Ramping up for Disaster
Wijits are the fast, fun, easy-to-use lever-drive & braking system that attach to your manual wheelchair and let you stop safer, turn sharper, climb higher, and go further than you can in a standard push-rim wheelchair; without the sore shoulders, torn gloves, or dirty hands that are endemic to push-rim use. Unlike power-assist devices, Wijits enhance your cardiovascular conditioning and help you sustain a healthy lifestyle.
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Mark Zupan

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From Hurricanes Katrina and Sandy to the wildfires of California and floods of South Carolina, there’s been one thing in common: The Red Cross hasn’t understood disability, and that has put lives at risk. PAUL TIMMONS reports that there’s progress. Meanwhile, WID policy analyst ALEX GHENIS says climate change is coming, and the time to get ready is now.

Cover and Contents Illustrations by Mark Weber
Since writing about my pressure wound battles and having to have my left leg amputated below the knee in August 2012, I’ve heard from many of you who have had similar experiences with persistent pressure wounds. They come and they go, and too often they come again. Just a week ago I discovered a wound on my heel (my only heel), which caught me off guard. I’m still not quite sure what caused it. But I know what I must do to get rid of it.

This wound is serious, not because it is big or deep (it is neither), but because of its location. Foot wounds, particularly heel wounds, are especially dangerous. They are as far away from our heart as a wound can get, so blood supply sufficient for healing may be a problem. They are also most prone to swelling, since they occur at the lowest point on our bodies. And they are often in contact with bathroom floors and harmful bacteria. As if that isn’t enough, the heel has relatively little flesh, so the bone is close to the wound and vulnerable to becoming infected.

So what can we do when a wound suddenly appears in a troublesome area? There are five essential requirements for a wound to heal: freedom from infection; adequate blood supply; no or minimal edema; freedom from pressure; and adequate nutrition, especially protein. If only one of these requirements is missing, the wound will fail to heal or take months or even years to heal.

Staying infection-free may require immediate antibiotic treatment. If you are prone to developing infections, taking a prophylactic antibiotic daily may be best for you. Consult your doctor. But other factors can put you at risk for infection. Edema, for example. As I write this, I’m sitting in my recliner with my foot elevated — one of the most efficient strategies for reducing swelling and speeding healing.

But no matter what you do, healing will not occur with inadequate blood supply. If you suspect this, go immediately to your doctor and ask for an ankle-brachial index to be performed. This will let you know if you need to see a vascular surgeon to discuss options to improve your circulation.

Keeping pressure off the area means just that — zero pressure. You may think a little offloading may do the trick, but nothing is better than zero pressure — even if it means taking to bed (or getting a new, specialized cushion). The final requirement is eating enough protein to stimulate healing. Quite often, the main reason for non-healing wounds is inadequate protein. If you are doing everything else right but are still not healing, you need to get serious about eating protein. For healing to begin and carry through to completion, you will need to eat 1 to 1.5 grams of protein per kilogram of body weight daily. Believe me, that’s hard to do, but absolutely essential. Besides protein-rich meals, handfuls of nuts and protein supplements may be needed to get there.

I’ll let you know how I do in my next column.

— Tim Gilmer
A fierce critic of how the American Red Cross serves people with disabilities, Paul Timmons was recently appointed the Red Cross Disability Integration Coordinator. When asked how that happened, he quotes a Star Trek proverb, “Only Nixon could go to China.” Timmons lives with his wife, Kelly, aboard their yacht, the Tumbleweed, Too, which is anchored in St. Johns, South Carolina. Follow his progress with the Red Cross at www.portlight.org.

Fine artist and illustrator Mark Weber says his main goal is to keep growing as an artist and visual communicator and to eventually take over the world — or perhaps a small cul-de-sac somewhere. Until that happens, he will continue to live and work in the port city of Wilmington, North Carolina. His art has appeared in The New York Times, Rolling Stone, Chicago Tribune, The Atlantic, The Washington Post and many more. He has been a contributor to New Mobility since 2013, when he illustrated the idealized world of “Criptopia.”

A psychologist residing in San Juan, Puerto Rico, Gretchelle Dílán says acquiring a T5 spinal cord injury after a 2012 gun shot accident gave her a “new perspective.” Since then, she founded Vivo Sin Barreras (Living Without Barriers), which is affiliated with United Spinal Association as the Puerto Rico chapter. She also founded a quarterly publication for people with SCI/D and their caregivers called La Voz Corre (Spreading the Word), found online at lavozcorre.org.

Although Mississippians are pros at preparing for hurricanes, Christy Dunaway says Katrina was beyond anything anyone had ever experienced. She was director of LIFE, Mississippi’s network of Centers for Independent Living, when the hurricane devastated the coast and the experience forged her into one of the nation’s finest advocates for disaster relief policy that includes disability. Dunaway lives in Jackson, Mississippi, and chairs the National Council on Independent Living’s Emergency Preparedness Subcommittee.
Reveca Torres is breaking down barriers for everyone with a disability.

Person of the Year
I applaud and thank Reveca for everything she has accomplished through Backbones [“Person of the Year: Reveca Torres,” January 2016]. Reveca has channeled her enthusiasm and creativity into making Backbones a great way for people with disabilities to connect and express themselves. I can’t wait until the app is available. She is breaking down barriers for everyone with a disability.

Carlos Saez, Independent Driving Systems
Houston, Texas

POY Well-Deserved
Reveca is an amazing spirit and well-deserved Person of the Year!
Ellen Stohl
Northridge, California

Generous Heart
Reveca is an inspiration to all of us! Amazing energy and a generous heart!
Sudesh Kannan
via newmobility.com

Snorkeling’s the Best
We love Cancun! [“Mexico’s Yucatan,” January 2016]. We usually stay at the Royal Caribbean/Royal Islander resort [twin “neighbor” resorts]. They have a pool lift (under a tarp in the bar area) and a wheelchair cabana. The whole place has ramps and wide-enough doorways. The only hard part is the ramp to get in the hotel is extremely steep, and it takes you to, of course, the freight elevator. But we have returned to that resort four or five times. We loved Chichen Itza, but thought Tulum was way too much work. My favorite thing is snorkeling! It’s the closest I’ve found to not being a wheelchair user for a few hours.
Carrie Lamont
via newmobility.com

AJ Brockman: Soul Food
A most inspiring story of two amazing people [“AJ Brockman: Portrait of An Artist …” January 2016]. Allen Rucker’s writing goes right to our heart and soul — just what I am needing right now. Will be in south Florida next week and will head to the Brewhouse Gallery.

Del Foxton
via newmobility.com

Brockman and Brewhouse
What a great article for an amazing person and an awesome mom! Love The Brewhouse. You have to experience it to understand it!
Pam Beiter Sartory
via newmobility.com

CPAP Expands Lungs
I acquired my SCI 40 years ago. I was diagnosed with sleep apnea about three years ago [“Healthy Tips for Healthy Lungs,” January 2016]. I have found the CPAP to be very helpful with clearing my lungs. Often, at night, I find myself with productive coughing after about 30 minutes of CPAP use. I think it helps to loosen the phlegm and expand the lungs.
Georzetta Ratcliffe
via newmobility.com

Richmond Chapter
As a new member of the Richmond chapter of USA, I echo and appreciate Richard Bagby’s well worded comments [“Spotlight,” January 2016]. We hope to be impactful in our community, positively shedding light on accessibility.

Clement Sydnor
via newmobility.com

What Wheelchair Service?!
I vowed not to use the wheelchair dealer in town when they had me sit in the lobby for 45 minutes while they were supposedly putting in new wheelchair batteries, only to be told they didn’t have any in stock [“Poor Wheelchair Service,” Everyday Advocacy, January 2016]. My chair then stopped running and displayed an error code. They told me it was the controller, and would cost me $1,900. Luckily I had my old chair as a backup.

After two weeks I called to see what progress was being made. They told me they were still waiting for the part. I called Invacare to ask why it was taking so long, and Invacare told me they had never received a call, and they had plenty of controllers in stock. I called the dealer back and learned they were ordering the part from their own in-house parts department. When the part finally arrived, they installed it and the chair still didn’t work. Finally someone opened up the chair and discovered a disconnected wire. It could have been fixed the first day for the minimum labor charge of $75!
Diane Mettam
via newmobility.com

Wheelchair Light Available
As a volunteer with Vancouver-based Tetra Society of North America, I hasten to make your readers aware of an effective multi-purpose LED wheelchair light available from www.tetrasociety.org [“Wheelchair Users More Likely to be Struck …,” January 2016 News]. Just now moving into production, it is impressive.

Burke Corbet
Vancouver, B.C., Canada

Feedback
Please send letters, comments and story ideas to tgilmer@unitedspinal.org or visit us at newmobility.com.
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Budget Impasse Closes Social Service Agencies

Many social service agencies in Illinois are under pressure to reduce services or close altogether, as the Democrat-controlled legislature cannot reach agreement with Republican Governor Bruce Rauner on a fiscal budget that was supposed to go into effect July 1, 2015. As of late 2015, the state had unpaid bills of about $6 billion and a $111 billion pension deficit.

According to Rahnee Patrick, director of independent living for Chicago-based Access Living, many CILs across the state are having to borrow money on lines of credit to stay open. “At least one CIL has closed, and two more are facing imminent closure,” says Patrick. “The largest social service agency in the state, Lutheran Social Services, has had to cut 750 positions statewide. People are not getting the assistance they need.”

Access Living is not receiving full state funding and has a deficit, yet is being asked to continue providing services. So far Access Living has not had to cut staff. “People with disabilities are not only going without needed services, but on a visceral level it is awful. We are being made to feel like our lives don’t matter,” says Patrick. “We depend on state-funded programs, so we need a budget to be passed.”

Shepherd Offers Self-Defense Classes

Wheelchair users in the greater Atlanta area now have the opportunity to learn life-saving self-defense techniques for free at the city’s renowned Shepherd Center. The rehab hospital has been providing self-defense training for its inpatient population, but is now expanding their quarterly classes to the broader community of wheelchair users after a member of their peer group was mugged and assaulted at an area Target.

“I didn’t think about offering it to our community, but when Kim had this incident, it brought it to the forefront,” says Shepherd Center Peer Support Supervisor Minna Hong. “So we said why don’t we see if we can’t get something going for the community?”

Wheelchair user Kim Smith, 30, was shopping in early January when two assailants mugged her for her purse. “She was inside Target at 7 p.m. on a Sunday, and someone gut-punched her,” says Hong.

Smith says she was surprised nobody came to her aid, but nearby shoppers seemed unaware of the attack. “When it happened, the aisle I was on was empty but I knew people were around me,” she says. “It’s amazing that nobody happened to turn the corner and see it happen.”

Although she escaped virtually unscathed, Smith says the experience left her feeling uneasy. “I want to take the class so that if anybody gets their hands on me, maybe I can learn something that will help me,” she says.

The class meets four times a year and is free to all wheelchair users in the Atlanta area. Contact Minna Hong at Minna_Hong@shepherd.org for more information.

— MAUREEN GAZDA

In March, Dallas Dietrich, a T1 para, gets busy planning Meeting the Need’s annual motorcycle run from Rapid City, South Dakota, to his retreat for people with disabilities near Mount Rushmore. A restored mining camp, the 102-acre retreat will host more than 100 visitors for food, fundraising, and disability education. Last year, the event featured an Ekso Bionics exoskeleton demonstration by Gary Linfoot, para and former Special Ops Army veteran. This year’s run will take place August 2.

Meeting the Need, a nonprofit founded by Dietrich in 2001, specializes in providing unique camping and lodging experiences for people with disabilities. This year several groups of disabled visitors, many of them wheelchair users, will stay in the completely renovated historic wheelchair-accessible mining camp. Funds raised will help complete a road to the top of the property — where a new lodge will have a view of Mount Rushmore — as well as defray costs of stays for people with disabilities. “We are really looking forward to the 2016 season,” says Dietrich. “We had 300 camper nights in 2014 and 500 camper nights in 2015, so we are on an upward trend.”

Dietrich has been a disability supporter since before the 1997 accident that damaged his spinal cord. He led the group that established the Black Hills Ski for Light chapter in 1979 (for those with visual and mobility impairments). President George H. W. Bush honored the chapter in 1990 as his 80th “Point of Light.” For more info, go to www.meetingtheneed.com.
When it comes to safety, we’ve turned the mobility world upside down.

We built the MV-1 with all of the features wheelchair users need, and we focused on safety at every turn. We like to say we started with a ramp and created the entire vehicle around it for safe and easy wheelchair access. And because you’ll spend most of your time driving or riding in your vehicle, we designed the MV-1 to have exceptional handling and plenty of ground clearance for the everyday obstacles you’ll encounter. Right off the assembly line, the MV-1 is accessible, durable, robust and reliable. It’s the one vehicle for you, protecting you and your family even as it gives you easy access to the world around you.

- Factory built for universal wheelchair access
- Safest wheelchair accessible vehicle on the road*
- Durable performance with high ground clearance

* Based on NHTSA safety recall data

2016 MODELS
See them at mv-1.us
“Going from growing up in a mud hut to mingling and having tea with the queen of England is not something I can take lightly,” says Anne Wafula Strike, MBE — Member of the Most Excellent Order of the British Empire — for her service to disability sport and charity.

Now 44, Wafula Strike, the first Paralympian to hail from East Africa, is not only a sporting ambassador, but also a speaker, author, wife and mother.

She became paralyzed after a bout with polio at the age of 2. Coming from a small Kenyan village, she traveled a hard road growing up. After meeting her husband in 2000, she moved to the United Kingdom, had a child, and not long after got involved in wheelchair racing. “I started racing to lose weight, but my natural ability was soon spotted, and I quickly began to win lots of medals, gold ones!”

Before she knew it, she was competing in the Paralympics for Kenya in 2004. Then in 2006, after becoming a British citizen, she began competing for Team GB and became its number one racer in the 100 meter and 200 meter categories for wheelchair racing. She carried the Paralympic torch in 2012 when the Paralympics came to London.

Since retiring, Wafula Strike has dedicated her life to humanitarian efforts. Her Olympia Wafula Foundation delivers healthy-living solutions to people with disabilities in Africa, Nepal and other emerging areas of the world. In 2014, her foundation delivered 40 wheelchairs to children in Kenya.

She has also written an autobiography, In My Dreams I Dance, which has been a powerful motivator for many, especially her most oft-quoted piece of advice: “I have suffered discrimination, but what I have come to realize is that when I carry out grudges, I am the one who suffers most.”

Beautiful insight from one of the most hopeful souls we’ve encountered. Her book can be found on Amazon.com.

Visit annestrike.org and olympia-wafulafoundation.org.

The Universal Upgrade

After a spinal cord injury, you learn how expensive equipment can be, including adapted workout equipment. However, if you’re in need of a serious workout and your local fitness centers are void of accessible equipment, the Wheelchair Fitness Solution — an accessible universal gym — may be the answer you’re looking for.

Created by a paralyzed veteran living in Miami, Florida, this accessible gym has a pulley system, hand pedal bike, punching bag and chin-up bar, to name a few features. It also has exercises to target all areas of the upper body, like a military press for your shoulders and a chest press. In total, it has more than 40 exercises using a single entry point harness system.

While the cost is steep at $8,000, if you are serious about your workouts, the Wheelchair Fitness Solution may be just the machine for you.


Strength on Film

Injured in a car accident in 2014, Carina Ho, 28, a musician from Oakland, California, has had to redefine her life — transitioning from ballet dancing to the wheeling life as a T2 para. She can still play the piano independently, but moving on has proven difficult, which is why she created the web series, Onward Ho, a film and art project profiling her post-injury life and the resurgence of her adventuresome spirit.

See more at www.onwardhoseries.com.
Preventing Hemorrhoids

Hemorrhoids — swollen veins around the anus and in the rectum — are more prevalent among people with SCI than the general population. It is believed that this higher incidence is due to several factors, such as chronic constipation (which intensifies pressure and may weaken the veins in the rectal area), prolonged sitting, straining, irritation through repeated digital stimulation and/or use of suppositories or enemas.

A major sign of hemorrhoids in individuals with SCI is bleeding during your bowel management program.

People with SCI obviously cannot avoid risk factors such as prolonged sitting, and in some cases digital stimulation and use of suppositories. However, there are many foods that can help strengthen your veins and help prevent the development and/or recurrence of hemorrhoids:

A high-fiber diet is extremely important in the prevention of hemorrhoids. There is a strong correlation between constipation and hemorrhoid development. Preventing constipation is one of the best ways to reduce your risk of developing hemorrhoids. A diet rich in vegetables, whole grains, fruits and legumes promotes movement of stool through the bowel. Fiber also absorbs water to help keep feces soft, bulky and easier to pass. The recommended daily intake of fiber for people with SCI is 19 to 30 grams. A chart of popular foods and their fiber content follows.

Flavonoids are found in foods such as blackberries, blueberries, cherries and citrus fruits, and they help to strengthen vein structures.

Vitamin C is found in foods such as citrus fruits, broccoli, spinach and kale, and helps increase the strength of blood vessels to help prevent hemorrhoids from rupturing.

This smoothie is loaded with fiber, vitamin C and flavonoids. Drink it for breakfast or as a snack!

High Fiber Berry Smoothie

½ cup strawberries (fresh or frozen)
½ cup blackberries (fresh or frozen)
½ cup unsweetened blueberry juice
½-1 cup water
1 tbsp ground flax seeds
Handful spinach
Blend until smooth and enjoy!

Popular Fiber-Rich Foods for Meals and Snacks

Nuts:
Almonds, raw, 1 ounce (23 almonds): 4 grams of fiber
Sunflower seeds, raw or dry-roasted, 1 ounce: 3 grams of fiber

Fruits:
Apples, 1 medium: 4 grams of fiber
Berries (blue, black, boysen, cran, rasp), 1 cup: 4-8 grams
Mango, 1 medium: 5 grams
Orange, 1 medium: 3 grams

Vegetables:
Artichokes, 1 medium cooked: 10 grams of fiber
Avocado, ½ medium: 7 grams
Broccoli, ¼ Cup cooked: 7 grams
Carrots, 1 cup sliced, cooked: 5 grams
Collard greens, 1 cup chopped, cooked: 5 grams
Green beans, 1 cup cooked: 4 grams

Beans and peas:
Black beans, dry, ½ cup cooked or canned: 8 grams of fiber
Black-eyed peas, dry, ½ cup cooked: 6 grams
Kidney beans, dry, ½ cup cooked: 7 grams
Lentils, dry, ½ cup cooked: 8 grams
Navy beans, dry, ½ cup cooked: 10 grams
Pinto beans, dry, ½ cup cooked: 8 grams
Q. As a reader of your columns and a mid-level quad, I’d be interested in your thoughts on the decision to drive, or not. I don’t drive and am constantly being told that I should. Sometimes I feel almost guilty about not driving. I would love to drive, but only if I felt like I was doing so at the same, or near the same, level of competence I did prior to my injury. I was driving when the accident happened that left me paralyzed. It was a no-fault accident and, from what I know, I didn’t do anything wrong. Luckily, no one else was seriously hurt.

I have met similarly injured quads who drive and it seems like they are driving at a reduced level of control. I can’t do that. I can’t imagine jeopardizing the lives of others for my own benefit. I know that sounds like an excuse/self-justification, but it is a very real feeling.

Since I am unable to transfer independently and have reduced strength and dexterity in my arms, I’m interested to know if there are controls available that will allow me to drive safely; also, cost information. Are joystick-type controls available, and affordable, for someone in my situation? Thanks for any information you can provide.

— Wavering on the shoulder of the byways

No need to apologize for exercising some level of caution when it comes to deciding whether or not to drive. Some reluctance would certainly be understandable in light of the type of accident that caused your paralysis, but even with that in mind, it is important to explore all avenues before making your final decision. A variety of driving systems are in place that make it possible for people with a very high level of injury to drive safely. That competence requires a systematic approach to decision-making about the type of vehicle and the mechanisms or electronics that will allow you to control it.

The very act of driving is a risky undertaking. Minimizing opportunities for accidents is the primary reason that the products developed, manufactured and serviced by mobility equipment dealers and hand control companies have evolved to their current status.

Those of us who are paralyzed and who drive with hand controls today find it much easier, and safer, than did people with similar disabilities who started driving 40 years ago.

Resources at the end of this column will provide links to a previous Motorvation column and an article in New Mobility that discussed hand controls and how to find affordable vehicles. I will restrict my response in this column to considerations, potential expenses and challenges for someone deciding whether or not to drive.

First and most important, do you really need to drive? Many people, with and without disabilities, live in communities that have excellent public transportation options. Unless a need exists to take trips out of the area, it may be possible to forego vehicle ownership in favor of taking a train or bus. This may become even more feasible if rideshare and taxicab companies actually become wheelchair accessible, as many municipalities are requiring them to do at this time. The availability of someone to drive you in your or their vehicle may also be a cost-effective option.

If you want to proceed, what type of vehicle do you need, or want? Lift-equipped pickups and SUVs are now available, along with many different sizes and types of vans. Once you decide on what you want, check with a local mobility equipment dealer to see about purchasing costs. Before making that final decision, load into a similar vehicle and make sure that it fits with your mobility device and reach ranges, etc. At that point you should be able to get a price estimate from the dealer that sells what you want and need.

The dealer, in partnership with a driver rehabilitation specialist, can evaluate your driving capabilities based on your level of function. The DRS will be required if your vehicle is being subsidized, provided or financed by another entity, and sometimes in order to receive a driver’s license, depending on disability.

Other cost considerations are vehicle modifications, assistive technology and installation, tax on the sale, insurance, routine maintenance, fuel, license, parking fees and repairs if parts fail. If you are ready to take that on, know that at the end of the process you will be ready, and safe, to drive. Good luck, and happy motoring.

Resources
- Certified Driver Rehabilitation Specialists, www.aded.net
I absolutely love my iLevel chair! It’s great going out and being able to speak to people face to face instead of having to look up at them. They have an easier time hearing me, too. I can also use my computer or watch TV more easily using environmental controls with Q-Logic. I feel more comfortable and confident now.

Tim Gaynord

To learn more, visit us at Medtrade Spring Booth #130
From the pristine landscapes of remote Iceland to the beautiful Hawaiian island of Maui to a sailboat moored on the sunny coast of Florida, wheelchair users live anywhere they want — successfully. It takes problem-solving, creativity and flexibility, but living in paradise more than makes up for any access-related inconveniences.
It may be a stretch for most Americans to think of Iceland as paradise, but for those who call it home, the dramatic beauty of the island nation is as close to Valhalla-on-earth as one can get. And like most Icelanders, Jón Gunnar Benjaminsson, 40, is protective of his home island. “Our nature with its vast wilderness, towering mountains and glaciers, black volcanic sand beaches and lush green valleys, is not ours but something we borrow from the next generation and generations to come,” says Benjaminsson. “We simply must treat it that way and not like it belongs to us.”

Benjaminsson, a para and founder/owner of the travel company Iceland Unlimited, invites lovers of the outdoors to come spend a week in his nation. “Iceland is a small island. You can capture the whole experience in an eight-day round trip of the island,” he says. “You can experience paragliding in a specialized, custom-built chair with an experienced instructor, boat cruises on glacial lagoons, ATV tours on black sand beaches, snowmobiling on glaciers, and bathing in natural geothermal hot springs in the highlands. And you can go snorkeling in crystal clear water in a lava fissure, to name a few options.”

He says his favorite spot is probably Eyjafjörður fjord in Northeast Iceland. “That’s where I was born and grew up. My parents and oldest brother still live there and I spend half of the summer there, fishing and spending time with my family.”

But the most beautiful site in Iceland is probably around Skaftafell, located within the Vatnajökull National Park. “It’s a lush green oasis of birch trees, located between the vast Vatnajökull glacier and the black volcanic beach of Skeiðarársandur, so you have these contrasts there in one spot — white glacier, green trees and black beach. It’s spectacular.”
Benjaminsson says the city’s amenities make it a good place to call home. “In Reykjavik I’m surrounded by better facilities for therapy — swimming and physical training facilities that are available to people with disabilities,” he says. Though downtown Reykjavik is not the most accessible place in the world, improvements are being made on a regular basis. The city is becoming more and more aware of disabled people.

If you want to experience Iceland’s pristine beauty for yourself, don’t expect American-style access. “Iceland is definitely rough. We’re still in the process of updating our infrastructure when it comes to accessibility,” says Benjaminsson. “You have to be aware of this and be ready for rough conditions in some places, but don’t let this discourage you from coming. Anything is possible and if you’re up for adventure, we promise Iceland won’t leave you disappointed.”

- Iceland Tourist Board, iceland.nordicvisitor.com
- Iceland Unlimited, www.icelandunlimited.com

Carole Zoom: ALOHO FROM MAUI

“Everyone is jealous that I live in Maui, and I completely understand it because it took me 10 years to move here,” says Carole Zoom, 50. She lives on the south side of the island of Maui in Kihei, one of the most recently developed areas on the island, with newer construction. “The weather is fantastic and there are only six days of rain all year” — her favorite thing about the island. Zoom, who has muscular dystrophy and uses a vent, loves the mellow Hawaiin lifestyle and can often be found relaxing on her lanai, reading a book while basking in the sun.

An accomplished travel writer, Zoom and her husband started coming to Maui in 2003 from their home in Austin, Texas, to take advantage of their timeshare. They soon found it was easier to travel to some of their favorite destinations in Asia from Maui. “In June 2012, we were on vacation here, and I told my husband that I didn’t want to get back on the plane and leave,” says Zoom. So they stayed.

The Kihei region has small shops to visit, restaurants that cater to both tourists and locals, and a bustling farmer’s market. Zoom especially enjoys going to the theater and local events. Plus, Maui’s not that large, so all of its attractions can be accessed from Kihei. “In Maui you have this nice balance of quiet with activities when you want them.”

Zoom loves to wheel along the shoreline path near her home, watching for sea turtles bobbing in the surf.
ing Maalaea Bay that had been recently updated. They widened the small bathroom’s door, removed the tub and built a roll-in shower. There are accessible shops and places to eat right downstairs.

When she broke her femur soon after moving into the new condo, Zoom discovered that, to her surprise, “the caliber of doctors on Maui is exceptional, incredibly high quality for the small island. And they accept Medicare. There are some very, very good specialists.”

ALMOST HEAVEN
Hawaii has a reputation for being very expensive since almost everything has to be either flown or shipped in. But Zoom says if you’re careful, it’s not that much more expensive than Portland or Austin. She saves money by buying her fruit at farm stands instead of the grocery store, and she avoids processed food that has to be brought in from the mainland.

Also, the ADA hasn’t yet fully penetrated our 50th state. “Most of Hawaii is not as advanced in disability rights and wheelchair access as other places in the United States,” says Zoom, who once served as the executive director for the Coalition of Texans with Disabilities. “It’s still lagging way far behind. Some of that is because infrastructure here is not kept up.”

In some areas on the island, Zoom has to roll in the street. The buses are all accessible and there is a paratransit system, but
they don’t run late in the evening. And although the ocean is very beautiful, beach amenities aren’t always built or provided with wheelchair users in mind. Wheelchair users who enjoy swimming may need to rent a beach chair from Gammie Home Care in Kahului. Also, Kamaole I beach has a free beach wheelchair available on a first-come, first-served basis.

Still, Zoom has no complaints. “There are ways for those of us who use wheelchairs and who aren’t swimmers to enjoy the beauty of the ocean,” she says. She rolls along the shoreline on a mile-long pathway near her home to look for giant sea turtles bobbing their heads up in the evenings at sunset. From November through March, pods of whales come to western Maui for calving season. Many whale-watching boats are not wheelchair-friendly yet, but Zoom hopes to influence that now that she’s living in Maui full time.

Anyone interested in moving to Hawaii should first plan a visit, says Zoom. They could even stay at her place, a wheelchair accessible condo she rents out on Home Away when she’s traveling. “I believe that anyone who wants to live in Maui can do it. It just takes some planning and some saving money to get over here,” she says. “Maui is a great place to live, and we welcome any visitors with ‘Aloha!’”

• Gammie Homecare, 808/877-4032; www.gammie.com

Allen Fiske: SAILING AWAY IN FLORIDA

Who wouldn’t want to live on a sailboat? Sun on your face, wind in your hair — the smell of the ocean and the freedom to just pull up anchor and sail up or down the coast makes it a dream.

At least, Allen Fiske always thought so. “That was my dream,” he says, but after his T11-12 injury in 1982, he just didn’t think it would be possible. “People told me I wouldn’t be able to drive or work, all kinds of things. But nothing in the world ever gave me the same feeling as sailing. I’ve been around the ocean my whole life, and it just blew my socks off. It continues to blow my socks off.”

Fiske became involved with Shake-A-Leg, a Miami-based organization set up in 1990 to help disabled people enjoy the ocean, including sailing. Eventually he and a friend started chartering big sailboats, and he got some of his confidence back. Then, in 1994, he bought a sailboat using his rent money for the payment. Over the years he has stayed involved with the organization. He was director of watersports, facility and fleet maintenance from 1997 to 2007 and still serves as a part-time sailing instructor.

He has lived the last 25 years in south Florida, 20 of those on his 35-foot sailboat near Miami, the past three years in Fort Myers. Just recently Fiske, 69, bought a condo to give his body a break from the physical toll of constantly being on the boat.

“Just realized you only live once … one chance to do this,” says Fiske, about living on his boat. “It’s not easy being paralyzed, but if you can find one little thing that really excites you and makes you want to get up in the morning, you’ve got to go with it.”

Fiske has sailed to places like the Bahamas, Key West and along the coasts of Florida. He tries to do as much as he can himself and always takes at least one person with him when he goes sailing.

It is easy for Fiske to find a fellow sailor since he’s only recently wrapped up serving a term as commodore, or presiding senior officer, of the Fort Myers-based Caloosahatchee Marching and Chowder Society, the largest sailing club on Florida’s west coast. In a club of 110 sailors, he’s the only one so far who uses a wheelchair.

MAKING IT WORK

The biggest modification was a lift that lowers Fiske from the cockpit down into the boat, where another wheelchair waits for
him. Rigging and sails are electric-operated, and a special cushion allows him to scoot around the upper deck. Fiske says it’s easier to get in and out of the boat if you have a floating dock. “It isn’t easy being paralyzed and climbing on and off the boat, but I love it so much that I make it work for me,” he says.

Just making the boat accessible wasn’t enough. Fiske also undertook some serious lifestyle changes — eating right and exercising — to be at 110 percent for the boat life. He dealt with pressure sores that required flap surgery, and also had shoulder surgery, but made it through the ups and downs. “I think the reason I’ve been able to deal with all this is because of the positive feeling I got from living on this boat,” he says.

Fiske says he doesn’t think most people take the time to think about what’s involved for a paralyzed person to live on a boat, and if they knew, it might scare them off. “Nine out of 10 might see what I’m doing and say, ‘forget it, too much work, it’s not worth it.’” Fiske grew up in Massachusetts in a fishing family and has been on or near the ocean his entire life. “To me it’s been worth it because I love it.”

- Caloosahatchee Marching and Chowder Society, www.cmcs-sail.org
- Shake-a-Leg Miami, 305/858-5550; www.shakealegmiami.org

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“IT ISN’T EASY BEING PARALYZED AND CLIMBING ON AND OFF THE BOAT, BUT I LOVE IT SO MUCH THAT I MAKE IT WORK FOR ME,” Fiske says.
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Having a pet, no matter how big or how small, can improve our lives greatly. They provide companionship and entertainment, bring us joy, cheer us in our sorrow and teach us compassion. Taking care of their daily needs gives us purpose, and it’s a fact that a pet can also be the best medicine for those of us who have pain, high blood pressure, depression or feelings of isolation. Our pets can bring out the best in us and allow us to share our love, even while trying our patience.

The pet lovers interviewed admit their pets are a major part of the family, and somewhat in charge of household activities. Here, they share the many ways their fur babies add so much to their lives.

**ACTIVIST SIDEKICKS**

Doug Craig is a tireless advocate for raising funds and awareness to benefit people like himself with FSH muscular dystrophy, and his dog, Gracie, is always right there beside him.

This past summer, Craig and his 80-pound Bernese mountain dog mix took a 300-mile walk-and-roll from Yonkers, New York, to Washington, D.C., to raise funds and awareness for the FSH Society. They walked and rolled for up to 10 miles per day while Craig’s friend, Rob Dye, drove along in his van. “When she and I got tired, we rode in the van with Rob to make time,” explains Craig, 62.

Author and activist Maria Palacios’ favorite of her six pets, Nacho, a small Chihuahua mix, loves to attend ADA marches with her and enjoys protesting nestled in the net under her wheelchair. “Nacho figured out quickly that taking naps in the little net under my wheelchair was not only comfortable, but also a way to be with his mom all the time,” says Palacios.

Palacios was enjoying her dog-free lawn after losing her beloved Labrador, Buddy, when one of her mother’s customers insisted on bestowing a little yellow puppy as a gift of appreciation for services rendered. “My mom was not thrilled...
about bringing a puppy home until she thought of giving it to me as ‘revenge’ for all the animals I’d brought home to her throughout my life,” says Palacios, a polio survivor from Houston, Texas. “As she put the puppy on my lap, she said, ‘He will be a special angel to somebody.’”

And he is. Palacios, 50, who has two sons and now four more dogs and two cats, says Nacho is her “best son” and a natural activist.

**FOOD SNOBS**

Palacios says Nacho gets a daily bowl of chicken while his four-legged siblings get a combination of dog food sprinkled with chicken. “Nacho has to have company when he eats and only accepts food when he’s hungry. If he’s offered food when he’s not in the mood, he’ll just roll his eyes,” she says.

Tim Vermande’s cats, Blaze and Chessie, are food snobs, too. “Blaze likes Ritz and Triscuit crackers, as well as Corn Chex,” says Vermande, 61, from Indianapolis. “She can tell the difference between the boxes, and won’t even come for Wheat Thins. If I don’t give her anything, she will open the box and dig into it for one.”

About a few times a week both cats get a spoonful of milk from Vermande’s morning cereal. And when he comes home from being out and about, they do the “where’d ya go, what’d ya do, who’d ya see, what’d they say?” routine, sniffing him and his wheelchair. When Vermande transfers to his recliner, the two cats tussle over who gets to sit in the wheelchair.

The clever felines learned to operate the lever door handles in the house Vermande shares with his wife. “We can’t close off anything now,” he says. A polio survivor, Vermande uses crutches around the house and Blaze will come around every hour or so to make sure he gets up and moves around. Chessie curls up next to him while he’s getting his TENS treatment and adds a purr to the other side.
GOOD FRIENDS IN HARD TIMES

Six-year-old Agatha Louise, Lydia Nunez Landry’s Chihuahua mix, loves being up on furniture to be with her humans. Unfortunately, she broke her leg after leaping from a bed and now, with a plate in her leg, someone has to pick up “Ouisie” and set her on the bed, couch, or Nunez Landry’s wheelchair and closely monitor her so she doesn’t jump off.

“She loves riding on my power chair as we go around the neighborhood,” says Nunez Landry, who has dysferlinopathy muscular dystrophy and lives in Seabrook, Texas. “Apparently, this makes her feel invincible as she curses out other dogs who probably view her as a Chihuahua McNugget. For propriety’s sake, I cannot repeat her foul utterances.”

When asked how Agatha Louise helped her, Nunez Landry said the tiny pooch filled a depressing void after she lost both her parents and another beloved dog, Sigmund.

“Since I do not engage in many social

“My dog America ran away about a year ago,” says Cory Lee, 25, from Lafayette, Georgia. “I called all the shelters around here but nobody had her. Three weeks later, a friend looking to adopt went to one of the shelters I had called and there was America, sitting in a cage. She was found 30 minutes from my home but the shelter didn’t check her microchip. I even described her and left my phone number with them. I was so worried, she’s my baby.”

DO YOUR HOMEWORK

Certain pets are not for everyone. Research the species or breed before you choose. Understand their energy level and be ready to match it or have someone who can help. If the breed is a runner such as Siberian huskies or greyhounds, they’ll need to be fenced in or on a leash at all times, and some animals such as Persian cats need regular grooming. Understand that certain breeds can be prone to problems such as ear infections or hip dysplasia, or require special diets that can ring up the grocery and vet bills.

Keep in mind annual costs for having a pet can range from $235 for a fish to $1,843 for a large dog. More specific information from the ASPCA on average costs for particular species can be found at www.aspca.org/sites/default/files/upload/images/pet_care_costs.pdf.
activities, my family and pets are a significant and meaningful part of my life," says Nunez Landry, 46. "Both provide me tremendous joy and comfort, especially when I am down.”

Gary Karp, 61, is best known for his motivational books, workshops and speeches, but the author says he sometimes struggles to get out of bed due to depression. "On those days I know my Labrador retriever Trilby needs me to get motivated to take care of her needs, and it’s just the nudge I need," says Karp, a T12-L1 para from Tempe, Arizona.

THE UNUSUAL AND EXOTIC
Since childhood, Kelsey Little, 27, from Sevierville, Tennessee, has cared for wildlife such as squirrels, a skunk and a raccoon, all abandoned by their mothers. She named her skunk “Pumpkin,” after her friends found him alongside a road.

“Taking care of Hank is like taking care of a toddler,” says Kelsey Little. “I was trying to paint something outside and he was getting into everything. My mom said it’s like having triplets. While sleeping, he digs around in my ears, my face and hair, and curls up against me. And just like a 3-year-old, if you try to take something away, he starts pitching a fit.”

One night she saw in a mirror that he was following her, and when she turned to look, he started his spray dance. They’d made a game out of it chasing from room to room.

Pumpkin, like most of the wildlife she cares for, was successfully released back to the wild once he was able to look after himself.

Little’s raccoon, Hank, came from a local who breeds coon dogs to trap raccoons, and raises raccoons to train his dogs. “He trapped a momma coon, and the pups wouldn’t take to her,” Little explains. “I had told him that whenever he had pups I’d take one.”

Baby raccoons can’t regulate body temperature for their first two weeks, relying on their mother and siblings to keep warm. “I’d wear a sports bra and put him in the middle to keep him warm,” she says. “He was like a baby.”

SPIDERS AND SNAKES NEED LOVE, TOO
Jerry Diaz has had a fascination for exotics since being mesmerized by them while watching nature shows as a young boy. He has since become an expert on caring for snakes and reptiles and many tarantulas, including a Goliath named Zion and Banana are together but can’t interfere with each other. My dream is to buy a house and create a natural environment in a room just for Zion, who will grow to 5 feet long.”

“I get creative when building cages for my animals,” says snake owner Jerry Diaz. “Recently, I used an entertainment center my brother was getting rid of and sectioned off so Zion and Banana are together but can’t interfere with each other. My dream is to buy a house and create a natural environment in a room just for Zion, who will grow to 5 feet long.”
Micayla. The largest of tarantulas, a Goliath grows to the size of a dinner plate sporting half-inch fangs.

Yes, you read that right.

Diaz, 29, from Kissimmee, Florida, is a lover of all animals, no matter how little appeal they may have to others. He has a wealth of knowledge and much of it is uncomfortable. As he was telling me about Micayla and Banana — his pastel ball python — and Zion, his water monitor, I felt something biting me hard on the right side of my neck. It might have been a nerve throbbing from an age-old fear of creepy-crawlies, but whatever it was, Diaz just laughed when I told him.

Then he said something so profound about his experience with people and exotics that the biting in my neck ceased, I stopped squirming in my chair, and as a wheeler, I began to relate to the creatures for whom he cares. Before you run screaming, consider this:

“I see the beauty in all animals and have just always wanted to be around them,” says Diaz, a T10-12 para. “But there was something about exotic animals that drew me. You know, they are living dinosaurs, amazing creatures.”

Diaz worked at a pet shop helping customers choose pets. He says customers could be standing next to a snake cage for 20 minutes before they would notice it, grab their kids and bolt out the door. Teaching a child to fear or feel disgust about an animal irks Diaz.

“I saw a lot of parents or grandparents come in with their kid or grandkid,” he explains. “They’d point to a snake or reptile cage and tell them how it’s gross or ugly, and I’d think, ‘Why are you teaching them that?’ If you don’t teach your kids that, they won’t fear or hate these beautiful creatures,” he says.
TRAINING THE RED CROSS FOR DISASTER

ILLUSTRATIONS BY MARK WEBER
“Are you and Kelly gonna be OK? They’re predicting terrible flooding!”

Our friend, Sister Colie, was calling to check on us, as she often does.

“C’mon, Sister! You’re a nun. Surely to God you’ve heard of Noah! We’re in better shape for this than anyone you know.”

And it was true. My wife, Kelly, and I live aboard the Tumbleweed, Too, a 34-foot sailboat docked at a marina just off Charleston Harbor. We had secured our office, removed our cars to high ground, stocked in plenty of food, drink — and candy — and settled in. We were ready for the rains, and the resultant flood. Our home floats. We were good.

As it turned out, we were in much better shape than thousands of others with disabilities in South Carolina dealing with the catastrophic October floods. Weather experts eventually referred to it as a flood that comes along once in 1,000 years.

The rain began Thursday evening, Oct. 1. It didn’t stop. Friday morning, flood reports began to come in from across the state. By Saturday morning, it was clear the event was shaping up to be a dangerous situation, especially for South Carolinians with disabilities.

My first clue was seeing an American Red Cross representative on television announcing shelter openings with the invitation, “Everyone is welcome.” After a few calls, it became apparent there were problems at shelters throughout the state, including one Red Cross shelter manager who responded to questions about accessibility by saying, “Honestly, people with disabilities just aren’t a priority for us right now.”

Bear in mind, the flooding in South Carolina came on the heels of egregious issues with the Red Cross response to Butte and Valley wildfires in California just weeks before. Those problems began immediately, when the Red Cross, faced with a lack of accessibility and needed care, moved two of our people from shelters to nursing homes. This culminated a couple of weeks later when I received a phone call from Vance Taylor, chief of the Office of Access and Functional Needs for the California Office of Emergency Services.

“Paul, I’m sitting here in a shelter right now,” said Taylor. “The shelter manager tells me he has turned away several people with service animals, saying, ‘Red Cross national policy...
prohibits us from accepting service animals at our shelters.”

As I sat on my boat, working the phones and trying to deal with the emergent situation in South Carolina and thinking about all that had happened in California, I was overcome by a feeling of hopelessness.

American Red Cross is the major player in emergency preparedness and response. What they do matters. It impacts how other players behave, as they are the industry leader and operate or are intimately involved in the operation of most of the emergency shelters in the United States.

For two and a half years, I and a host of other advocates have been beating our heads against the wall, begging Red Cross to let us help them get it right for our community. As the rains continued to fall in South Carolina, it was clear that we hadn’t moved the needle at all.

**THE KATRINA EFFECT**

Hurricane Katrina was a clear benchmark of how bad things were for everyone involved, as few had given any thought about how to prepare for and respond to a catastrophe of its magnitude.

“The staff in the LIFE of Mississippi Biloxi office were certainly old hands at hurricane preparedness and had taken what they thought were the appropriate steps both personally and in terms of the LIFE office,” says Christy Dunaway, who was director of LIFE of Mississippi, the state’s network of Centers for Independent Living. “But no one expected a 30-foot storm surge. None of them ever expected to be swimming for their lives, roped together with their family, walking through head-deep water.”

It was three days before Dunaway, who lives in Jackson, Mississippi, knew all of her staff had survived and five days before all of the people served by LIFE could be accounted for. Once they were able to get in touch with each other, the staff members who were not in personal crises visited the shelters to see if they could find and serve people with disabilities.

“Most of the Red Cross shelters turned us away at the door, so we camped out in the parking lots and waited for people with disabilities to come outside,” says Dunaway, who now chairs the National Council on Independent Living’s Emergency Preparedness Subcommittee [see “Brokering Disaster Relief,” page 30].

Shaken up by what had happened to people with disabilities during and after Katrina, disability rights advocates like Dunaway started reaching out all over the nation, and some strong partnerships were formed with emergency responders on local, state and even federal levels. The good work of the Georgia Disability Emergency Management Coalition, run out of the State of Georgia’s ADA Coordinator’s Office, comes to mind. And in 2009, President Obama appointed one of our own, disability rights advocate Marcie Roth, as senior advisor, disability issues, for FEMA [see “Marcie Roth,” page 29].

The communication that went on after Katrina was good, as it resulted in introductions and some plans. But there was a view held by some of the stakeholder organizations that, “OK, we’ve done this, we’ve got it.” And so disaster relief planning for people with disabilities stagnated.

Disaster relief is a fluid business, and it’s very relationship-dependent. It’s critical that we stay engaged and continue to nurture the relationships and continue to look at our plans and fine tune them and address them on an ongoing basis. Part of the issue here is that, with the exception of Portlight, none of our stakeholder organizations are full-time disaster relief providers for people with disabilities. They’re doing great work, but they have...
other issues upon which to rightly expend their resources.

It’s my belief that while Katrina precipitated the beginnings of us building a foundation, in many ways, the efforts stopped there. The lack of a meaningful structure upon the foundation is at the root of a lot of the problems we continue to see.

**RED CROSS BREAKTHROUGH**

During and after Katrina, our people suffered and died in disproportionate numbers, and this continued with Hurricanes Ike, Isaac and Sandy. Ten years on, and our experiences in California and South Carolina showed no indication that things were much different.

The fact of the matter is, the climate is changing, and extreme weather events are going to get worse and more common. One of my great worries is the certainty of massive human migration as a result of climate change. If the emergency management overlords don’t get it right, our people will continue to suffer and die in disproportionate numbers. Aside from the migration issue, the simple fact of increased frequency and severity of disasters is enough to make this issue one of the most important ones facing our community.

But things may be looking better.

For years, Portlight and NCIL have been asking the Red Cross for two things: First, the opportunity to engage in meaningful, continuous training at the grassroots level with volunteers and staffers involved in the real-time delivery of sheltering and services; and second, a full-time disability inclusion coordinator at Red Cross national headquarters. We were stymied at every turn in our efforts to engage in meaningful training, and were flat turned down on our request for a disability inclusion coordinator. This meant there was no one internally within the Red Cross to whom we could turn for any satisfaction.

But then two long-term Red Cross employees who had been close to the situation in California, Katherine Galifianakis and Mary Casey-Lockyer, were deployed in South Carolina during the floods and saw first-hand what was needed for our community. They reported back to Brad Kieserman, who was new in his job of vice president of disaster operations and logistics for Red Cross. He

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**MARCIE ROTH LIGHTS UP THE DARK SIDE**

Equally important — or arguably more important — as the role of the Red Cross in disaster relief is the role of FEMA, and there is no better example of the failures of the emergency management community to serve people with disabilities than its performance in the aftermath of Hurricane Katrina. Contrary to myth, they did not do “a hell of a job.”

In fact, they didn’t try to do any sort of job at all. FEMA was a vast wasteland of disability competency. To the best of my knowledge there was one person with the word disability in their job title, and she worked in a cubicle in the basement of the building and had no authority to do anything useful.

Longtime disability rights advocate Marcie Roth watched in horror the missteps by FEMA that caused death and suffering of people with disabilities, including a dear friend of hers. It took her a few years, but in 2009, she was placed in a position to do something about FEMA’s incompetence when she was appointed by President Obama to be the disability point-person for FEMA. And when Marcie called to tell me about her appointment, she said, “Well, I’m going over to the dark side.”

During her six-plus year tenure at FEMA, Marcie has created an Office of Disability Integration and Coordination, staffed it with subject-matter experts, created a cadre of deployable reservists, and worked diligently and with great success to develop an inclusive culture within the agency.

Once Marcie got on board, we knew we could take our concerns directly to her. Prior to that there was no one in the agency whose ass we could cut when things went sideways. Because things are going to go sideways, and you need to have a responsible person to contact who can run the problems to ground and fix them. After all, we are in the chaos business.

One of Marcie’s greatest accomplishments has been the establishment of a network of disability stakeholder partner organizations. To some extent during the California wildfires we saw the effectiveness of these partnerships, and during the South Carolina flood response, these partnerships knocked it out of the park. Although my despair in South Carolina was over the shortcoming of the Red Cross, FEMA and its stakeholder organization partners — including the National Disability Rights Network, the Pass It On Center, NCIL and our own Portlight — worked seamlessly to serve disabled people after the floods in South Carolina.

Marcie says we can expect more of the same in the coming year. “I’m seeing Portlight leading its many partnerships towards a national alliance that will really bring folks together around how we can optimize each organization’s agenda to best prepare for whatever that next emergency is going to be,” she says. “We’re particularly gratified because we’re seeing much greater interest in preparedness, much greater involvement during disasters and in optimizing the opportunities for universal accessibility and inclusion in recovery. And much more understanding of what true community resilience means and how to achieve it. What I hope to see over the coming year is continued exponential growth and a lot more engagement between disability organizations showing how they can be a resource for community preparedness.”

So Marcie was right — she did go over to the dark side. And as it turns out, she has lit it up.
had served as general counsel at FEMA, and worked closely with Marcie Roth to create and nurture FEMA’s Office of Disability Integration and Coordination.

While at FEMA, Kieserman had seen firsthand successful efforts to embrace our community and our issues, so he inherently understood the problems we were having with the Red Cross, and was in a position to effect immediate change. In mid-October, within just 72 hours of Galifianakis and Lockyer proposing the idea, I found myself standing before about 150 Red Cross staff and volunteers, giving them training and insight as to how to serve our community. By the end of the month, I had spoken to about 500 such people in South Carolina, California and Texas.

Their response was universally positive, encouraging, and gratifying. Many of the same players who heard these trainings in South Carolina and California were soon after present in Texas in response to the late October floods there, and I’m pretty sure it’s no coincidence that this disaster response operation was probably the Red Cross’ finest hour, relative to their service of our community.

Prior to the trainings, it was a different story. “In California, I was free to survey all of the Red Cross shelter facilities, but when I pointed out issues of inaccessibility to shelter managers, they showed no interest in fixing the problems,” says George Kasper, a Portlight staffer who deployed alongside Red Cross for the California wildfires. “I wasn’t even able to do something as simple as deliver a couple of much-needed wheelchairs to survivors in one Red Cross shelter, even though there were stacks of them going unused in another.”

Just a month later, after the trainings, Kasper reports, “Things were so much better on the flood response in Texas. We were recognized as respected partners, and as the main point of contact for volunteers and staff when they encountered survivors with disabilities who had immediate needs.”

So the training has gone from a theoretical request to a meaningful reality, and the Red Cross has even agreed to stand up a disability inclusion coordinator, and to work with Portlight, NCIL and other stakeholder organizations to create and nurture a disability inclusion infrastructure throughout their organization. It is not hyperbole to say these commitments are game-changing, and are already bearing substantial positive fruit.

In the last few years, we’ve seen lawsuits, fierce advocacy, hell-raising and friend-making, and frustration to the point of hopelessness and despair, but now, the pieces seem to be coming together. There’s still a ton of work to be done, but at long last, we may have a disability community infrastructure combined with a newfound willingness from the emergency management community, which gives me hope that future response and recovery efforts will come more closely to serving all people.

Paul Timmons has residual quadriplegia as a result of Guillain-Barre syndrome and lives on St. Johns Island, South Carolina, with his wife, Kelly.

I was director of LIFE, Mississippi’s network of Centers for Independent Living, when Hurricane Katrina devastated the coast. After Katrina, three days went by before I was certain that LIFE’s Biloxi and Hattiesburg staff members had not perished. We lost all consumer files in the Biloxi office as well as all computers with data, and it was five days before we could contact consumers and check on their welfare.

Those of us not personally affected went to shelters to see if we could find people with disabilities, and most of the Red Cross shelters turned us away at the door. All they saw was a bunch of crips that they thought would not be able to help, and would just get in their way. We knew our abilities to serve, but they didn’t. Not then. They do now, though.

After Katrina, many of our staff enrolled in any volunteer training they could find by their local Red Cross or Salvation Army, so they would be registered and certified with those agencies and never denied access to a shelter again. About half even became certified through the Certified Emergency Response Teams, and eventually we developed partnerships with emergency managers and began to participate on the State Emergency Management Task Force.

Perhaps our largest success is the development of memoranda of understanding with NCIL, FEMA, Portlight and the American Red Cross. These benefit the disability community in several ways:

First, a formal agreement indicates that we will work together to provide quality services to individuals with disabilities in the event of a disaster. Organizationally, each entity operates quite differently, and these memoranda encourage senior administration personnel to communicate with one another to ensure that appropriate and accessible services are provided in emergency planning, response and recovery efforts.

Second, this will ensure that in the event of a disaster anywhere in the country, we can facilitate communication between the entities on a local level. For example, if senior Red Cross staff contact NCIL for assistance in locating a local CIL in an area recently affected by a tornado, we can share that information and facilitate a meeting or phone call between the emergency responders on the ground and the disability stakeholders in the area.

Third, we can assist one another in developing internal policy or crafting documents to ensure that appropriate language is used and that equal access remains the number one priority.

These memoranda allow us to begin making systemic changes in the provision of emergency management services to individuals with disabilities, and these changes will eventually filter down to the regional and local levels to impact emergency preparedness and response to our community. We believe this can save lives.
Imagine it’s sometime in the near future. You recently moved from Los Angeles to Portland, Oregon, and are desperately searching for accessible housing with no luck in sight. You’re also trying to enroll in Oregon’s Medicaid program and trying to get anti-spasm meds and funding for attendant care. So far, it’s not going well, so you are relying on a couple of friends in Oregon who were gracious enough to do an emergency retrofit of their home and attend to all of your morning routines. You’ve also been able to manage the spasms enough to get by, and you have a memory foam topper so you can crash on their couch without getting pressure sores.

The last couple months were tough ones — and this one’s no different. You’re grateful, though, that there are people in Oregon who care (and that you’re not on so high a dose of baclofen that the withdrawals would be unbearable). You still miss Los Angeles, but you decided to move when California’s ongoing drought resulted in severe water shortages that affected your quality of life. The fact that you waited until the last minute to evacuate also made your move tougher than it needed to be. You were just lucky enough to have a buddy with a hauling van who was also heading north. Goodbye, thirsty LA — Portland is home now.

START PREPARING NOW

Let’s be honest — climate change is scary. The warmer atmosphere and oceans will lead to stronger storms, deeper droughts, more intense heat waves and flooded coastlines, and those impacts will endanger lives and livelihoods worldwide. Climate change will even lead to larger global population shifts, such as when people move in droves to escape flooded cities or areas without water. In fact, many of these changes are already happening. 2015 was the warmest year on record, and last year saw the largest hurricane ever recorded. The crazy storms and New England’s record high Christmas temperatures this year were made more intense because of climate change, and people are beginning to abandon Pacific island nations whose coastlines are gradually submerging.

It’s clear people are taking notice — and they want to do something about it. Leaders and activists worldwide are recognizing that we need to cut emissions to slow down the climate crisis, and the recent
COP 21 Summit in Paris created a global agreement to keep warming below 2 degrees Celsius, a level that many scientists have set to avoid the “worst impacts of climate change.” Still, climate change will continue getting worse to some extent no matter how much we cut emissions — and unfortunately, we are likely to overshoot that 2 degrees Celsius target no matter how hard we work to try to meet it.

This means we have to start preparing as much, and as soon, as possible. Good preparation entails building more storm shelters for stronger hurricanes, managing our water better for deeper droughts, and maybe even starting to move people away from flooding (or soon-to-be-flooded) coastal cities. It’s a daunting task, but teamwork and effort can smooth the transition.

WE HAVE A CHOICE TO MAKE
There’s another stark reality that the disability community needs to accept and work to fix: The impacts of climate change will hit people with disabilities harder than our nondisabled peers. We are more vulnerable during storms, as we generally have more medical needs and require accessible evacuation shelters and transit. Many of our disabilities make us more prone to heat exhaustion in heat waves. We tend to rely on support networks, such as friends, family, and personal attendants to stay healthy and independent, and those networks can be fragile in tough times. And because we have disproportionately lower income, savings, and assets, we have less of an ability to support ourselves when the tough times hit.

When you combine climate change with our vulnerability, it’s more than a bit daunting. That LA-to-Portland journey might sound like a dystopian future, but in the coming decades, moves like those may be a reality for many of us. So will struggling to find accessible emergency shelters during stronger storms, to pay air-conditioning bills in hotter heat waves, or to keep health care as economies falter and governments cut back spending. The list goes on.

We have a choice to make. We can become resigned to the scary reality, we can ignore it entirely and get caught off-guard when it’s too late, or we can prepare for the future — and fight to be included when the world finally does the same. In
CLIMATE JUSTICE
The concept of “climate justice” is incredibly important to our community. It acknowledges that some groups will get hit by climate change harder than others, and we need to give them special attention as we prepare for the future. Up until now, the concept has included those in poverty, people of color, those in developing countries, and others as especially vulnerable groups, but people with disabilities have consistently been left out. Unfortunately, this is par for the course in social justice conversations: our community is all-too-often the “forgotten minority,” even though we experience harm just as other minorities do. We are also one of the largest minority groups, at about 15 percent of the population, so leaders must address our needs.

Our fight for climate justice requires focus, strategy, and action. We must identify how climate change affects our community, come up with actions to keep ourselves safe, and work with allies to turn those actions into reality. All of this — and more — is needed to protect the lives of people with disabilities nationwide and globally.

We’ll also have to address all aspects of climate change, not just the straightforward ones. Besides our obvious need for more disability-inclusive disaster readiness and strategies to make that happen, we must also address more complicated issues, such as spiking food prices and large-scale migration.

Think for a minute about somebody making that long-distance move. Finding accessible housing will be a whole lot easier if apartments are built in advance. Keeping health care will be more likely if the state protects Medicaid funding and revises the application process (or if rules change so that Medicaid can be transferred between states). And the move will be smoother if the person switching cities plans ahead of time and finds support to do so. There are many other actions that can ease the moving process for migrants with disabilities.

Preparation will be much better if we start early rather than wait until problems get worse — or until it’s entirely too late. We should push leaders today to plan for the critical needs of people with disabilities. Luckily, there is already change afoot. Disability activists are fighting for disaster prep nationwide. We need to jump into conversations around complex issues like managing climate migration and raise our unique vulnerabilities and demands. Long story short: we must take advantage of every opening to fight for the inclusion of our needs.

Above all, we should always push for climate justice. At 15 percent of the population, we belong to every demographic group. Climate justice demands that the world recognizes our unique needs as we all prepare for the coming global changes. But will it happen if we don’t fight for it? We’ve fought for disability inclusion before, and we’ve won. We can win again.

A policy and research specialist at the World Institute on Disability, Alex Ghenis manages the New Earth Disability project, which addresses how climate change will affect people with disabilities and how people can prepare. Learn more at www.WID.org/NED.

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SPOTLIGHT: PUERTO RICO

BY GRETCHELLE DILÁN

MY TAKE

Mofongo. Asopao. Lechéon. You might not know these words now, but once you come here and taste what they mean, you will remember them forever. If you’re one of those who believe that a culture is best understood through its food, you’re in for the trip of a lifetime.

Our island hasn’t just become a magnet for foodies; it’s grown into the gastronomic capital of the Caribbean. World-class chefs run the kitchens at many restaurants in San Juan.

Our culinary tradition spans centuries and combines Taino, Spanish and African cultures, recipes and ingredients. In recent years, it has combined with flavors from around the world to create mouth-watering fusion creations. From gourmet fine dining to roadside kiosks, you will love exploring our menus and discovering the many tastes of Puerto Rico.

PLACES TO GO

Puerto Rico might be a small island, but it is surrounded by more than 270 miles of beautiful coastline. And it’s not just the quantity of beaches that’s impressive. There are countless activities you can do under the sun. Some offer you world-class kayaking. Others feature miles of reefs with plenty of marine life to admire.

Even if you just want to spend the day relaxing and taking in the beauty of white sand and turquoise water, there’s a beach just for you. Luquillo Beach offers an accessible beach area, where you can enjoy the warm waters of the Caribbean. It’s about 45 minutes out of San Juan. If you enjoy kayaking, the Bio Bay Night Kayaking Tour is for you. Located in Fajardo, this bay has microorganisms that produce glowing, or bioluminescence, in the water. This 1.5-mile tour is spectacular and educational.

Puerto Rico’s lively fusion of cultures extends to almost every aspect of Puerto Rican life: the aforementioned cuisine, colorful arts and crafts, vibrant music, and traditional festivals. You’ll experience this diversity anywhere you look, listen, and taste. Our museums feature both European classics and Afro-Caribbean sculpture. Our buildings blend traditional colonial styles with a bright palette of colors. Our music brings together instruments, rhythms and sounds from eras and places as distant from each other as 18th century West Africa and medieval Spain.

MUST SEE, MUST DO

El Yunque is the only subtropical rainforest in the U.S. National Forest Service, a place so indescribable that it must be seen, heard and felt. Trails are not accessible, but you can enjoy the short movie and display at the visitor’s center and also see La Coca waterfall, which is amazingly gorgeous.

Toro Verde features one of the longest zip lines on Earth: La Bestia (The Beast). Adventurers use a specially designed harness to soar through the air across 4,745 feet of terrain.

GETTING AROUND

 Transportation in Puerto Rico is complicated, and can be difficult without your own accessible car. As for public transportation, if you are a resident of the metro area, the government has a service called “Llame y Viaje” (Call and Travel). This paratransit service provides accessible transportation for residents with disabilities and runs on the regular public transportation bus routes. To use this service, you must file a request, and each case is evaluated individually.

If you are not a resident of the island, our United Spinal chapter can provide you with a list of private companies that have accessible transportation, but there is a lot to do still regarding this matter.

MEDICAL FACILITIES

Puerto Rico has a number of medical facilities that treat people with spinal cord injuries and disorders, including the VA Caribbean Healthcare System and HealthSouth Rehabilitation Hospital of San Juan. In my experience, it has been difficult to find access to advanced SCI/D rehab options and treatment.

Editor’s Note: United Spinal helped produce a great accessible travel guide to Old San Juan, Puerto Rico. You can download it for free at bit.ly/23wyivB
We have a big problem when it comes to people living with disabilities,” says psychologist Gretchelle Dilán of her native Puerto Rico. “We have a big population and they are all young, but you don’t see them because they are not leaving their houses, and they don’t know how to handle their finances.”

With her doctorate in psychology, Dilán has long been aware of the problem, but she gained a new perspective when she was paralyzed by a stray bullet in a 2012 accident. Despite a difficult recovery, Dilán immediately set out to improve the conditions for the SCI/D community on the island.

She started off by founding Vivo Sin Barreras (Living Without Barriers), a new organization aimed at helping people with disabilities, caregivers and their families. She went on to affiliate with United Spinal Association as the organization’s Puerto Rico chapter.

Dilán used her background in media to also launch La Voz Corre (Spreading the Word), a quarterly Spanish-language magazine for that same community, funded by advertising from companies and providers that serve it. “I started the magazine because I saw the need for information,” she says. Finding and producing relevant content and staying in the black has not been easy, but Dilán says she never thought it would be. She is currently devoting all of her time to the organization and magazine, and trying to start programs that appeal to the island’s SCI/D community.

“We need to have activities to get people out,” she says. “We need to get people out of their beds and out of their wheelchairs — whether it’s going to the beach, movies or something else.”

To that end, Dilán converted a property she owned into a rehab gym, but to her surprise, very few members of the SCI/D community showed up, with the facility mainly being used by the elderly. “I wanted my people to be there and take advantage, but my people didn’t respond to that,” she says.

Dilán has had more luck with a donation-based equipment recycling program. “Let’s say you have a bed or a manual chair, or even something like wheelchair tires — whatever you have that could be useful to someone in a wheelchair, we will collect it,” says Dilán. She stores the goods in her garage until she finds someone who can use them. “My garage never gets full!” she says. “As soon as we list stuff online someone comes to get it.”

Dilán’s latest venture is starting an accessible vehicle dealership. Right now residents and visitors looking to buy or rent an accessible vehicle have no real options. She wants to change that. “We are not a big commonwealth, but we have a lot of people with a lot of needs,” she says. “I’m hoping I can help unite the community here and improve its quality of life.”

To find out more about the Puerto Rico chapter, visit www.lavozcorre.org.
SCI Hall of Famer Joins United Board

Bringing up Gary Karp’s name in the disability community is akin to talking about Joe Montana or Vince Lombardi with a bunch of football fans. With over 40 years of disability education, advocacy and leadership on his resume, Karp’s legacy is known far and wide. Heck, he was even inducted into the SCI Hall of Fame in 2007. Karp will now bring his expertise and insight to United Spinal, as the newest member of the board of directors.

Karp, 61, comes to United Spinal on the heels of a highly successful 11 years where the Christopher and Dana Reeve Foundation sponsored him to educate people working with and around disability about how best to work with the SCI/D community and people dealing with new injuries. During that period, Karp spoke at 70 universities and 25 rehab centers and helped thousands of future professionals, while also honing his own understanding of disability.

Despite ending his affiliation with the Reeve Foundation, Karp continues to speak, write and train others about disability. His books, Life on Wheels, From There to Here and Disability and the Art of Kissing, are available online and remain must reads years after publication. At the root of much of his work, is his gift for telling stories and his understanding of their power and potential to change the way others think about disability.

“I’ve always tried so hard to tell my story in a way that gets across the universal lessons of disability, that human beings are adaptable in our nature and everybody wants to find their way to be OK with themselves and what’s possible,” he says. “It can’t be a matter where people with disabilities are seen as remarkable individuals, it has to be a matter of everybody getting a shot and believing everybody has the potential.”

Karp conveys that message in all of his efforts, and is looking forward to delivering it via United Spinal’s advocacy efforts.

“I think that through our advocacy we can help the legislature by having conversations to help them get their heads around the new frame of disability and get over all these old ideas — that they are taking care of unfortunate people, that the disabled are a burden — it’s a new world where we want to invest in independence and what is actually possible without having to be inspirational heroes to do it. The chance to get that across to legislators and the broader population is really exciting.”

In addition to helping bring about that cultural shift, Karp is eager to work on funding for complex rehab technology, addressing how short rehab stays have become and improving employment opportunities for people with disabilities while also helping employers better understand how to work with people with disabilities. “Very early in this process I set my sights on making myself a value to employers and that meant I had to go beyond mobility and start learning about broader disability.” One outgrowth of that process is Real People, Real Potential, a video training series specifically geared to helping educate workplace cultures about disability.

“We are honored to have Gary Karp choose to serve our organization. He has been a role model for many with spinal cord injuries. He is an excellent and well known author and speaker, and I am certain he will be a great asset to United Spinal Association.”

— United Spinal President James Weisman

Working on a board will be nothing new for Karp. From 2004-5 he sat on the board of directors for the National Spinal Cord Injury Association. During his involvement with NSCIA he served as the executive editor of SCI Life, the organization’s newspaper. He has also been a regular contributor to New Mobility.

Karp was born in Detroit, Michigan, but currently resides in Tempe, Arizona. He has been living with a T12 SCI since 1973 when he fell from a tree at the age of 18. For more information on his speaking, books or Real People, Real Potential, visit his website www.modemdisability.com.

A Farewell to Our Friend Finn

We lost a great friend and a powerful and unique voice Jan. 21 when Finn Bullers passed away from complications from Charcot Marie Tooth disease, a rare neurological disorder. Bullers, 52, leaves behind two children, Alora and Christian Bullers, and a long and impressive record of advocacy for people with disabilities.

Bullers spent most of his life as a reporter, starting as the editor of the Iowa State Daily in college, and moving on to stints with the Ames Tribune, Bismarck Tribune, the Dubuque Telegraph Herald, the Quad City Times and the Kansas City Star. He stayed on the desk as long as his disease allowed him, and when he could no longer work full or part time, he turned his reporting skills to exposing the problems facing people living with disabilities. Like any good reporter, he knew the tough questions to ask and he often knew the answers before he asked them. He was never afraid to challenge authority when he saw it treating people unfairly and he always had solutions.

He brought a relentless approach to fighting for a number of key advocacy issues, including preserving access to complex rehab technology, ratifying the Convention on the Rights of People with Disabilities and expanding Medicaid in Kansas to include greater in-home care he and other Kansans desperately needed. He also fought to get governments to adopt more modernized wheelchair accessibility signs.

In honor of his advocacy efforts and the genuine zeal with which he pursued them, United Spinal Association named Bullers its 2014 Advocate of the Year. He was presented with his award at United Spinal’s 3rd Annual Roll on Capitol Hill, legislative and policy conference in Washington, D.C., June 22-25, 2014.

“Finn Bullers was a courageous and tenacious advocate, both for himself and others with disabilities,” said United Spinal President James Weisman. “He used his writing skills to promote
independent, community living for all who need attendant care. He was a staunch proponent of integration, self-determination and self-management. His presence and participation will be missed by Kansans with disabilities, the members and staff of United Spinal Association and people with disabilities everywhere.”

As a member of United Spinal’s Kansas City chapter and a policy advisor for the chapter, Bullers was a shining example of how one advocate’s voice could break down barriers and spark positive change on the local, state and national level.

Memorials may be made to his children’s college fund; Sisters, Servants of Mary (who helped care for him for many years); the Society of Professional Journalists Education Fund; and/or the Greater Spinal Cord Injury Association of Kansas.

A Touchscreen Solution for Quads

Touch screens are the future and they’re everywhere, and if you’re a quad with limited or no hand function they can be a conundrum. Virginia quad Josh Smith has solved the conundrum with the invention of the Handizap, a slick little stylus users can slip onto their pinky to make using touch screens easier.

Smith introduced the product, originally branded the Sixth Digit, via a Kickstarter campaign last March and quickly raised over $2,000 to put the product into development. Late last year backers received the promised Sixth Digits. Smith has since rebranded his product as Handizap, and now sells it through handizap.com. For $30 you get two Handizaps, two replacement tips and a carry bag.

In early February, Smith was recognized by Governor Terry McAuliffe with Virginia’s 2016 STEM [Science, Technology, Engineering, Math] Catalyst Award for his invention. “I was very surprised since I didn’t even know I was being considered,” he says. “The chief wonder officer of the Science Museum emailed me Friday saying he had some great news and was going to call me Monday. When he told me I won the award I was really excited. It was definitely a great surprise.”

Smith thinks the success of the Handizap is just the beginning. “We’re hoping to either develop more products for the disabled community or offer products we think could help make their lives better,” he says. “We also want to be a resource for people that want to create products.”

Handizap inventor Josh Smith was surprised his simple idea has already garnered an award.

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Beach wheelchair users know that one of the most effective substances for stopping their movements is soft sand. Venturing off a sidewalk or boardwalk to head for the water can turn a pleasant outing into a frustrating adventure that can even be life-threatening in some circumstances.

I witnessed this firsthand a few years ago on a beach in Hawaii when I learned a lesson about the value of wider tires when crossing sand. On many Hawaiian beaches, the sand is compacted, thanks to wave action and the weight of foot traffic. In other locations the sand is soft, creating a potential trap for unwary wheelchair users.

My power wheelchair has smaller diameter wheels with tires that are wider than some other models. During a break from attending an international independent living conference, I joined my daughter Leslie at the beach. The sand was fairly compact, so I was able to roll closer to the water where we could talk while she enjoyed the sun.
Max Starkloff, co-founder along with his wife, Colleen, of one of the first independent living centers, Paraquad, in St. Louis, was a conference presenter. Like me, Max was also quadriplegic, but he used an older power chair with narrower tires. Unbeknownst to Leslie or me, Max attempted to join us at the beach but was able to travel only a few yards off the paved sidewalk before his wheelchair became trapped in the sand.

He was by himself, and no passerby offered to help.

About 30 minutes later, Leslie happened to look back and saw Max sitting, immobile, with no one around him. She was able to pull his chair loose from the sand and get him back to the sidewalk, but by the time Starkloff returned to the hotel, he was severely overheated. Fortunately he survived that incident, but it serves as an illustration of the potential consequences of being stuck in sand in the blazing sun.

That all took place at a time before beach wheelchairs, with their wider tires, were as available as they are today. Fortunately, thanks to the urging of disability advocates around the world, hundreds of public and private beaches now offer beach wheelchairs to borrow. In some locations, private businesses that rent other items for use by the vacationing public — like bicycles, beach umbrellas and lounge chairs — also include beach wheelchairs in their inventory.

California Wheelin’

In California alone, more than 100 beaches now have beach wheelchairs available that can be borrowed for the day or checked out by the hour, usually at no cost. Thanks to the nonprofit Accessible San Diego, San Diego County’s beaches have several available. Longtime president Wes Johnson takes pride in pointing out that several of the beach wheelchairs available in the San Diego area were the result of a broader push for people with disabilities to enjoy and access the same features that make San Diego such a popular tourist destination.

Further up the coast, Bonnie Lewkowicz, founder and president of Access Northern California, has created a project called Wheeling Cal’s Coast, which lists locations in the state where beach wheelchairs are available to borrow. “The movement has grown relatively quickly, fueled by recognition of a need, rather than the threat of a lawsuit or ADA complaint,” she says. The Department of Justice has not taken a position on beach wheelchairs, so it’s unclear whether they are required by the ADA. “As more people continue to witness the chairs rolling up and down beaches, undoubtedly many other locations will make those devices available in the future.”

Lewkowicz recalls the first time she transferred into a beach wheelchair. “It was like when I was a child and first visiting the seashore. The feeling was absolutely exhilarating, and completely natural,” she says. “I could easily maneuver among the scattered beach towels and visit any part of the beach that I chose. No one paid any attention to me, as beach wheelchairs were a common sight on that beach and many others.”

The variety of products manufactured for beach use can meet the needs of most anyone with a physical disability. There are even walkers available equipped with large balloon-type tires for rolling across sand and other loose surfaces. Strollers for infants, fitted with similar tires, are also available. Some vendors, like Deming Designs and Hotshot Products, offer parts or kits that will convert everyday wheelchairs, strollers or walkers for use on the beach.
Many beach wheelchair companies are small businesses that do not have huge production facilities, but they share the common goal of helping people with physical disabilities enjoy time at the beach. In some cases, they started in the business simply because they had the skill and saw a need.

Hank Weseman, Jr., owner of Hotshot Products, became quadriplegic in 1992 after a horrendous crash that occurred while he was racing a drag boat at 140 miles per hour. Weseman was a talented mechanic prior to his accident, doing all of the work on the motorcycles and boats that he raced. He soon started seeking ways to enhance beach mobility for himself and others in his situation. Hotshot Products now sells power beach wheelchairs and related products and can even convert customers’ older power chairs for use on the beach or off-road as well.

Similarly, Deming Designs, of Pensacola, Fla., was formed by Karen and Mike Deming after Karen was injured in a 1990 car accident that resulted in quadriplegia. They finished the first prototype beach wheelchair for her use in 1994, and since then have branched out to sell a variety of other products. Their De-Bug chairs, designed to be pushed by individuals rather than powered by a motor, can be used both on the sand and in the water. Dozens of beaches around the world have Deming products available to borrow, and they have even been purchased by cruise lines for use by passengers.

Beach Powered Mobility is one of the companies that has Deming products and other beach wheelchairs available to rent. Owner Morris Padgett says the store in Panama City Beach, Fla., rents and sells beach wheelchairs, along with attachable umbrellas. His interest in making beach wheelchairs available started when a friend with ALS built a power chair for his own use, and he witnessed the impact it had on his friend.

Padgett started with two beach wheelchairs. His fleet of rental chairs has now grown to 20, with future expansion planned. He touts the ability of the beach chairs to move across the fine “sugar
sand” found along the Gulf Coast that causes even people who walk to sink in several inches. “I was initially amazed at how few people even knew beach wheelchairs existed and had never used one,” Padgett says. “The amount of joy that first ride creates is very gratifying for me, especially when I watch the reactions on the faces of kids.”

Semper Fi

The owner of Beach ’N Wheelchairs of Foley, Ala., Chance Blaker, is a skilled mechanic who began by building bicycles when he was young. He then progressed to constructing electric bicycles and was eventually contacted by a friend from his Marine Corps days who interested him in building a powered beach wheelchair. Since 2007, the Blaker household’s garage has been occupied by wheelchairs in various stages of construction.

Blaker has joined with Eric Wooten, a friend from boot camp, to form The Other Side Of The Dunes, a nonprofit with a mission of donating powered beach wheelchairs to disabled veterans or other deserving individuals with a military connection. This year the group will donate two beach wheelchairs and have established a GoFundMe account to cover future donations. Funds raised will pay for materials and Blaker will donate the labor to build the chairs.

Those donated wheelchairs can make a real difference in quality of life and can even inspire other individuals to “pay it forward.” When Alan Earl, a T6 para who works for the Paralyzed Veterans of America, moved from Northern Virginia to Carolina Beach, N.C., he looked forward to telecommuting and enjoying life by the ocean. Although he could watch the waves break on the shore from his condo unit, frustration soon set in when he realized he could not get across the sand to access the water.

Friends in the veterans’ community shared Earl’s story with The Other Side Of The Dunes, and the decision was made to provide him with a chair. “The sense of freedom from rolling across the sand is very exciting, and I realized that others needed to have access to the same mobility,” says Earl. “I’ve always been someone who believes you shouldn’t give up, but instead you should just do it.” He initiated a fundraising drive that resulted in the purchase of 12 manual beach wheelchairs that are now available for loan at surrounding beaches.

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Sometimes They Float
Are there drawbacks to beach wheelchairs? Of course, but they are relatively minor complaints. Some people may find it difficult to perform independent transfers into the chairs, especially those models with seating in a low-slung position or wider protruding tires. A more common problem is there are just not enough of them available, especially when beaches are busy. Often they are available on a first come, first served basis, although in some locations they can be reserved a day in advance. Some of that demand may be fueled by the public finally recognizing that beach wheelchairs are a great way for people with all types of disabilities to enjoy a day at the beach with family and friends.

Some people are surprised to learn that many types of beach wheelchairs are solely for traveling over sand, and not for entering the water. It may be obvious that water would damage electronic components on the powered models, but even non-electric models are only designed to roll across the beach, not serve as boats. Those that are designed to float, such as the Mobi-chair, Sand Rider and Water Wheels, make that feature clear with photos and descriptions on their websites.

Most manual beach wheelchairs require someone to push, but Box Wheelchairs is selling the Beach Bomber, a manual wheelchair equipped with wider tires and push rims for those who prefer to power themselves across the sand.

How much have things changed, thanks to the push for equal access and the widespread availability of beach wheelchairs? Quite a bit, says Colleen Starkloff. “I am glad to see those chairs gaining some ‘traction,’ to use a pun,” she says. “At Innsbrook, Missouri, where we spend vacations, there is a new pool being built with a ramped entry. The management told me they will also install a pool lift and purchase a beach wheelchair to accommodate any people who want to get into the pool and enjoy it.”

If beach wheelchairs are not yet available on your local beach, the following resource list is a good place to begin making their availability a reality.
A wheeler can push herself across sand with Box Wheelchairs’ Beach Bomber manual chair.

Resources

- Accessible San Diego, 619/325-7550; access-sandiego.org
- Aqua Creek Products, 888/687-3552; aquacreekproducts.com/ floatingbeachwheelchair
- Beach ‘N Wheelchairs, 251/978-8051; www.beachnwheelchairs.com
- Beach Powered Mobility, 800/533-1168; beachpoweredmobility.com/sales-2
- Box Wheelchairs, 760/801-6399; www.boxwheelchairs.com/ #/beach-bomber/c1thn
- Crosswind Concepts (Freedom Chair), 707/523-7535; www.crosswindconcepts.com
- De-Bug Beach Wheelchairs, 850/478-5765; www.beachwheelchair.com
- Freedom Trax; www.freedomtrax.com
- Global Extreme Mobility, 205/337-3911; www.facebook.com/global.extreme.mobility
- Hippocampe, www.vipamat.com
- Hotshot Products, hotshotproducts.org
- Mobi-chair, 800/957-6287; mobi-chair.com
- Other Side of the Dunes, www.facebook.com/othersideofthedunes
- Sand Rider Custom Beach Wheelchairs, 757/847-9338; www.custom beachwheelchair.com
- Water Wheels, 973/955-0514; www.accessrec.com/waterwheels
- Wheeling Cal’s Coast, www.wheelingcalscoast.org


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“What do you mean, it quit?”

“It just totally shut off. I think maybe it’s wet.” Panic sets in as I repeatedly click the switch to restart it.

“It can’t just quit,” she says, inserting a glimmer of hope.

“It did, it won’t turn on.” I say, extinguishing the glimmer.

“Maybe you hit the ‘off’ button?” Frustration mounts.

“No, I didn’t.” Dead stop.

And then the conversation went south from there. You get the idea.

Most people with disabilities have experienced situations like this. Just when you think this is one of the least desirable places to have a breakdown, or you need to run to the bathroom, your having-a-great-day bubble bursts with the worst-case scenario. Murphy’s Law states that anything that can go wrong, will, and at the worst possible time. This dead chair situation certainly applies. There is nothing like a little adversity to test and strengthen the bonds of a marriage. Ours ought to be really strong.

Let’s see. What would be stressful to a couple? Maybe distance from home, reliance on equipment, a time limit, bad terrain or extreme weather.

How about all of these? We are in Ketchikan, Alaska, thousands of miles from home. We are enjoying a Holland America Alaska Cruise, and of course we have no backup wheelchair with us. We are over a mile away from the ship, up a steep hill, with yours truly in a lifeless heavy electric wheelchair. It is pouring rain like I have never seen in my life, and we are cold, uncomfortable, drenched. We had just started to head back to a nice little café that we spotted on the way and were so looking forward to a hot coffee and a great meal. Our innocent little trek to retrieve a geocache and get some pictures of salmon spawning in the river had just turned into a nightmare.

Score: 1-0 Murphy.

“What do we do now?” my wife asks. I put on my thinking cap, as I am a firm believer that there is always a solution.

“Call Sheila, see where the guys are. Maybe they can get us back to the boat.”

We still have about three hours until we have to be back on board. That’s a positive. One point for us.

Terry makes the call — it turns out Sheila’s husband Jim and his brother Rob are bored with walking around town. This might be just the adventure that they need.

Score: Wrights 2, Murphy 1.

“OK, they are on their way, now what?”

“If you think you can hold my weight, let’s put the chair in freewheel mode and

Covering the joystick with plastic could have prevented the anxiety of a dead chair 1,000 miles from home.

Friends and hairdryer to the rescue!
get closer to the ship," I say.

Terry puts my chair in freewheel mode, we stick to the edge of the curb and head down the steep hill. She has to work hard to hold my weight as there are no brakes, but she does an amazing job. It is a little stressful crossing the roads with vehicles zooming up and down the narrow roads beside us, but soon we have made it down to level ground.

Terry texts with Sheila and relays our location to the guys. Soon Jim and Rob are with us, throwing sick but funny suggestions and grinning as usual. The sarcastic bantering diffuses the tension and seriousness of the situation.

"So what do we do now?" asks Jim, taking a much-needed break from teasing.

"Get us back on board the ship. Then we'll worry about the chair."

The guys switch off pushing every so often, block traffic, and zoom us back to the ship. Soon we are checked in and safely on board. We head up to the cafeteria to regroup and come up with a plan, already feeling a lot safer now that we are on the ship.

Wright Team pulls ahead, 3-1.

"So now what?" asks Jim.

"I think we go back to our room, take the joystick apart, and put a hair dryer on it to dry it out good," I say, after pondering.

I keep a set of Allen wrenches and screwdrivers in my backpack at all times, along with an assortment of screws and bolts that normally cause big problems when they fall out. We finish our coffee and head to the room.

It only takes Jim about five minutes and he has the joystick apart on the table. Water pours out of the screw holes!

"I'll be surprised if you didn't fry it," says Rob, a qualified electrician.

"We'll need to celebrate with a bottle of wine if it runs again!" I say.

Jim switches the hair dryer on and blows it into the joystick for approximately 15 minutes. It starts to look dry.

"Shall we plug it in and see what happens?" he says, nervously.

"Let's do it — only one way to find out." Jim plugs in the joystick, we flip the switch on, the screen lights up half bright, but the chair does not work.

"The screen lit up part way, I think that's a good sign!" I say, the eternal optimist. "Let's try it some more and see what happens."

After another 15 minutes with the hair dryer on, Jim plugs the joystick back in. He hesitantly reaches for the power switch, turns it on and — it lights up and beeps!

"It worked! I'm back in business!" I'm incredibly relieved. "Where's that wine?"

We win! Wright Team 4, Murphy 1.

Why did my wheelchair get wet? Pilot error. The on/off switch was missing its rubber boot, allowing water to get into the joystick. The rain situation was extreme. Ketchikan gets about 155 inches a year! We have never experienced this amount of rain and should have had the joystick covered.

A potential holiday-ruining calamity was averted. I still carry the tools and spare parts everywhere. Many times we have had to sit and figure out how to fix a wheelchair, usually in some remote situation where there is no outside help. There is always a solution.

Take that, Murphy!

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It is a sad irony that the most powerful person in a wheelchair in America, Greg Abbott, current governor of Texas, has seemingly no interest in advancing the rights or opportunities for people with disabilities. He is by all accounts a straight shooter, but in the words of Jonathon Tilove, chief political correspondent for the *Austin Statesman*, “he is a conservative, free-market, Texas Republican with all that entails.” If you are of like mind, this is good news for you. If you are of any other political persuasion to the left of Ted Cruz, or Ted Nugent, this whole Abbott thing is a head-scratcher.

Abbott became a T12 para when, as a young law school graduate, he was out jogging one day and part of a giant oak tree fell on him and crushed his spine. He sped through rehab and kept going, sidestepping the usual depression and despair. After making a name for himself as the attorney general who stood up for “Texas values,” he ran for governor as one tough hombre with literally a spine of steel. He won in a landslide.

At first, leaders in the Texas disability community cut him considerable slack. Hey, he’s a guy in a wheelchair in the front office. His very presence is good for us. He isn’t ashamed or sensitive about his condition and is in no way defined by it. For Texans, the wheelchair doesn’t exist.

At first blush, Abbott’s disregard for his disabled “brothers and sisters” runs counter to the conventional wisdom about a post-paralysis response. Studies show that survivors are more compassionate and more forgiving towards others in the same straits. They’ve been there. They know all about the pain, anguish, anger and confusion. They’ve come out stronger and want others to feel the same.

Abbott ain’t that cat. But why? Since I don’t know him at all, I can only guess. The simplest explanation is that in many cases a trauma like paralysis doesn’t change a person much at all. The newly disabled people who seem more sensitized to people with disabilities probably had those same tendencies before their own injury. They didn’t change as much as find a new focus for their compassion.

But there is another explanation for the Abbots of the world outlined in a recent *New York Times* article entitled “The Funny Thing About Adversity.” After laying out all the “more compassionate” data, the authors note a glaring exception: People tend to feel less empathy for those who experience the exact same trauma. The attitude is, “Hey, I got through it, so should you. Don’t come crying to me, bud. Man up, for chrissakes.” In this case, disability doesn’t soften hearts. It hardens them.

Has Abbott generalized this attitude toward all people with disabilities, whether they have caregiver needs or not? No government program or charity helped Abbott get up off the floor and keep punching. All it took was his spine of steel. Life is no different than boot camp. If you can’t cut the mustard, sayonara, baby. No excuses. That’s the way the world works.

Maybe John Wayne isn’t dead after all. He just landed in a wheelchair and came back as fightin’ Greg Abbott.

The Strange Case of Fightin’ Greg Abbott

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PUSHLIVING.COM RESPONSE TO COSMOPOLITAN’S DATING ADVICE

Although Pushliving.com gave the women’s magazine Cosmopolitan props for publishing an article with advice on dating women who use wheelchairs, they had a few suggestions for next time.

Most jarringly, the mag used stock imagery of obviously nondisabled women in hospital-style chairs. Pushliving collected a few responses to that blooper:

Kristy Goosman Hughes: My first impression was, what a stupid picture!
Kara Ayers: Ouch … this literally hurts to see. What year is it?!
Tim Cox: HAHAHAHAHA! this might be my favorite picture ever.
James Shoemaker: … really, a hospital transport chair?

See the rest of Pushliving’s response, including excellent photos of real women who use wheelchairs, at pushliving.com/our-response-to-cosmos-advice-on-dating-a-woman-in-wheelchair/

#SAYTHEWORD

Activist Lawrence Carter Long (@LCarterLong) sparked a hashtag revolution with this tweet: “Disabled.” #SayTheWord. On purpose. Often. Until and unless we do, they won’t. #NotDifferent #NotSpecial #Disabled

Now the hashtag is popping up across social media platforms in response to presidential candidates, celebrities and others of note, daring them to #SayTheWord disabled.

LEGO’S FIRST-EVER WHEELCHAIR USER

Last spring, Rebecca Atkinson, a journalist with a hearing impairment from the United Kingdom, launched #ToyLikeMe, asking why can’t toy manufacturers include children with disabilities in their lines? And in late January, Lego answered with a young minifig wheelchair user. Part of the “Fun in the Park” set, it hits stores in July and is a marked improvement over Lego’s initial offering — an elderly wheelchair user in a hospital-style chair released as part of its Duplo line’s Community People Set.

Atkinson, a mom, says she got the idea for the project when she took a good look at her family’s toy box. “Not one plastic figure had a wheelchair, or a hearing aid, a white cane or any kind of disability at all,” she said to www.volup2.com.
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