the bay where old reef nets and old boats lay on the beach. “There are lots of seals in the area,” he says. “You may even see fishermen on their towers in the water with drift nets fishing for salmon in late July.”

Visitors to **Lopez Village**, which is four miles from the ferry landing, can roam among the shops and art galleries, coffee shops, bakery and restaurants. Marrett points out that this commercial hub of the island has no curbs, and gravel pathways — not paved — lead to most businesses. Public restrooms are wheelchair accessible.

Lopez Village Park has accessible restrooms and showers for boaters, says Calhoun, but they are often used by campers.

Lopez Islander Resort and Marina has useable docks and pier with easy access to the restaurant from boats. The pool area across the street has good access — once you get through the gravel parking area — for showers and restrooms. The restaurant there has an accessible restroom.

Odlin County Park, just a mile from the ferry landing, is another popular spot. It has been newly remodeled and offers some very accessible features, according to Calhoun. “There’s a day use

area, boat launch, small dock, one new accessible RV spot, four useable beach tent sites, some vault toilets and a covered accessible picnic shelter,” he says.

Shaw Island

Fewer than 10 square miles, Shaw is the smallest of the San Juan ferry-served islands.

Many visitors take a day trip to Shaw, and if they are staying on one of the larger islands, riding the interisland ferry is free. At the ferry landing, there’s a general store with a deli, but the island has no markets, restaurants or hotels.

Many visitors head to Shaw because its biking trails are easier than those on the other islands. Other tourists plan to visit the University of Washington biological preserve or Our Lady of the Rock Benedictine monastery, where the resident nuns run an active farm.

But even our San Juan Islands “expert” Rory Calhoun says he hasn’t spent much time on Shaw because “there isn’t much to do there.”

MM

HOW DID THE SAN JUANS BECOME ACCESSIBLE?

BY TIM GILMER

Every accessible location in the United States was inaccessible at one time, and the San Juan Islands are certainly no exception.

In 1987, attorney Mary McKnew, now 58 and an L2-3 para for 40 years, decided to visit the islands. She had lived in Washington, D.C., working on disability policy, but decided to move to the Pacific Northwest in 1984. “To get away from Republican politics I moved out to Seattle,” she says, and later, to Olympia, Wash.

“Friday Harbor on San Juan Island had real access problems. Practically nothing was accessible,” she says. She was so certain of her legal ground that she filed an administrative complaint with the state’s Human Rights Commission alleging that the entire city of Friday Harbor was out of compliance. This forced the city to begin complying, not with the ADA, which did not yet exist, but Section 504 of the 1973 Rehabilitation Act and a Washington state code that pre-dated the ADA. “There were

no curb cuts, no elevators, the city council chambers were inaccessible, and you couldn’t even buy a ticket at the ferry. The dock was inaccessible. They needed to put in a floating dock.”

Her actions stirred up local residents. “There was a big news article stating that the city was not supporting state law,” she says. “The state of Washington had instituted a barrier-free code in 1977.” Her complaint did not meet with unanimous support. “I actually got a hate phone call,” she says. “The call woke me up, and this voice on the other end says something like, ‘You people on Welfare have nothing better to do.’” At the time she had a good-paying job working for Governor Booth Gardner. “The guy got it all wrong,” she says, laughing.

McKnew has always been the kind of fearless advocate who does not hesitate to speak her mind. Earlier, when she lived in D.C., she had served on the board of directors of NSCIA. She got elected to the execu-

tive board because, she says, “I wanted to get a guy fired. He was one of these non-disabled paternalistic types.”

Now, 27 years later, when wheelchair users visit Friday Harbor, they will find the city has made many changes, including an attitude adjustment that has spread to include all the islands.

Thanks, Mary, for being a fearless pioneer.



WHERE TO STAY

Rory Calhoun advises travelers with mobility issues to reserve accessible rooms “way in advance — seven months to a year ahead of time” and warns that prices are higher in the summer.

And Barbara Marrett, communications manager, San Juan Islands Visitors Bureau, offers the following information:

San Juan Island

The Place Bar and Grille, a favorite Friday Harbor waterfront restaurant, is wheelchair accessible.

Tucker House Inn and Harrison House Suites, Friday Harbor, offers wheelchair-friendly rooms.

Friday Harbor House is accessible on the ground level, and has one ADA room. Its restaurant and restrooms have easy access for people with mobility impairments, and the restaurant opens onto a lawn with great water views.

Snug Harbor Resort has a one-bedroom

unit that is wheelchair accessible. Its waterfront, docks, lobby, gift store, conference space, coffee shop and public bathrooms are wheelchair accessible.

Trumpeter Inn has an ADA room and accessible garden and pond. The kitchen and dining room are not accessible, though breakfast can be brought downstairs to the public sitting room for guests.

Roche Harbor Resort has three ADA compliant rooms, a ramp to McMillin’s Restaurant and wheelchair access to the Lime Kiln Café.

Orcas Island

The Turtleback Farm Inn has one ADA room in the Orchard House Building, with a wide brick pathway leading up to it.

Doe Bay has two wheelchair accessible cabins; its famous spa tubs are accessible but there are no lifts to assist guests getting in and out. The café is wheelchair accessible.

Inn at Ship Bay has one ADA wheelchair-

friendly room and its restaurant has easy wheelchair access.

Lopez Island

These lodgings are wheelchair friendly according to the Lopez Chamber of Commerce — more complete information was not available:

- Edenwild Inn
- MacKaye Harbor Inn
- Lopez Islander Resort



Rory Calhoun and his colleagues survey Fisherman Bay.

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MY TAKE

San Diego County offers a great climate to complement the beautiful beaches. Many of these beaches have great access, with power/manual beach chairs available and paved sidewalks. Access to buildings, restaurants, museums, tourist attractions and shopping gets a thumbs up. Though San Diego may be the hub, there are many areas of interest in Riverside, San Bernardino and Imperial counties as well. Palm Springs offers all that a desert community can offer and is an easy getaway. The tram will sweep you away from the flat land and up the side of the mountain with a breathtaking view. Riverside offers the historic Mission Inn, a great place to visit that takes you back to the roots of the state. There are not many places in

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SKINNY ON THE CITY

San Diego, “the Birthplace of California,” is also the second largest city in the state. Just 15 miles from the border of Mexico with a birdseye view of San Diego Bay, this historic city is rich in culture and offers a diverse selection of accessible things to do during the day and a hopping night life.



America where you can start your day by surfing in the Pacific, spend the afternoon in the mountains sail-

ing on Big Bear Lake, and finish the day enjoying the night life of Palm Springs in the desert.

Learn about the SoCal NSCIA Chapter on next page

GETTING AROUND

Accessible van transportation within San Diego County actually gets a thumbs down. A recent study showed that there are only six accessible vans for transporting a wheelchair within the county. The cost of securing transportation from one of the cab companies with an accessible van is on the high side. However, if you are already downtown, rolling access is very good — just a bit of a push up and down the hills when going away from the harbor. Should you decide to use the Metropolitan Transit System, you will find accessible buses and trolleys. I have used Amtrak when moving up and down the coast and found the access quite good. The staff is friendly and willing to help with access on and off of the train.

FULL RANGE OF ACTIVITIES

San Diego and surrounding counties offer just about anything someone would want to see or do in Southern California.

MUST SEE, MUST DO:

RESTAURANT: Nonno’s Ristorante in Murrieta is about 60 miles north of downtown San Diego. The ravioli and atmosphere are outstanding. Enjoy the black-and-white Sophia Loren movies running most nights.

ATTRACTION: San Diego Zoo Safari Park is a great place to spend the day, especially with kids. Be sure to take the tram ride, which is fully accessible. Ask to sit right up front with the driver, for the view.

SHOPPING: Sea Port Village (downtown) is a great place to spend the afternoon doing a bit of shopping before you head over to watch the Padres play at nearby Petco Park. Disabled services at Petco are outstanding, and seating is affordable.

In southwest Riverside County you can find a large number of wineries that offer wine tasting and fine dining. Family attractions such as Sea World are close by and accessible. Other than a slight hill to get to the accessible seating area, Shamu the Killer Whale is very accessible, and the viewing area is just out of the splash zone. The historic Hotel Del Coronado on Coronado Island is right by downtown San Diego and very accessible. Harbor tours, sightseeing or a tour of the USS Midway are right within the downtown area, also accessible. And who wouldn’t want to spend an evening dining and enjoying some great music in the Gaslamp District located within rolling distance from the harbor area? With great restaurants, stores and entertainment venues, this historic district has something for everyone. Despite many Victorian-era buildings, accessibility is mostly good, though a phone call ahead won’t hurt.

Southern California Chapter: Building Synergy

Editor's Note: After checking in on well-established chapters the last few issues, in this issue we check in on one of the newer NSCIA chapters to learn about the logistics of getting a chapter off the ground.

Having lived and worked in and around the Southern California disability community for almost 30 years, Rick Hayden would seem to be perfectly positioned to start an NSCIA chapter serving the region and its many members. Hayden, a T8 para, has worked for Everest & Jennings, Colours and Icon Wheelchairs and has a long background in sales and marketing that has connected him across the disability industry and community. Yet when United Spinal Association's Nick LiBassi approached him about launching a chapter in 2013, the road forward didn't seem obvious.

"I didn't have a vision initially," says Hayden. "I knew we needed something, but how it was going to interface with what was already in place, and how it could be a benefit to folks in these four counties was a little obscure."

The first point of order was defining exactly what area the new chapter would cover. Hayden quickly decided there was no way to cover all of Southern California and settled on four counties that make up the southeast corner of the state: San Diego, San Bernadino, Riverside and Imperial.

The next step was assembling a board of directors. Hayden chose his board with an eye toward ensuring all the different areas of the SCI community were represented. "There were certain people that were just naturals," he says. "I wanted a rehab doctor, a physical therapist, an occupational therapist, a social worker, a rec therapist, a parent, a business owner, and it's always nice if you can get an attorney."

Finding those individuals proved easier than Hayden had anticipated. "The big thing was being able to sell them on what we want to do," he says. "My intention was not to take up a lot of peoples' time, because if you do that, you end up losing people as they get frustrated."

With an excited board in tow, Hayden and crew got to mission planning. He expects accessible transportation and policy will be key focuses, but the chapter's main purpose will be connecting and supporting area members.

"As we took a look at the four counties and what we needed, we are so fortunate down here, there are all sorts of resources — you've got adaptive sports, you've got adaptive recreation, you've got peer counseling, you have support groups, even on the social side there are lots of events and lots of resources and lots of things going on down here," he says. "We decided, number one, let's not reinvent the wheel. Everything is here. But what we tend to hear on a frequent basis is that people are not able to find things because they are so scattered, so our primary objective at this point is to gather all of this information and have it in one spot to be a resource hub and to work with these other groups and to let them know we're not here to compete with them ... but to build a better synergy between the groups down here."

All the planning and hypotheticals started to become more tangible when the



Steve Goldman, left, is the treasurer of the new SoCal chapter started by Rick Hayden, right.

There are all sorts of resources — you've got adaptive sports, recreation, peer counseling, support groups. We decided, number one, let's not reinvent the wheel. Everything is here. So our primary objective at this point is to gather all of this information and have it in one spot to be a resource hub.

— Rick Hayden

chapter opened a bank account and picked up a banner for events. Hayden has been hitting up other chapter leaders for advice.

"Instead of reinventing the wheel, in some cases we'll copy and paste," he says.

Since signing the paperwork to officially become a chapter, names and contacts for area members have been flowing in, but the board is waiting to start regular meetings. "We didn't want to put the cart before the horse and not have enough follow through," says Hayden. "We're getting close, though." He anticipates holding meetings in different locations to accommodate the widely-dispersed members.

To find out more about the Southern California chapter, or to get updates on their progress, visit www.facebook.com/SCChapter.

NSCIA Chapters Are Adding Up

The Southern California Chapter is one of many new NSCIA chapters popping up all over the country. The recent additions of chapters in Seattle, Montana, the San Francisco Bay Area and Buffalo, N.Y., has pushed our chapter count to almost 50. For a full listing of chapters, visit www.spinalcord.org/chapters/directory/. If you live in an area without a local chapter and are interested in starting a new chapter like Rick Hayden did, email Nick LiBassi, United Spinal's director of special projects, at nlibassi@unitedspinal.org.

United Spinal Works with Google on Self-Driving Car

United Spinal was one of several key stakeholders in the disability community to attend a demonstration of Google's self-driving car on Apr. 28 in Washington, D.C. The prototype car is equipped with a top-mounted laser that generates a detailed map of the environment around the vehicle and then uses that information in conjunction with real-world maps and Google's evolving software to autonomously drive the vehicle.

"This is really exciting because the technology has huge potential for users with various functional limitations," says Alex Bennewith, United Spinal's vice president for government relations. "In their current form, the vehicles aren't accessible for wheelchair users, but I look forward to seeing how they can be adapted."

Google executives detailed their progress and explained their hopes for the project over breakfast at the Willard Hotel, highlighting their assertion that the car will help decrease vehicle accidents due to human error. Attendees, including Bennewith, then got a chance to ride through the streets of Washington, D.C., and on highways in one of two Google cars.

"It was crazy," reports Bennewith. "It was like I was in a sci-fi movie. There was a woman in the driver's seat, but she didn't have her hands on the steering wheel or her feet on any of the pedals. The car did everything itself. There was also a man in the driver's seat holding a computer that allowed you to see whatever the car saw. There is a manual override feature and there are still some software adjustments that need to be made but I can't wait to see what upgrades Google makes."

Google has not announced any firm dates for the next steps in the self-driving car's development, but United Spinal is excited to be involved.



Alex Bennewith (left) got a first-hand look at Google's self-driving car.

Third Annual 'Roll on Capitol Hill' Approaches

At press time, close to 80 advocates from 24 states, plus the District of Columbia, are registered to attend the third annual Roll on Capitol Hill, June 22-25 in Washington, D.C. Roll on Capitol Hill is United Spinal's annual legislative advocacy event that addresses issues that impact the health, independence and quality of life of individuals living with spinal cord injuries and disorders. Roll on Capitol Hill is a time when United Spinal Association members and advocates converge on our nation's capital to speak directly with the legislators who make decisions that affect our daily independence and quality of life.

What's on tap for this year? Well, after the welcome reception Sunday night and a full-day of speaker presentations and advocacy preparations on Monday, advocates will be ready to spend the day on Tuesday meeting with their legislators and making sure that our voices are heard on the following critical issues — access to Complex Rehab Technology (HR 942/S 948), the UN Convention on the Rights of Persons with Disabilities, improving access for adapted housing modifications (HAVEN Act); and establishing the ability for individuals with disabilities and their



Willis Washington and Jose Hernandez: ready to "Roll" again.

families to save tax-exempt private funds for education, housing, transportation, employment support, assistive technology/personal support services (ABLE Act), among many others.

We will wrap up a full day of meetings on the Hill with our 2014 Congressional Awards Reception. Senator Bob Casey, D-Pa.; Rep. Al Green, D-Texas; and Rep. Cathy McMorris-Rodgers, R-Wash., will be among those recognized for their support of people with disabilities.

Video Released to Improve Gas Station Accessibility

United Spinal Association and the Disability Gas Coalition, a national and state level disability rights organization, have released a video of Congresswoman Tammy Duckworth, D-Ill., that highlights her ongoing struggle to get gas at service stations as a

double amputee, war veteran heroine and wheelchair user.

The two organizations, which have joined forces to advocate for refueling assistance at the pump for people living with

disabilities, are releasing the video (<http://bit.ly/1oxvc8F>) as the busy summer driving season approaches. Fifteen million drivers with disabilities in the United States are unable to easily access gas at 159,000 stations nationwide.

"All persons with disabilities, including thousands of returning veterans, understand the difficulty of filling up their tanks at gas stations that are supposedly accessible," said Rep. Duckworth.

In the video, Rep. Duckworth discusses how currently, Americans with disabilities often have to resort to ineffective and humiliating means of requesting assistance like honking their horn and flashing lights in typically loud and crowded gas stations.

She cautions that the alternative, having the disabled driver exit the vehicle, is either impossible at some gas stations, or dangerous.

continued on next page

News (continued)

“We must do better. The ability to drive independently is key to the American lifestyle. Ensuring that disabled Americans can consistently and safely refuel their vehicles is critical to their ability to live independent and fulfilling lives,” she added.

The Americans with Disabilities Act was passed over 20 years ago, requiring refueling assistance at the pumps when there is more than one employee on duty. Yet for people who use wheelchairs, disabled veterans and other people with disabilities, service remains elusive.

The problem according to the Disability Gas Coalition is that while gas stations are scrupulous about meeting EPA requirements for fuel storage tanks, or about meeting brand requirements for signage and logos, they are often uninformed and do not meet the legal requirement to provide refueling assistance for drivers with disabilities at the pump.

“United Spinal urges all people with disabilities to contact their elected officials and ask for legislation that requires assistance be provided at gas stations,” said James Weisman, United Spinal’s general counsel.

United Spinal is asking the disability community to help spread the word on the lack of gas station access by enlisting state or national

organizations to join Disability Gas Coalition.

Individuals can also tweet gas station accessibility issues and include @disability-gasco or share photos of ineffective signage or videos that document the struggle to get gas on Facebook and by joining the Disability Gas Coalition group.

CRPD: Tell Your Story

United Spinal remains committed to passage of the United Nations Convention on the Rights of Persons with Disabilities. The convention promotes the ideals of the Americans with Disabilities Act around the world.

Senator Tom Harkin, D-Iowa, vowed to continue fighting for United States ratification of the treaty. Senator Harkin has asked for individuals to let him know why the CRPD matters.

Relaying any experiences living, traveling, working or studying abroad and any barriers that were encountered can help senators understand why United States ratification of the treaty is important.

To date, 158 nations have signed the treaty, including the United States, and 143 nations have ratified the CRPD.

Senator Harkin believes that an important part of winning this fight is ensuring that the personal stories of people with disabilities, including disabled veterans,

are shared with senators.

United Spinal remains hopeful that with the commitment of leaders in the Senate to move the treaty forward it will be ratified this year. Tell your story at www.harkin.senate.gov/help/crpdstories.cfm

Improve Access to Wheelchair Repair Now

Wheelchair repair is essential to a wheelchair user’s mobility, independence and ability to contribute to and participate in society. However, access to wheelchair repair services is being restricted by Medicare’s policies.

It is critical that wheelchair users have access to a Medicare supplier with trained and experienced service technicians and the infrastructure and inventory to be able to repair the equipment they rely on. Please take a minute to complete this quick online survey about your access to wheelchair repair so we can share the results with Medicare officials and policymakers: www.surveymonkey.com/s/wheelchair-repair

You can also help by telling Congress that Medicare must improve access to wheelchair repairs now. Use this linked form to easily send an email to your representatives and senators with just the click of a button: <http://goo.gl/UrRRmz>.

Calendar

JUNE 11

[Free Webinar]

Advice for Parents and Caregivers of Children with Special Needs

Time: 1 p.m. to 2 p.m. Eastern time

Presenter: J. Oni Dakhari, PsyD, licensed psychologist, Dakhari Psychological Services, LLC

Overview: This webinar will focus on the importance of self-care for parents and caregivers, especially given the demands of a child with disabilities.

Register: www.spinalcord.org/webinar-archive/

JUNE 22-25

[Event]

The 3rd Annual Roll on Capitol Hill

Where: Washington, D.C.

Overview: Members and advocates converge on our nation’s capital to speak directly with the legislators who make decisions that affect our daily independence and quality of life.

Information: www.unitedspinal.org/events/roll-on-capitol-hill/

JUNE 26

[Free Webinar]

Raising a Child with Special Needs: A Mother’s Story

Time: 1 p.m. to 2 p.m. Eastern time

Presenter: MaryAnn Raccosta, author, moti-

vational speaker, and mother

Overview: A personal and motivational story of raising children with disabilities from a mother’s perspective. Author MaryAnn Raccosta shares her experiences on caring for two sons battling a rare, life-threatening illness. She will also offer tips and insights to help other parents of children with disabilities.

Register: www.spinalcord.org/webinar-archive/

JUNE 27-29

[Free Event]

Abilities Expo

Time: Friday 11 a.m. to 5 p.m., Saturday 11 a.m. to 5 p.m., Sunday 11 a.m. to 4 p.m.

Place: Renaissance Schaumburg Convention Center, Chicago

Foundation for a Healthy Future

You can get just about anything in Los Angeles, from globe-spanning cuisine to world-class entertainment to year-round blue skies, but after being paralyzed in 2007, Brett St. James couldn't find an accessible place to work out nearby. For some, the lack of an accessible gym would have provided an easy excuse, but for St. James, a former college athlete, it was a source of frustration, and eventually motivation.

Initially St. James, a T7 para, took to the streets, trying to stay in

shape by wheeling around LA's sidewalks. But too many cracks and unkempt walkways forced him into the actual streets. The smoother surfaces were a welcome change, but the honks and yells of impatient drivers forced him to accept that the situation was untenable.

"I really needed a place to go work out," he recalls. "When I started looking for one in the area, I didn't find any adaptive fitness centers. I

St. James, left, displays drawings for the fitness center he hopes to fund.

just kept doing more research and looking into building something and everyone was like, 'That's a great idea,' so I kept going for it and started the foundation."

"The foundation" is the St. James Foundation. Using the savvy and skills he learned while earning his business degree at Cal-State Northridge, he launched the foundation in 2010 with the goal of providing accessible recreational activities for people with spinal cord injuries. At the heart of his vision is an adaptive fitness center for the thousands of area residents like himself – with and without disabilities. And though there is such a center in Northridge now (C.O.R.E. Center), there is nothing for L.A.-area residents who live too far from the Valley to make regular workouts feasible.

"I want it to be a low cost alternative," St. James adds. "I know that a lot of people don't have funds to spare when they become disabled. I want it to be a social outlet where they can mingle and get involved."

St. James has put together an architectural rendering and some interior images of the center he envisions, but knows erecting the actual building will be a much more difficult — and more expensive — task. He is currently trying to raise funds to host a charity concert at the Forum, which he believes will generate enough money to move the center much closer to reality.

He has partnered with NSCIA to launch the Los Angeles chapter and unite the local SCI community behind his vision. As far as fundraising, he held the first annual "Defy Limitations" golf tournament last year and is already planning its sequel this September. He is also working on a gala dinner event this Nov. 13 at the Taglyan Complex.

St. James is proud of the progress he has made so far, but admits it has been a learning process and hasn't always proceeded as quickly as he had hoped. "I've learned a lot from everything I've been through and I feel like it is all preparation for the overall campaign and the eventual establishment of the fitness center," he says. "I just want to promote a healthy city lifestyle. It makes me feel better every day, and I know it can do the same for others."



Gold

Permobil introduced a Virtual Seating Coach system that works with smartphones to coach wheelchair users through their seating regimens. 800/736-0925; www.permobil.com

Redman Power Chair invites you to see the story of John Johns, C3-4, who travels extensively with his standing chair: redmanpowerchair.com/category/testimonials. See a live demo at the Chicago Abilities Expo, June 27-29. 800/727-6684; www.redmanpowerchair.com

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GO! Mobility Solutions is now offering its products through vendors and dealers worldwide! 800/359-4021; www.GoesAnywhere.com

Numotion announced this month their new customer survey website, NumotionListens.com. 800/500-9150; www.numotion.com

Spinergy is proud to be a member of the NSCIA and is committed to improving the lives of others! 760/496-2121; www.spinergy.com

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

Acknowledgements on our website, in NEW MOBILITY, in NSCIA e-news or any other United Spinal publication should not be considered as endorsements of any product or service. It is the individual's responsibility to make his or her own evaluation of such. To see a complete listing of NSCIA business members, visit www.spinalcord.org/resource-center/nscia-business-members.

National Spinal Cord Injury Association's mission is to improve the quality of life of all Americans living with spinal cord injuries and disorders (SCI/D). Membership in NSCIA, a program of United Spinal, is open to anyone with an interest in SCI/D. For more information on the benefits of joining, visit www.spinalcord.org or call 800/962-9629.

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Disability Policy Advocacy

Washington, DC 202/556-2076



ARIZONA

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

St. Joseph's Hospital and Medical Center, Phoenix, AZ; 602/406-3000

CALIFORNIA

CareMeridian, Fresno, CA; 559/431-8594

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

Community Regional Medical Center - Leon S Peters Rehabilitation Center, Fresno, CA; 559/459-6000

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

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

COLORADO

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

CONNECTICUT

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

Mount Sinai Rehabilitation Hospital, Hartford, CT; 860/714-3500

DISTRICT OF COLUMBIA

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

FLORIDA

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

Pinecrest Rehabilitation Hospital, Delray Beach, FL; 561/498-4440

GEORGIA

Central Georgia Rehab Hospital, Macon, GA; 478/201-6500

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

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

HAWAII

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

ILLINOIS

Edward Hines Jr. VA Hospital (Veterans Healthcare Administration), Hines, IL; 708/202-8387

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

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

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

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

INDIANA

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

KANSAS

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

KENTUCKY

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

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

LOUISIANA

The Gilda Trautman Newman Rehabilitation Center, New Orleans, LA; 504/899-9511

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

MASSACHUSETTS

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

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

MARYLAND

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

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

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

MICHIGAN

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

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

MISSOURI

Rusk Rehabilitation Center - A Joint Venture of HealthSouth and the University of Missouri, Columbia, MO; 573/817-2703

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

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

MISSISSIPPI

Methodist Rehabilitation Center, Jackson, MS; 601/981-2611

NORTH CAROLINA

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

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

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

UNC Acute Inpatient Rehabilitation,
Chapel Hill, NC; 919/966-4131

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

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

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

NEBRASKA

**Madonna Rehabilitation Hospital Spinal Cord
Injury Rehabilitation Program, Lincoln, NE;**
402/489-7102

QLI, Omaha, NE; 402/573-3700

NEW HAMPSHIRE

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

NEW JERSEY

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

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

NEW MEXICO

**HealthSouth Rehabilitation Hospital Spinal Cord
Injury Program, Albuquerque, NM;** 505/344-9478

NEW YORK

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

James J. Peters VA Medical Center, Bronx, NY;
718/584-9000

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

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

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

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

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

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

OHIO

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

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

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

OKLAHOMA

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

OREGON

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

OHSU Rehabilitation, Portland, OR; 503/494-8311

PENNSYLVANIA

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

Aristacare at Meadow Springs,
Plymouth Meeting, PA; 610/279-7300

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

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

Thomas Jefferson University Hospital,
Philadelphia, PA; 215/955-6579

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

SOUTH CAROLINA

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

TENNESSEE

**Memphis VA Medical Center Spinal Cord Injury
/ Disorders, Memphis, TN;** 901/577-7373

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

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

TEXAS

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

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

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

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

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

UTAH

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

VIRGINIA

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

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

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

VERMONT

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

WASHINGTON

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

WISCONSIN

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

Organizational Members

Center of Recovery & Exercise (CORE)
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Florida Spinal Cord Injury Resource Center
Tampa, FL; 813/844-4711

Journey Forward
Canton, MA; 781/828.3233

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

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

Neuro Fit 360
Pembroke Pines, FL; 954/252-8020

Neuroxel
North Palm Beach, FL; 866/391-6247

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

Project Walk - Austin
Austin, TX; 512/719-4300

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

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

Project Walk - San Francisco
Freemont, CA; 510/623-1924

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

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

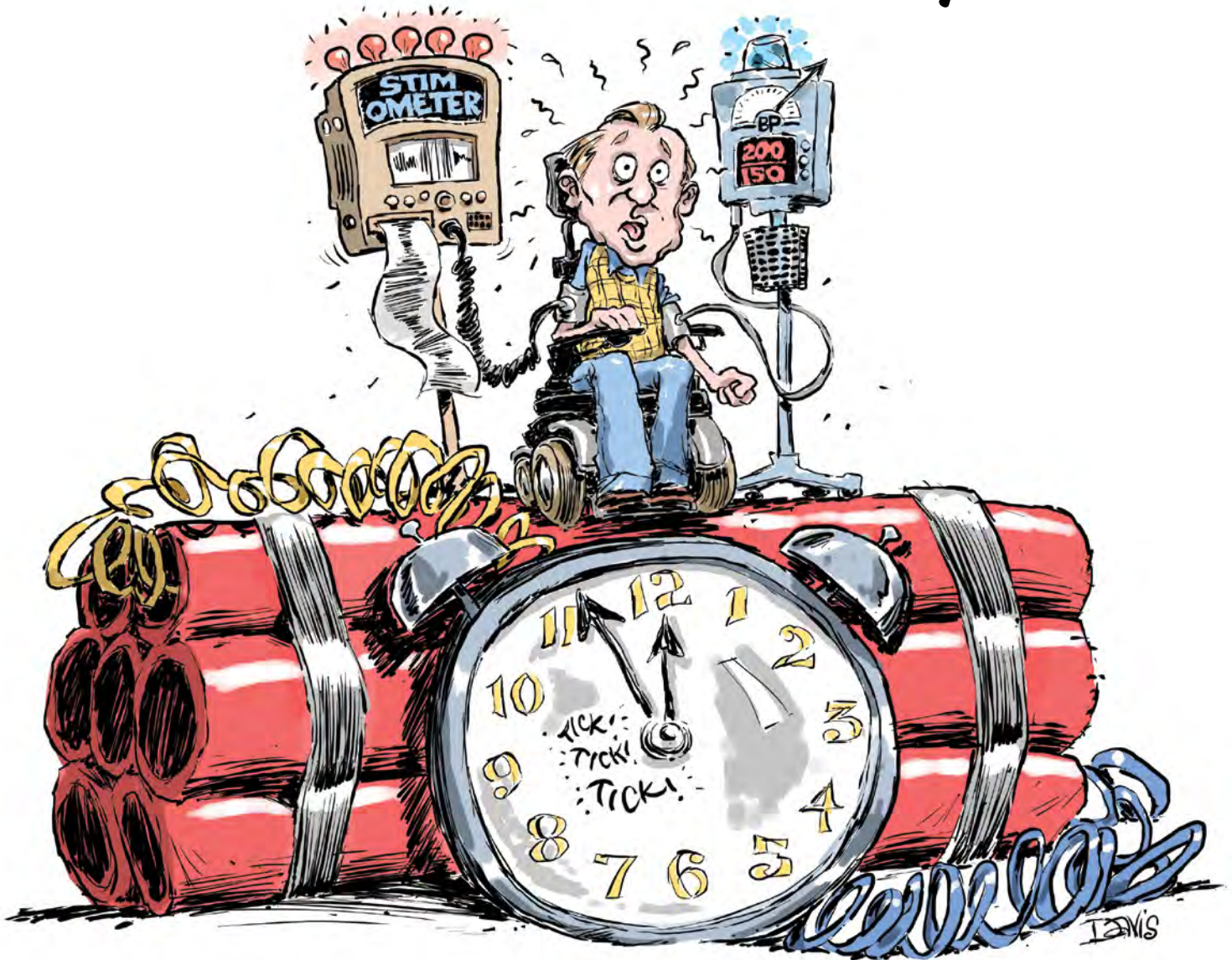
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SCI and Your Immune System



BY BOB VOGEL

Does autonomic dysreflexia affect our immune system response? As anybody with a spinal cord injury should be aware, AD — an overactive nervous system response to pain or discomfort below the SCI level — causes a sudden spike in dangerously high blood pressure that must be immediately ad-

dressed. AD affects people with SCI levels above T6 and in rare cases as low as T8. It can be a medical emergency that, left unchecked, can cause stroke, seizure, organ damage or even death.

According to a recent study done at Ohio State University's Wexner Medical Center, AD damages the immune

system of mice. Titled "Autonomic Dysreflexia Causes Chronic Immune Suppression After Spinal Cord Injury," the study says that people with high-level SCI have weakened immune systems that leave them more susceptible to infections, which can lead to an untimely death. The study showed that AD plays a

part in immune suppression of mice. On the hopeful side, researchers found drug compounds that mitigate immune suppression caused by AD.

In the study, researchers created SCI in two groups of mice at T3 and T9 respectively, then added a “stimulus” consisting of a specific amount of overfilling of the bowel and “pinching” of the skin near the hip. The stimulus triggered AD in the mice with T3 SCI. Researchers also found that each bout of AD caused a release of hormones called catecholamines — specifically adrenaline and noradrenaline — part of the body’s “fight-or-flight response” that causes an increase in heart rate, blood pressure and blood glucose levels. This increase kills immature white blood cells, the cells that fight infection, and results in immune suppression.

Repeated, frequent bouts of AD caused extensive damage to the immune systems of the mice and created a disorder called “central nervous system injury-induced immune deficiency syndrome.” The immune systems of the mice were so damaged that they were open to recurrent or chronic life-threatening infections, and they also had poor immune response to vaccines.

The mice that had SCI at T9 did not develop AD, and while their overall immune response was mildly depressed, the study reports the effect was “nonsignificant.”

The good news: During the study, researchers found a way to mitigate the immune damage caused from AD by injecting mice with compounds that act as blocking agents. This prevents the catecholamines from attaching to white blood cells. Repeated injections of the compounds restored immune function, suggesting that further research could eventually lead to the development of a drug that would prevent immune system damage from AD and restore immune function in people with SCI.

Meet the Researcher

One of the researchers in the study, Mark S. Nash, Ph.D., a professor and princi-

pal investigator at The Miami Project to Cure Paralysis, has been studying immune suppression in people with SCI for the past 14 years. He says that earlier studies support the growing body of evidence that people with SCI above T6 have higher rates of immune suppression and are more susceptible to infection than people with SCI at levels below T6. The big question has been, why? “Consensus used to be that it was all due to neurological mechanics of SCI, things like bladder management, reduced respiratory control, and skin breakdown,” he says. However, Nash and others believed there was more to it.

The idea for the study came about in part because immune suppression in nondisabled people is well associated with stress or stressors, says Nash. He and other researchers started thinking about AD as a big-time stressor, which led to the Ohio State study.

T6 is a critical level in terms of AD because the nerves between T6 and T9 control the adrenal glands, where catecholamines come from. With SCIs at or above T6, says Nash, control of the adrenal glands is no longer connected to the brain, so they act reflexively to stimulus, such as a full bladder, full bowel, skin pressure or any type of pain below the level of injury. AD doesn’t happen in lower SCI levels because the brain can control and moderate the release of catecholamines when there is some type of pain or stimulus.

The study also included monitoring changes in a human subject during a bout of AD. A volunteer with C5 quadriplegia underwent a mild episode of AD caused by letting his bladder overfill. This caused an elevation of his blood pressure and release of catecholamines. “His immune system went haywire for a couple of hours after the AD episode,” says Nash. “People with SCI above T6 generally have episodes of AD four to six times a day, commonly due to stimulus from dealing with bowel and bladder issues.”

Stress appears to be the culprit that AD creates. Nash says that in people with SCI, the effects of AD can be similar to stress experienced by nondisabled people when they over-exercise. “We know that after people run marathons, they

have high levels of long-lasting catecholamines in their systems, and marathon runners have high rates of upper respiratory infections,” he says. “A colleague who looked at the stress AD puts on a person’s system remarked to me, ‘So it’s like they are running four to six marathons a day, that’s a lot of stress!’”

Like many aspects of SCI, immune suppression in relation to SCI is complicated, including how prevalent it is. Although a PubMed search on immune suppression and chronic SCI didn’t come up with many results, this is likely to change as life expectancy with SCI continues to grow. According to a 2009 University of Washington study, in the 1940s people with SCI only lived, on average, 18 months post-injury. As of 1998, life expectancy of quadriplegics had risen to 70 percent of the general population, and for paraplegics it is up to 86 percent. We are living longer, and the Ohio study is timely. Especially because there are varying experiences on SCI and immune suppression.

Not Everyone Agrees

Dr. Diana Cardenas, chair of the department of Physical Medicine and Rehabilitation at University of Miami Miller School of Medicine, says that clinically, she doesn’t see much immunosuppression in patients with SCI. What she does see are lots of UTIs, bowel management problems, and pressure ulcers, as well as respiratory complications in quadriplegics. She says that infections and complications related to infection are a result of mechanics — the result of vulnerability due to the loss of normal neurologic innervation with SCI — and the people she sees with these infections respond to the usual treatments.

“I haven’t seen good evidence that there is suppression of the immune system simply because of a spinal cord injury,” says Kathleen Dunn, a clinical nurse specialist and rehab case manager.

Dunn’s clinical experience in chronic SCI and immune suppression is similar to Cardenas. People with chronic SCI are more vulnerable to infection because of

mechanical issues. Neurogenic bladder leads to UTIs, reduced sensation and muscle mass leads to pressure ulcers, and higher level SCIs lack respiratory muscles that enable a full, deep cough. All of these things can be associated with infections, explains Dunn.

When it comes to cervical level injuries, NEW MOBILITY has prematurely lost quite a few friends where immune suppression may have played a part. However, although some with SCI succumb to infection all-too early, Dunn points out that she sees people in her clinic who are 20-50 years post-injury. A quick visit to the Quad-List Discussion Group shows there are quads celebrating 45 years post-injury.

If this seems confusing, it's because there are no clear-cut answers. The discussion at the end of the Ohio study states that although AD is prevalent after high-level SCI, not everyone with high level SCI and AD gets serious infections or responds poorly to vaccines. Unlike lab mice, people with SCI have different lifestyles and genetics. Some do better than others in terms of exercise, attention to diet, bladder, bowel, and skin care. Everything plays a role.

Kim Anderson-Erisman, Ph.D., a researcher and director of education for The Miami Project to Cure Paralysis, and also a quad, explains that part of what seems like a disconnect is that health care providers are not necessarily looking for immunosuppression. They are looking for a way to cure the problem, and the cure may be antibiotics, teaching better bladder or bowel care, instruction on how to do a mirror-skin check or prescribing a better seating system — so they wouldn't generally wouldn't run lab tests to look for immunosuppression.

"We do know something happens when people pass over the 20-plus year post-injury mark. At some point things that were fine for years start going wrong," says Erisman. "In people, we don't know what the 'something' is yet." In the animal research Nash worked on, immunosuppression in chronic injuries

is absolutely evident. "The takeaway for me is that we do not know enough about how SCI affects the immune system chronically, and we do not know enough about repetitive daily bouts of mild or silent AD. We need more research on both of these and how they interact."

The Takeaways: What to Do

Nash found similar patterns in his research. Immune suppression appears to be a piece of the puzzle that is growing in importance in regard to why people with SCI are able to fight off infections such as pneumonia, UTI or infections from skin breakdown in earlier post-injury years, but when you go further out, 20-30 years or more, they succumb to the same infections, he says.

There are several goals of the Ohio State study, according to Nash. The first one is to draw attention to the significance of AD and the part it plays in infection susceptibility. "The study confirmed that AD is much more serious than we thought. It is much more than just an annoying symptom."

The second takeaway from the study, Nash says, is that people who get AD often can't tell how serious these episodes are. When the subject in the Ohio State study underwent an AD episode, he thought the symptoms were pretty mild — the researchers didn't drive him to a crisis headache — and yet even with this mild bout of AD, there was a substantial change in his autonomic function. But these changes may not be very perceptible to people with SCI.

For readers, the takeaway should be that AD is very serious, and it's important to do what you can to keep bouts to a minimum. Trying to manage AD is akin to detective work. You often have to eliminate certain potential causes to arrive at the actual cause.

Dunn advises focusing on things you can control. Take proper care of your

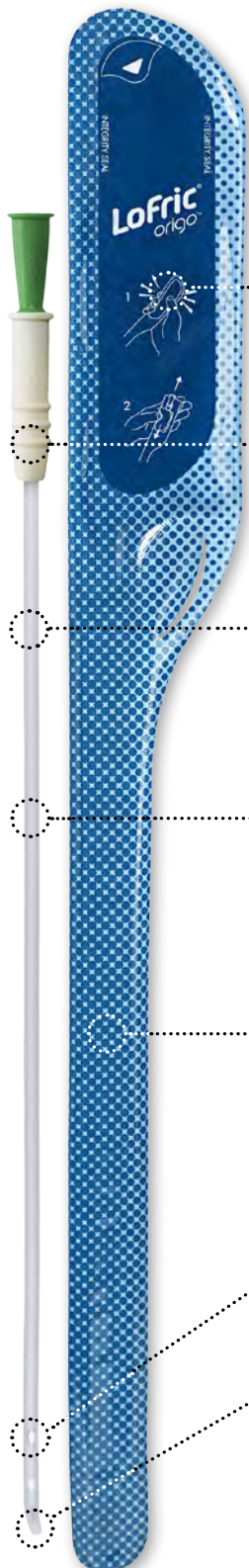
bladder — empty on a regular basis and don't let it overfill. Work with your urologist and get checked for bladder and kidney stones. Do weight shifts to keep your skin intact, and check pressure spots with a mirror. Stay on a regular bowel routine.

Also, work hard to stay healthy. Eat right and try and stay at the proper weight. Dunn advises talking with your doctor about getting an annual flu vaccine and also a pneumovax. Dunn says at the VA they give the pneumovax to new SCIs at T12 and above and recommend they get it again when they turn 60. "I pretty much consider somebody has an impaired cough all the way down to T12," she says. "Even at T10 or T11, a person doesn't have all the lower abdominal muscles needed for a full, robust cough," she says. Finally, if you have a higher level of injury, be sure to understand how to have somebody help you cough. **MI**

Resources

- Autonomic Dysreflexia Causes Chronic Immune Suppression After Spinal Cord Injury, www.ncbi.nlm.nih.gov/pmc/articles/PMC3735880/
- Autonomic Dysreflexia Education Module, courtesy of Craig Hospital, www.craighospital.org/repository/documents/HeathInfo/PDFs/765.AutonomicDysreflexia.pdf
- Bladder Management for Adults With Spinal Cord Injury, www.craighospital.org/repository/documents/HeathInfo/PDFs/310.CPGBladderManagementafterSCIforHealthcareProviders.pdf
- Bowel Problems, www.craighospital.org/repository/documents/HeathInfo/PDFs/706.Bowel.Problems.NOD.pdf
- Preventing Pressure Sores, www.craighospital.org/repository/documents/HeathInfo/PDFs/322.ModelSystem-PreventingPressureSores.pdf
- Quad-List Discussion Group, www.makoa.org/quadlist.htm

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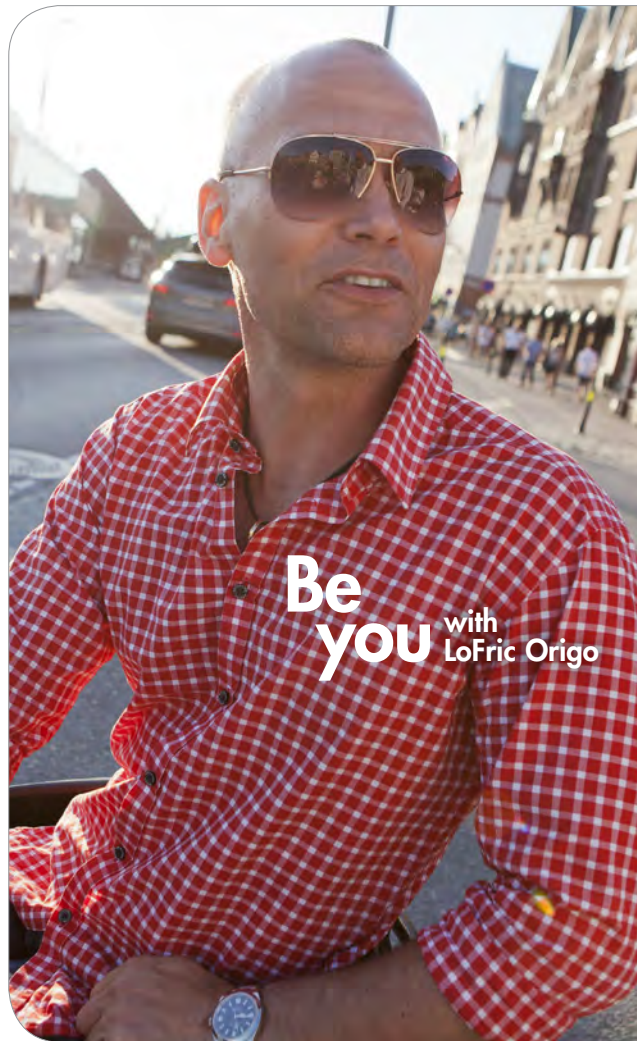
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MAT BARTON: GET HAPPY!



BY TIM GILMER

If you go to Mat Barton's website — Get Happy! — and click on "About," you will feel drawn into his world instantly. He invites you to put yourself in his shoes: "You're a cartoonist living in Portland, Ore. You graduated from Cal State Fullerton with a MFA in animation/illustration in 2004. You've worked for Cartoon Network and Warner Bros. Animation. You've built sets for stop motion films, created illustrations for billboards and many publications, won an award for a short animated film and work as a graphic designer in the daytime. In your

free time you focus on drawing comics."

As early as the second or third grade, he realized that drawing was something he not only loved but needed. "I think that was the first time I kind of got lost in it. I'd draw Ninja Turtles nonstop on the bus just to get away from being picked on and bothered." Barton, 33, was born in Santa Ana, Calif., but the family moved wherever his dad's job took him. He lived in Louisiana during his grade school years, then moved back to California, where he went to junior high and graduated from Centennial High in Ba-

kersfield. That's where he met Jessica. "I always had a crush on her, but I was kind of shy. But we kept in touch by email."

When Barton was at CSF in Orange County, Calif., Jessica was attending Westmont College in Santa Barbara. She was taking an elective art class, so she asked him if he wanted to go to the Los Angeles Museum of Contemporary Art with her. A few weeks later it became clear that she had always had a crush on him, too. "Mat didn't believe it when I told him. So I showed him the copy of the Bakersfield Californian I had kept with



the lyrics of a song he had written about me,” says Jessica. “They had done an article on Fat Chance, the punk band he was in. And then I showed him all these flyers he had drawn for the band that I saved.” That was the beginning of a long distance relationship that grew over the next few years, no matter where their lives took them.

* * *

During temporary internship stints with both Cartoon Network and Warner Brothers while in his senior year of college, Barton realized that he wanted something more creative, less formulaic than the production mentality of a major studio. After graduating, he started drawing signs for Trader Joe’s to bring home a paycheck, but what he really wanted to do was draw cartoons, so he started working on a comic book and longer projects in his spare time. Also, he and Adam Cooper, his co-collaborator on their four-minute film that won Best Animated Short Film at CSF’s annual film festival, spent almost two years on a more ambitious, 20-minute animated film project. “But it just kind of fell apart,” says Barton. “Maybe it was too ambitious. All that work and nothing to show for it.”

In 2007 Jessica made plans to enroll at Pacific University in Forest Grove, Ore., with a goal of becoming an occupational therapist, so she relocated to the Portland metro area. Barton followed and got a job at a bike shop doing graphics for online promotion and some print illustrations as well. They were married in 2008. Cartooning, though always present, took a back seat to more mundane affairs and his growing infatuation with mountain bike racing — a natural extension of an earlier passion for BMX bikes when he was much younger.

* * *

On June 11, 2012, Barton was injured in a mountain bike racing competition at the Portland International Raceway. “I just wrecked, flew over the bars, flipped and landed on my neck and back,” he says, sustaining a T5 SCI. Good thing he was wearing a helmet. Jessica was there, as were his racing buddies. True to his unassuming nature, Barton’s first concern, lying there, was how would he get out of the way so he wouldn’t cause a huge pileup. He knew exactly what



was happening with his paralysis. “I remember Mat telling me,” says Cooper, “I think it was on the way to the hospital, or sometime very soon after the accident, that he was grateful he would still be able to draw.”

He was taken to Emanuel Hospital, not far away, and when he was stabilized, he was transferred to the Rehabilitation Institute of Oregon, also in Portland, where he spent just one month before being discharged.

At first, he says, he was in partial denial. Still employed by the bike shop, he came home from RIO feeling pretty certain that he would be back on the job in a week or two. “It was horrible, quite a shock, coming home to a small apartment where nothing was the same as before. It was a full month before I could get my bearings and go back to work.”

His friends in the mountain bike rac-

ing community stepped up and raised \$75,000 to help with medical costs and home modifications. He had been racing at the local pro level, competing in two or three races per week for about three years. “Bikes were like my life,” he says, “but I

for paying medical bills, adaptive equipment, and some home modifications. Their parents and grandparents helped them with down payment money to buy a modest home in North Portland. They added a ramp and wraparound deck, hardwood floors for easy rolling, and a kitchen with roll-under sink and stove. “I like to cook,” he says, matter-of-factly.

And, oh yes, they dedicated a small room as his studio, so he could seriously pursue his first love of drawing and cartooning. “He’s got a really great light box — an animator’s tool — a computer and two monitors and some real nice pens and pencils that he won’t let me touch,” says Cooper.

“I just let mountain biking go and decided to move on,” says Barton. “I knew it was time to focus on drawing.”

Now, less than two years post-injury, Mat and Jessica have covered a lot of



knew immediately that I would never go back to the same level of interest and commitment.” He and Jessica made out a spreadsheet and earmarked the money

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ground in adapting to a new way of living. Jessica's being an occupational therapist has been a huge boost. "I knew the way everything should be set up in our home for Mat, so we saved a lot of trial-and-error time." Also, just six months after his injury, Mat was invited by Oregon Active, an adventure recreation group, to go to the X-Games in Aspen, Colo., all expenses paid. Not only did he get his baptism in sit-skiing, snowmobiling and dog sledding, they learned the tricks of traveling and staying in motels. "We are very grateful for how things just fell into place for us," says Jessica, "very grateful."

* * *

It's clear after just a few minutes of informal conversation that Mat Barton is not a blowhard, not egocentric, despite his accomplishments. "For me, I just like sitting at my drawing table and drawing something." It's that simple. No grand ambition, he just likes doing what he does. But it also serves an important need, just like it did in the second and third grade. Some of his work draws on his experiences adapting to the sometimes strange and challenging world of spinal cord injury — physically, emotionally, psychically.

"One of my favorite cartoons of Mat's is 'Walk-Ins Only,'" says Jessica. I think that was the first time he drew something that expressed what he was feeling about the kinds of things that go on in his everyday life."

His caped para-superhero on wheels, Ted the Terrible, more than likely evolved as a way of dealing with the frustrations of finding his place in a society that tends to marginalize wheelchair users. Ted is often frustrated, sometimes angry, but his actions make us laugh and feel better about ourselves.

Underneath Barton's humble demeanor, perhaps taking shape in some well-lit corner of his creative subconscious, a unique cartoon character is just waiting to break out of the comfortable anonymity of a quiet Portland neighborhood and leap onto the pages of *The New Yorker*.

It's every doodler's dream to see one of his drawings in the nation's quintessential showcase for cartoonists. But Barton, perhaps a doodler in grade school, is a serious contender these days. He has

partnered up with Cooper again, who usually supplies the captions for Barton's cartoons. Their plan is to begin submitting cartoons soon, in hopes that at least one of them will land on the desk of Bob Mankoff, the magazine's cartoon editor since 1997 and a *New Yorker* cartoonist himself for 20 years prior to moving to the business side of the desk.

Barton knows that getting into the *New Yorker* is a long-odds proposition, but that doesn't discourage him. "I sup-

pose you've heard," I asked him, "that Mankoff had 500 of his own cartoons rejected by the magazine before his first one was accepted?"

"Yeah, I read that, too. I thought that was encouraging," he says. Encouraging? 500 rejections? "It tells me that if you keep at it, something good eventually happens," he says. "What's cool about art is you're not going to get worse, you're only going to get better. It's not a waste of time as long as you're having fun doing it." *MI*

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MOTORVATION SPECIAL EDITION:

All About Hand Controls

By Uncle Mike

Learning to drive, safely, is a serious matter for everyone. To maintain control of a rapidly moving vehicle in a flow of traffic takes finely-tuned motor skills and an extraordinary level of alertness, sometimes for hours at a time. Adding paralysis to that mixture increases the complexity of the situation. Fortunately, we are benefiting from the work of early driving pioneers and manufacturers who developed the tools and mechanisms to help drivers with paralysis maintain their “safe driver” status.

Without being able to control all of the functions of driving by hand, many of us would be unable to drive. Some of the first types of hand controls available over 50 years ago were fairly simple, with metal rods extending from the brake and throttle pedals to levers mounted near the steering wheel. Pushing, pulling or twisting a control lever in different ways controlled the speed of the vehicle and could bring it to a stop. That simplicity was a plus, as it minimized equipment breakdowns and helped those controls last for years.

Those basic types of controls remain popular with drivers today. The MPS Monarch is one of several examples of such products. It allows a driver to apply the brakes while still pulling the hand control lever down toward the driver’s lap and applying the accelerator, which is helpful while stopped in traffic on a steep uphill grade, and even for driving some types of race cars. Marc Sagal, owner of Access Options in Watsonville, Calif., has been installing hand controls for 26 years and says the Monarch has remained a top seller even with so many other choices now available.

Knowledge about the types of hand controls and how they work is important for those beginning to drive. Cody Unser, founder of the Cody Unser First



Step Foundation, was paralyzed by transverse myelitis at age 12. “In a matter of moments,” she says, “I found myself completely paralyzed below the waist with no apparent cause.” As a member of the well-known Unser racing family, she knew from an early age that she wanted to drive, so she has been using the same type of portable hand controls that were first installed by her brother when she was old enough to take driver’s education at age 15.

“It was confusing for us when I was

first starting to drive, as it seems that there was a lack of guidance or information allowing us to make the best choice of which controls to use,” she says. She advises those searching for their first hand control system to check around and thoroughly investigate the options that are available. That recommendation was echoed by several others who were interviewed, and it should be part of a multi-step process prior to making that initial purchase.

Getting Started, Some Basics

First, an evaluation by an occupational therapist or other professional who has been certified for driving evaluation and instruction can determine physical capabilities and identify the type and location for preferred types of hand controls. Their training allows them to make recommendations that are based on the individual’s needs and the type



Cody Unser prepares to take on her famous dad, race car driver Al Unser Jr., at her cousin’s indoor kart track.

Photo courtesy of Cody Unser First Step Foundation

of vehicle they would like to drive, as no two people are identical in that regard even if they have similar disabilities. If hand controls are going to be funded by some type of government agency, that evaluation will probably be required.

Typing "hand controls" into any Internet search engine will bring up an extensive list of websites that showcase over two dozen different types, brands or models of hand controls. There is even some overlap between manufacturers, as the same basic type of hand control might be available under different brand names. Mobility equipment dealers can provide information about the types of hand controls available, and if needed, they can also help with advice on how to obtain financing for purchasing them.

Mobility equipment dealers know how to mix and match the many different types of controls needed by any driver. Scott Poore, owner of Advanced Driving Systems, did that for JR Harding of Tallahassee, Fla. Harding has been paralyzed at the C5 level since 1983 and at the C6 level since 1988 due to two separate accidents that occurred 15 years apart. He has combined different types of systems that help him control his vehicle safely. His steering is assisted through Drivemaster reduced-effort steering, a tri-pin device to help him maintain a grip on the steering wheel with his left hand, and an extension to move the wheel closer to his body. Another tri-pin device mounted to his right helps him handle the acceleration and braking by pushing and pulling on the handle of a Mobility Products and Designs control. Auxiliary functions of driving are controlled through use of a Digipad or by touch controls mounted on his headrest.

That same professional advice can serve those who have been driving for years, but who are curious about how they might benefit from a switch to one of the newer hand control models. After using a MPS Monarch hand control for years, Allen Garrett, a C6-7 quad from Vero Beach, Fla., recently switched to one of the Sure Grip models. An amputee from Santa Cruz, Calif., Allen Carman, also made the same switch when he found it was more comfortable for him. Both men encourage other drivers to check

periodically to see if a particular product, whether newly introduced or in common use for years, might work better for them.

Many drivers continue to use the type of hand controls they used when they first started driving. David Norley, a T4 para from Soap Lake, Wash., has been driving with hand controls for about 50 years. He started with a used set of Wells-Engberg controls donated by a friend after his 1964 auto accident and has remained loyal to that brand. The simple design initially allowed him to move the control himself whenever he changed to a new vehicle, and those he rented, during that half century. During the last few years he has let the professionals make those hand control swaps for him.

Nancy Starnes of Sparta, N.J., paralyzed from a spinal cord injury at the T12-L1 level, has used the push-pull type of controls for most of the time that she has been driving. She simply moves hers to each new vehicle when she purchases a car. While she is completely comfortable with that type of control, she has also been able to drive safely when using rental cars outfitted with different types of hand controls.

Types of Hand Controls

The number of types of hand controls available for drivers with any kind of disability has continued to grow, and some even allow vehicles with manual transmissions to be operated safely with hand controls. Patrick Cottini is the owner of an automobile repair shop in Chico, Calif., that specializes in repairing, restoring and selling classic cars, and repairing wheelchairs. Cottini, paralyzed at the C7 level at age 15, believes in keeping active. He bought a three-wheeled motorcycle equipped with a paddle shifter in 2008 and recently installed a similar device in a new BMW Sport Coupe that he compares

to the feeling of driving a rally racecar. Not surprisingly, he believes that the use of paddle shifters is the wave of the future for people who drive with hand controls.

Steering modifications, when needed,



often include the addition of a knob or similar device on the steering wheel to allow it to be operated with one hand. Other modifications might include adjustment of the position of the wheel to move it closer to the driver, a smaller steering wheel, or a counterweight mounted opposite any other devices attached to the wheel to make it easier to turn. For those with minimal strength, power-assisted steering can allow the wheel to be turned easily.

In fact, the inability to turn a steering wheel at all is no longer a factor that prevents driving. Electronic Mobility Controls and other manufacturers now offer systems that provide complete control of acceleration, braking, and steering through the use of a joystick similar to what is found on any power wheelchair. Aaron Dysart, of Redmond, Wash., has been driving since 1996, and he just purchased his second van. Quadriplegic at the C4-5 level, Dysart does not have sufficient strength to use mechanical types of hand controls or turn a steering wheel, but that doesn't keep him from driving. Thanks to the Scott Driving System, his physical capabilities are maximized to allow him to drive safely. Both arms rest in a steering yoke that also operates the throttle and brakes with minimal effort, similar to the movement of a wheelchair

joystick, while an adjacent touchpad gives him the ability to operate all auxiliary controls.

That concept has also migrated to the common passenger car, as steering wheels on modern vehicles may hold controls for turn signals, cruise control, headlight dimmer, cell phone, music, GPS and more. Some designs of hand controls are less obvious and provide greater clearance under the steering wheel. Kempf has been manufacturing digital accelerator rings that mount on top of the steering wheel for almost 60 years. The accelerator ring is very touch-sensitive, and drivers can learn to steer and accelerate without taking their hands off the steering wheel. Menox offers a control for acceleration and braking that is similar in appearance to the lever used to operate a boat and can be mounted anywhere that is convenient for the driver.

For a more comprehensive list of hand controls, see the resource list below.

Taking Driving to the Competitive Level

One of the benefits of hand controls that might have been unexpected by the initial developers was leveling the playing field when it comes to motor vehicle racing. Drivers who use hand controls have excelled in all types of motor sports, competing and winning against other drivers who are not disabled. Hand controls allow drivers, including many who are not disabled, to retain a firm grip on the steering wheel even if driving a vehicle that requires shifting of a manual transmission.

Even after she started driving, Unser knew that she wasn't going to get into racing. She would leave that to others in the family, "as they were obviously very good at it." While she has not driven race cars competitively, it has not stopped her from supporting those who want to go fast. Her foundation has recently arranged for five racing karts to be equipped with hand controls at an indoor kart racing track in Denver.

The track advertises the availability of adaptive racing, and a transfer bench has been constructed to make it easier for people to slide into the driver seats from their wheelchairs. Those hand-controlled racing karts offer a great opportunity for drivers of all ages to try their hand at racing in a relatively risk-free environment.

Lance Magin, of Holtville, Calif., has become somewhat of an expert on the subject of hand controls used for racing through personal experience. The T4 paraplegic, injured in a 1974 motorcycle accident, has competed in a variety of types of races. One of his favorite controls has been the Monarch, as it allows him to synchronize acceleration and braking. That has been handy when he won his class in the Baja 500 desert races in 2005 and 2006. He still uses those controls while competing in a series of Sports Car Club of America autocross races, where he currently holds first place in his division.

Magin used a hand-operated lever to operate the clutch when he raced in the NASCAR Sportsmen's division, and it was mounted on his hand control. Planning ahead, he is working on a deal for sponsorship of his next race car, which he plans to equip with Guidosimplex hand controls. That would allow him to operate a manual transmission by use of a "duck shifter." Some of the Guidosimplex control's optional features include the ability to operate the car's functions through a variety of means, including a thumb



Lance Magin drives a race car with his hand controls.

accelerator, the duck shifter, buttons mounted on the steering control knob or a ring mounted on the front or back of the steering wheel. The Guidosimplex website points out that Albert Llovera, a World Rally Championship driver who is also paraplegic, has competed successfully while driving with their hand controls in rally races worldwide.



Aaron Dysart demonstrates his driving system.

Hand controls are currently available to operate airplanes, construction machinery, boats, long haul trucks and all-terrain vehicles. It seems apparent that the future of hand controls will continue to evolve based on the needs, and restricted only by the imaginations, of those who use them.

Resources:

- Carospeed Menox, Auto Adapt; www.autoadapt.com/en/products/hand-controls/carospeed-menox/
- Cody Unser First Step Foundation, 505/792-9551; www.cufsf.org
- Scott Driving System and similar products, Driving Systems Inc., 818/782-6793; www.drivingsystems.com
- Electronic Mobility Controls, 207/512-8009; www.emc-digi.com
- Guidosimplex, 888-599-8267; www.guidosimplexusa.com
- Kempf, 888/453-6738 or 408/773-0219; www.kempf-usa.com
- Monarch, MPS Corp., 800/243-4051; mps-handcontrols.com
- Mobility Products & Design, 800/488-7688; www.veigel-na.com/de/main-veigel-north-america
- National Mobility Equipment Dealers Association, 866/948-8341; www.nmeda.com
- Sure Grip, 506/363-5289 or 888/370-5050; www.suregrip-hvl.com
- Unser Karting and Events, 720/282-5000; unserracing.com
- Wells-Engberg, 877/864-8267; www.performancemobility.com/driving-aids/hand-controls/wells-engberg-hand-controls.php

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By Bob Vogel

Healthy Bones: Dos and Don'ts

Q. *I'm a T10 complete para, 25 years post-injury. Ten years ago I broke my femur during a simple fall out of my chair. The tumble was not as bad as the big-time falls I used to take playing wheelchair football. My doc ordered a bone scan, which showed no problem in my spine but osteoporosis in my hips, and she put me on Fosomax. I've taken it once a week ever since. However, subsequent bone scans don't show any improvement in my hips.*

Lately I've read articles suggesting long-term use of drugs like Fosomax can cause serious side effects. Is there information on whether these types of drugs help prevent fracture in people with SCI?

— Kirk

Fosomax is the brand name for alendronate sodium, an oral medication in the bisphosphonates family of drugs that are used to treat osteoporosis, a condition in which bones become so porous they fracture easily.

In order to understand how bisphosphonates work, it is important to understand that bones are living tissue. Throughout our lives new bone is growing and replacing old bone that is absorbed by the body. Bone tissue grows faster than it is absorbed, reaching maximum strength and density — known as peak bone mineral density — around age 30. After that, bone absorption slowly outpaces growth. Osteoporosis is bone loss of about 28 percent or more. Bisphosphonates help increase BMD by binding to the surfaces of the bones and slowing down bone reabsorption, enabling bone-building cells to catch up.

Like all medications, bisphosphonates have possible side effects, including nausea, heartburn, possible damage

to the esophagus, and gastric ulcer. In nondisabled people there have been rare reports of unusual femur fractures and extremely rare reports of osteonecrosis of the jaw — mostly in people with cancer receiving large doses of IV bisphosphonate on a monthly basis.

According to the National Osteoporosis Foundation, bisphosphonate use reduces fracture risk by an average of about 50 percent among nondisabled people with osteoporosis. This makes taking bisphosphonates seem like a no-brainer. But when it comes to osteoporosis and SCI, it isn't that simple.

Osteoporosis in nondisabled people — primarily post-menopausal women and older men — is systemic, meaning all bones in the body are affected the same. Osteoporosis caused by SCI, on the other hand, is regionalized in the lower extremities. Bones get thinner from the hip to the knee and thinner still from the knee to the heel, explains Dr. Douglas Garland of Memorial Orthopedic Surgical Group in Long Beach, Calif. He says the average person with SCI loses about 28 percent of BMD in their legs in the first 1.5 years following injury, then continues to lose bone at about 1 percent a year.

There is no evidence that bisphosphonates decrease fractures in people with SCI, says Garland. Also, most studies on SCI and osteoporosis are looking in the wrong place by using standard bone scans that check BMD at the wrist, lower spine and hips. He says a bone scan study is useless unless it is programmed to look at the knee.

Kathleen Dunn, clinical nurse specialist and rehab case manager, agrees. "In the absence of information that bisphosphonates are at all effective in improving density around the knee, and given their

potential side effects," she says, "most experts in the field feel that we should not use them for people with chronic SCI."

Dunn says her information was reinforced by an excellent presentation she saw at last year's Academy of Spinal Cord Injury Professionals conference about a 12-month double-blind study of people with acute motor-complete SCI, which is when most bone is lost. The experimental group received a dose of IV zoledronic acid — once-a-year IV bisphosphonate. The results showed that bisphosphonates made no improvement in the areas above and below the knee, those areas most at risk for osteoporotic fractures in people with SCI.

In the meantime your best shot at healthy bones is good nutrition. Garland says you should be getting at least 1,200 mg of calcium and 800 IU of vitamin D per day. Although supplements are better than nothing, ideally it should be real food — because the SCI population has a harder time with absorption, he says.

Nutritionist Joanne Smith, co-author of *Eat Well, Live Well with Spinal Cord Injury*, suggests eating calcium-rich foods such as green leafy vegetables (watercress, kale, arugula, broccoli), Greek yogurt, cheese, almonds, salmon and sardines (with bones), as well as a high quality calcium citrate supplement that contains nutrients such as magnesium, phosphorous, boron and vitamin D3.

Advice in this column is supported by Craig Hospital's SCI Nurse Advice Line, a toll-free hotline for people living with SCI, a community service partially funded by the PVA Education Foundation, Craig H. Nielsen Foundation and Caring for Colorado Foundation. For non-emergency nursing info about SCI health, call 800/247-0257 between 9 a.m. and 4 p.m. Mountain time.

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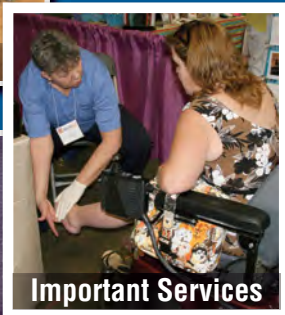
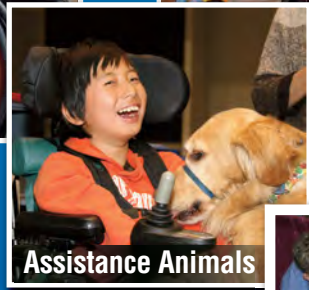
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ARE YOU A JERK TO PEOPLE WITH DISABILITIES WITHOUT EVEN KNOWING IT?

People with disabilities are the targets of a shocking amount of outright cruelty — the rate of violent assault against people with disabilities is triple that for the nondisabled. But even more common are everyday indignities borne more out of ignorance than malice: hearing people trying to talk to deaf people by talking very loudly and slowly, non-wheelchair users leaning forward to talk to wheelchair users, etc.

With that in mind, Scope, a British group that advocates for people with disabilities, has partnered with the advertising firm Grey London and TV presenter Alex Brooker to make a clever series of ads meant to help nondisabled people avoid being awkward — and, you know, actively offensive — when interacting with people with disabilities. They also devised a quiz to test if you learned anything at all from the campaign. Pro tip: if you're trying to chat up a



woman who uses a wheelchair, the correct move is not “ask her what medal she won in the Paralympics.”

— **Dylan Matthews, Vox, www.vox.com/2014/5/8/5694742/are-you-a-jerk-to-people-with-disabilities-without-even-knowing-it**



SEEN AROUND FACEBOOK:

So I'm working on my judging. I failed. When the beautiful nondisabled couple in the Mercedes zipped into the HP spot onto the crossed lines as I'm getting out, this is what happened:

Me: If you're going to use the spot at least know the rules.

Woman: Me?

Me: No, the other car illegally parked where I need to get out.

She moves off the lines and into the space, while handsome is on phone. I shop and they're still in the sparkling car when I return.

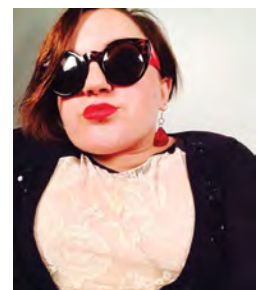
Woman: Well what would you need in that Nike store anyway?

Me: Have a nice day. (OK, that line isn't true. I said nothing. I took a deep breath and debated how fast my lawyer could bail me out if the lift should drop on their car.)

— **Elizabeth Treston**

Just had a dude ask to carry me on the plane. My little inner lawyer popped up to encourage him to beware of opening himself up to liability. Shaking my head! Onward!

— **Bethany Stephens**





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