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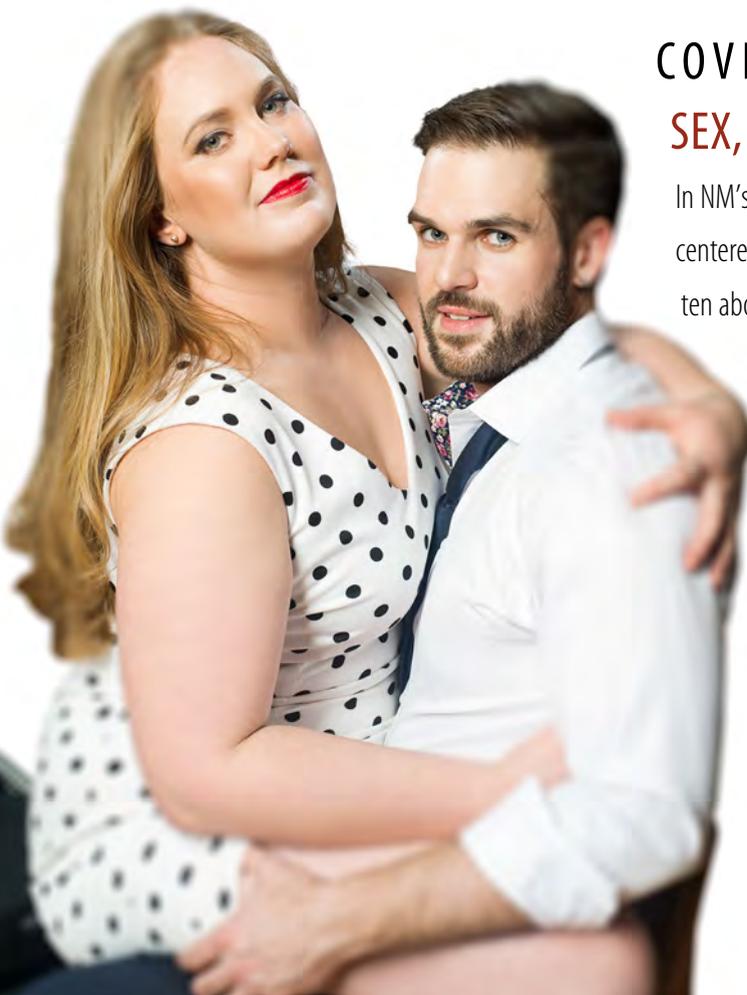


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In NM's 21 previous issues on disability and sexuality, the focus has often centered on men, mainly because more males sustain SCIs and more is written about them. This issue is definitely for women. MARY TOLAN profiles Christine Selinger, whose job and personal life are immersed in sexuality, and REGAN LINTON lets us in on some frank sex talk about women and sexual pleasure.

Cover and Contents Photos by N Maxwell Lander

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FEBRUARY 2017

NEW MOBILITY IS THE
MONTHLY MAGAZINE OF



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

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PRODUCTION MANAGER: DEANNA FIKE

CIRCULATION

CIRCULATION MANAGER:
BEVERLY SMITH
CIRCULATION COORDINATOR:
MARIA KURTZ

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

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

New Mobility (ISSN 1086-4741), Volume 28, Issue 281, is
published monthly by United Spinal Association, 120-34 Queens
Blvd, #320, Kew Gardens NY 11415.

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

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(BULLY PULPIT)



Forgiving Ourselves

In our journeys from disability to wholeness, often what holds us back is the inability to forgive ourselves. When accident or disease strikes suddenly, it is difficult to accept that there may be no good reason why it happened. And so we go searching for a reason, a cause that can lead to understanding and, perhaps, acceptance. Sometimes it is slow in coming; and sometimes it seems like it may never arrive. It is then that we turn inward and assign the ultimate cause — *I am to blame*.

Blaming oneself may happen subconsciously, lurking like a shadow just below the surface of our thoughts. We may feel its presence from time to time, yet we go on day to day, acting like everything is all right.

It can happen to anyone for any reason: You have had two drinks at a party and drive home, slightly tipsy. An animal darts in front of you, you swerve, the car rolls, and you wake up in the ICU, paralyzed. Or you fall asleep in the back seat, tired from working a long day, the driver swerves, the car rolls, and you wake up in the ICU, paralyzed. Or, exhausted from a long trip to see relatives, you return home, go to sleep, and wake up the next morning, paralyzed for no apparent reason, then go to the ICU, where you learn a rare disease has attacked your spinal cord.

Without clear understanding, you can always find a reason to blame yourself: You should not have had those two drinks; you should have stayed alert instead of falling asleep in the back seat; you were living a selfish life and the disease is some kind of punishment sent from above.

In my case, the Civil Aeronautics Board

determined that my friend, the pilot of the plane, was at fault for crashing in the mountains. Yet I alone knew that it was my desire to visit a girlfriend that led us into the dangerous box canyon on a hot day with too little lift, too little power in the single-engine Cessna, with a pilot with too little experience. When I woke up, paralyzed, knowing my friend had died in the crash, I blamed myself, and continued blaming myself for more than five years.

When the problem is soul-deep — I am to blame, I got what I deserved — it feels like there is no escape.

Then came the real crash — the one that took my entire being down after five years of running from self-guilt. In some ways it was worse than the physical crash. I knew that, despite my paralysis, I could get around, live a life, do things. But when the problem is soul-deep — *I am to blame, I got what I deserved* — it feels like there is no escape.

I finally turned from self-blame and asked God to forgive me. It took a few more years before I could believe that I had been forgiven, for everything — all my selfish behavior — out of God's love. Then, and only then, could I make peace with myself.

No, I am not to blame. That blaming inner voice did not come from love. Like the Good Book says: "Love keeps no record of wrongs."

— TIM GILMER

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FEBRUARY 2017

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An actor, educator and writer, Regan Linton is also artistic director of Phamaly Theatre Company in Denver. She has performed professionally with Oregon Shakespeare Festival, La Jolla Playhouse, Pasadena Playhouse, Big-I (Osaka, Japan), Mixed Blood, and Phamaly, among others. Her writing has been featured in national TCG Diversity Salons, the Hollywood Fringe and the Chalk Repertory Theatre in Los Angeles. She is also an adaptive swimmer, golfer, yogi, guest radio host and Broncos fan. She splits her time between Denver and Bozeman, Montana, where she enjoys life with her partner, Will, and dog, Zeta. Visit her website at www.reganlinton.com.

Mary Tolan teaches journalism at Northern Arizona University. A journalist and fiction writer, Tolan's articles have been published in *Arizona Highways*, *Teaching Tolerance*, *New Mexico*, *Phoenix*, *Matador*, *Trail Runner*, and *Horizon* magazines, and in newspapers, including the *Arizona Republic*, *Los Angeles Times*, *Albuquerque Journal*, *Santa Fe Reporter*, *Milwaukee Journal*, and *High Country News*. She writes a monthly column in the *Arizona Daily Sun*, "The Long & Winding Road." Tolan became familiar with wheelchair and accessibility issues due to her father's multiple sclerosis. She lives in Flagstaff, Arizona.



A semi-retired adrenaline junkie turned writer, Kenny Salvini lives in Sumner, Washington. He is a C3-4 complete quad from a snow skiing accident in 2004. He amuses himself by writing a blog, "Typical Guy, Atypical Situation," which started as a way to cope with life in a wheelchair but has recently transformed into a chronicle of his evolution as an advocate. In 2013 he started The Here and Now Project, a social support network for paralysis survivors and their families in the Northwest.

Gerry Dickerson has been involved in the complex rehab/durable medical equipment field for more than 40 years. His career has included design, development and custom fabrication of systems and devices for persons with disabilities. He was a member of the original question development group for the Rehabilitation Engineering and Assistive Technology Society of North America ATP/ATS exam and has also served on the board of directors and executive committee of RESNA and the board of directors of The National Registry of Rehabilitation Technology Suppliers. He can be reached at gdcrts@gmail.com.



Such a great article!



Seeing is Believing

Such a great article! — seeing the Paralympics through Seth McBride’s eyes and experiences.

Patricia Wolfe

Via newmobility.com

Helpful New Mom Tip

Thank you for sharing. I’m a tetraplegic with a 5-month-old and was able to pick up some tips [“My First Baby: Tips and Tricks I Have Learned,” December 2016]. FYI, I just found a thing called a Lap Baby that helps me wheel around the house with my son securely on my lap and use both hands to push my chair. And it’s not a hassle to take on and off like other carriers. It’s like a big Velcro wrestling belt!

Melissa Pera

Via newmobility.com

First Two Years Hardest

I didn’t become disabled until my kids were 3 and 5 years old, and although there are plenty of challenges in those ages and beyond, as a wheelchair-using Mama, I think the first couple of years would be the most difficult. Great tips!

Jennifer Loughrey

Via newmobility.com

Sharing Siblings

This story is just beautiful [“The Ripple Effect — Siblings and Adaptation,” December 2016]. It speaks to what is most important in life — those who share their strength with each other to lift each other up and understand the downs. Ours is a lovely woven quilt of people who make us who we are, support our journeys, and just *love*. We hope our children will know the same love and support of each other that Cindy [author Cindy Ranii] and her siblings feel.

Kirsten Johnson Pekarek

Via newmobility.com

Quad Tips Help

Thanks for the ideas [“5 ‘Quad Tricks’ for Managing a Day at Home Solo,” NM blog, December 22, 2016]. As my C5-7, three years post-accident husband’s only caregiver, I am always looking for little tricks/ideas to help him become more independent. He is just now coming “back to life” and starting to do things on his own. The light idea is great. I also thought of an extension cord with a big button on it like the ones used for cutting a Christmas tree on for lights and such. And the house swapping idea really sounds great. Where else would be perfect for a quad to stay but at a quad’s home that is already equipped for one!

Boyd and Lynn Hert

Via newmobility.com

More on Quad Tips

Great tips — since becoming an incomplete quad three years ago, I have gone through many adventures in learning how to be solo. Even looking after my son when he was crawling and changing diapers can be a disastrous endeavor. But the main thing is to never give up. What doesn’t kill you makes you stronger. And being a quad you are always learning something everyday.

Paul Hass

Via newmobility.com

Regs and Hoops

Thanks, Obama Minions. I have primary progressive MS and it progresses yearly. Luckily got power chair before all these regs [Everyday Advocacy, “Forced to Pay Wheelchair Rental?” December 2016] — because my doc keeps up on regs. They also have me jump through hoops for my MS-specific drug every year— like I might have been cured!

Steve Slobodzian

Via newmobility.com

EDITOR: The following letter was written to CBS News’ 60 Minutes and also sent to *New Mobility*. It has been edited for brevity and clarity. For more on the same topic, see Annie Elaine’s YouTube video: www.youtube.com/watch?v=h2PYFxLa0YM&feature=youtu.be:

Dear '60 Minutes' and Anderson Cooper

I am a long-time full-time wheelchair user, originally from New York. Yes, places like California and Florida are much easier to navigate and live, if you use a wheelchair. But there are still major obstacles and barriers for persons with disabilities. *These are not being addressed throughout the USA.*

Every day I see many new buildings not in compliance, with steps, no curb cuts, no path of access ... and many other issues. I can’t shop at Sears, Macy’s, Walmart and other places ... can’t get down the aisles. These are not just ADA or access laws, but health, safety and fire codes and laws that are not being enforced.

Parking (disabled or wheelchair) is a huge barrier and the most difficult. There are many more permits than there are parking spaces. We have an aging and expanding population with more needs. Existing laws on the books way before the ADA was enacted are not being enforced. New buildings and old buildings are not always in compliance with minimum standards (required under federal and state laws), much less with readily achievable standards, which are subjective. ... Most people won’t understand this level of detail and nuance. Each disability is so different. It is not just about wheelchair access. This is a systemic problem that needs to be fixed.

David Daniels

Via newmobility.com

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Connecticut Passes Law Updating Access Symbol

The famous blue and white access symbol that depicts a wheelchair user and has been widely used throughout the world since the 1960s will soon be replaced in Connecticut. On Jan. 1, the Constitution State passed a law to replace it with a new symbol that illustrates a more active wheelchair user. Additionally, parking signs bearing the new symbol will say “reserved” instead of “handicapped.”

“It’s 45 years old,” said Connecticut Governor Dannel Malloy about the outgoing symbol. “It was developed at a different time, when our own ideas as a culture

and a society were much more about concentrating on that which held people back, as opposed to that which moves people forward, and so it was time.”

The new symbol shows a wheelchair user leaning forward pushing their own chair. This active stance is meant to depict people with disabilities as not just passive, sedentary beings, but rather active, independent members of society.

“When I looked at it, and certainly when the governor looked at it, we saw the spiritual sense of what it is trying to represent — that there is an active component, an active element to the disabled community,” said Jonathan Slifka, Malloy’s liaison

to the disabled community. “We felt there was no better way to show that than the symbol we will be using going forward.”

The new law echoes the efforts of the Accessible Icon Project, a Boston-based activist group championing the need for a new logo. The group has been placing the logo on signs and parking spaces around Boston since 2010, its efforts aimed at changing the perception of what disability looks like. The group has sparked conversation and attention among disability advocates around the world, with its logo being used as far away as a hospital in Delhi, India.

“Since the start of the work in 2010, we’ve started seeing our icon in hun-

People in the News: Swede Reaches South Pole in Sit-Ski

On Dec. 21, 2016, Aron Anderson, a Swedish man, reached the South Pole by sit-ski in what is believed to be the second such journey by a paraplegic. Although many media outlets have reported that Anderson was the first, Grant Korgan, an L2 para, skied to the South Pole in 2012.

Anderson, a wheelchair user as a result of childhood cancer, completed a 21-day journey that took him some 398 miles from the edge of the Antarctic continent to the geographic South Pole. He traveled in a custom cross-country sit-ski outfitted for the extreme conditions. The expedition aimed to raise money for children’s cancer treatment.

Anderson was joined and assisted by Doug Stoup, a long-time polar guide and explorer, whose website states he has “skied to both the North and South Poles more than anyone on the planet.” Stoup skied towing a sled that carried the pair’s gear and supplies.

Leaving Sweden on Nov. 19, Anderson, a four-time Paralympian, adventurer, and public speaker, flew to Punta Arenas, Chile, where he and his partner made final preparations for the journey before flying on to Union Glacier Camp in Antarctica. The pair had originally planned to ski the entire distance from the Leverett Glacier, up to and across the Polar Plateau to the South Pole. Conditions and fatigue, spurred by an untimely stomach illness for Anderson, forced them to shorten the human-powered portion of



the expedition. In total, Anderson managed to ski over 186 miles through temperatures that averaged -22 degrees.

Despite the hardships, Anderson remained upbeat about the journey. In a post-expedition interview, he told the BBC World Service: “I like to push myself, and see what’s possible because I enjoy the journey. Being at the South Pole was really, really hard, but it was also amazing.”

At the age of 9 an operation to remove a cancer from Anderson’s lower back left him with limited function in his lower body. The expedition, dubbed the “Pole of Hope,” succeeded in reaching its goal to raise some 6.4 million Swedish Kroner (approximately \$725,000 USD) for the Swedish Childhood Cancer Foundation.

dreds of different iterations and contexts, some edited versions, and some replaced wholesale with the new one," the group said. "The project doesn't belong to us now. It's way beyond what we originally authored, and we're glad. We've seen the icon become a kind of megaphone for our partners and friends with disabilities who see this image as a metaphor, as a symbol of their own wishes for agency and dimensional action in the world."

With the new Connecticut law officially in effect, the updated signs and symbols will start being placed at all new construction and in places where a sign needs replacement within the state. Businesses, such as insurance giant Cigna, already started using the logo last year.

— MAUREEN GAZDA

EDITOR: *Substantial opposition exists within the disability community to implementing this updated version of the universal access symbol. For more, see "The Great Blue Man Debate," www.newmobility.com/2014/12/accessibility-symbol.*

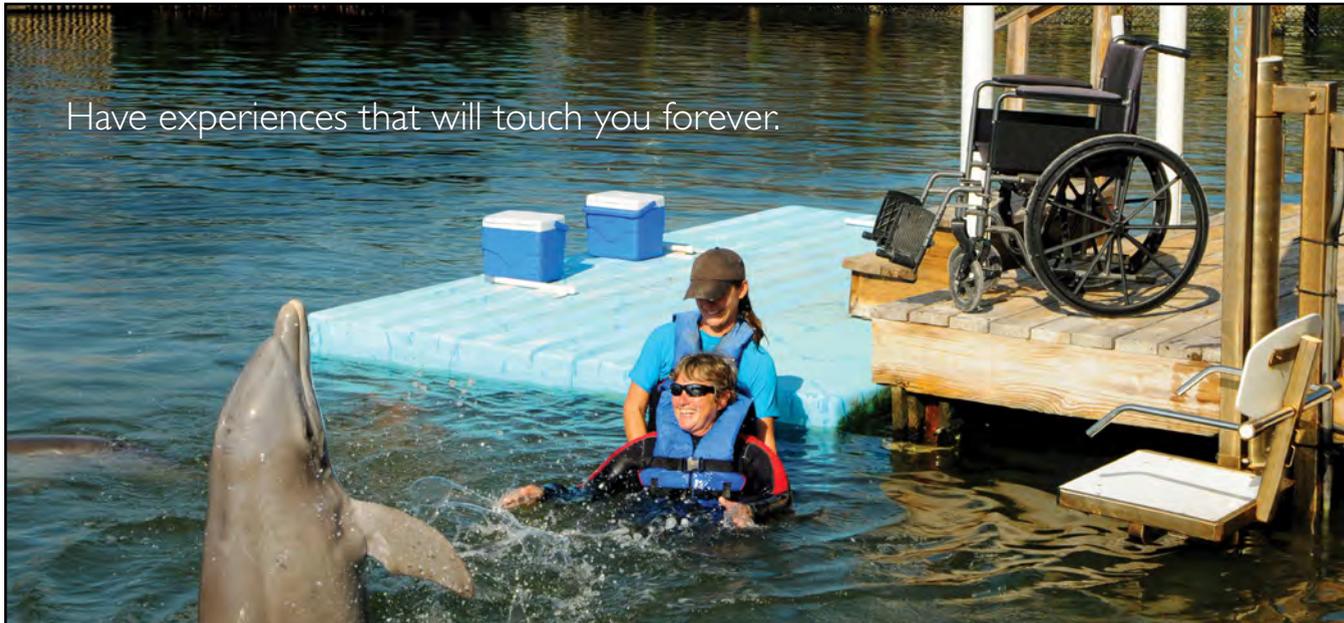
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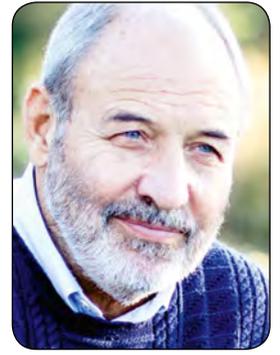


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By Michael Collins

Housing Purchase Hassles

Q. *I retired recently after working more than 36 years as an airline pilot. My wife and I are now planning to move to Southern California from the Pacific Northwest. We plan to buy a home in a new development where we will be joined by our paraplegic adult son. Making the home wheelchair accessible is an important part of our plans, but we have run across some challenges in making that happen. We picked out a new housing development in an area that we like, which is also near where our son will be working. The developer has five types of model homes to choose from, so we picked the floor plan of one that had some important features located on the first floor — kitchen/dining area, bathroom with large tub, roomy bedroom. These features will make it possible for our son to live there with us, and for my wife and I to remain there if our health deteriorates as we age.*

I figured the home, still in the planning stage, would be fairly simple for the builder to provide modifications. I was already intending to pay whatever excess costs were involved, a construction foreman agreed to grade the site so that there was a level entry, and I was seeking an architect to change the basic floor plan. Then the sales agent advised me that the developer would not allow such changes due to the need for enforcement of their covenants, which even involved certain colors and type of landscaping. Even after I explained the reason for our requested changes, she was not willing to budge.

These homes are not cheap, so I was surprised that there was resistance to meeting our needs. It doesn't appear that the ADA will help us, and at first I excluded the Fair Housing Act, as I assumed it covered only multifamily dwelling accessibility. I have since learned that there is a provision in that law that applies to detached single-

family dwellings being purchased. I am interested in how that can be applied and enforced so that the developer will comply with our requests. We will then need to find an architect who is familiar with the types of changes we will need, and perhaps an agency or organization to help us if we run across more roadblocks. Where can we turn for help at this stage of the game?

— *Grounded for now*

Restrictive, sometimes frivolous covenants have been used by some developers to exclude people with disabilities from their communities for many years, even when they were marketing their homes to seniors. Fortunately, the federal Fair Housing Act does apply to your situation and can help you gain the accessibility needed. Hopefully the development company will cooperate without the need for complaints or enforcement actions, once the facts are presented. For instance, the introduction to the Act states: "One type of disability discrimination prohibited by the Act is a refusal to permit, at the expense of the person with a disability, reasonable modifications of existing premises occupied or to be occupied by such person if such modifications may be necessary to afford such person full enjoyment of the premises." Your modifications seem reasonable, so knowing that the law is on your side should be helpful as you negotiate next steps with the developer.

First, compose a letter to the president of the development company listing the potential improvements you will need to fully use and enjoy the home. That may include such obvious items as wider doors and greater turning radius space and maneuverability for a wheelchair in the bathroom and kitchen. Also important is backing in the bathroom walls for

later installation of grab bars if needed. Be sure to identify any special features of the home, like a back deck or garage, that need to be wheelchair accessible. Request the development company to provide you with estimated costs of each improvement, and if they are higher than what would be constructed under normal circumstances. If acceptable, you will be responsible for paying those excess costs.

You can get backup at no cost by informing the company that a copy of your letter is being sent to a disability rights law firm or agency. Disability Rights California is part of a national network of similar agencies in every state that are staffed with disability civil rights attorneys and/or others qualified to protect the rights of people with disabilities under the broad variety of federal and state disability civil rights laws; many state laws provide similar protections as their federal counterparts and sometimes allow recovery of financial penalties not available for violations of corresponding federal laws. Another great Southern California resource is the Disability Rights Legal Center at the Loyola University School of Law, located in Los Angeles. Each of those resources would also be familiar with any accessibility consultants or architects in the area who might be able to help you in the design stage.

Good luck, and hopefully you will be settled in your new home before the warm summer temperatures arrive.

Resources

- To file a housing discrimination complaint, portal.hud.gov/hudportal/HUD?src=/program_offices/fair_housing_equal_opp/online-complaint
- National Disability Rights Network, ndrn.org/en/about/paacap-network.html



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By Tiffany Carlson

“I would love the world to see the definition of dance that I see.”



Discovering the Dancer Within

Always positive, never looking back, Edna Serrano, a 23-year-old aspiring actress and dancer, entered the disability world shortly after birth when doctors discovered a neuroblastoma on her back. While it caused T7 paralysis, Serrano, who lives in San Diego, California, is grateful it happened when she was so young.

“Growing up in the wheelchair made it normal to me,” she says. “I love using my voice to show the world how wonderful this life is and how much you can do in so many different ways.” One of the things she loves to show the world is that dancing is still possible from a wheelchair. She discovered this watching *Push Girls*, the reality show that followed women with SCI.

“When *Push Girls* was on, I was a huge fan of Chelsie Hill. I used to follow her on social media, and that’s how I found out she had a dance team and was looking for new dancers.

I auditioned, and since then I’ve been on the dance team.” Serrano’s entire life has changed since joining Hill’s dance team, now called the Rollettes. “Being part of the foundation [The E.P.I.C Project — Empowering People in Wheelchairs] has been one of the best things that’s ever happened to me,” she says. “We are like sisters and have each other.”

Currently at Southwestern College studying communications, and having starred in her first musical play last year, “GREASE on Wheels,” her ultimate goal is for wheelchair dance to grow in popularity. “I would love the world to see the definition of dance that I see. For me, dance is a form of expression in which I dance with the music and my heart. I let the two move my body,” she says — and then lets her wheels take it from there.

Follow her on Instagram at [ednaaserrano](#).

The Access Earth App

A dream of every wheelchair user is to have an app that tells them how accessible things are, and there are a handful of apps that provide this. One of the most popular is Wheelmap, which has almost 10,000 downloads. A new app, however, is aiming to become even more popular. It’s called Access Earth.

Dreamed up by Matt McCann, a young software engineer who has cerebral palsy, Access Earth won third place in the World Citizenship category of the Imagine Cup in 2014, a Microsoft technology competition. It is a user-driven platform that asks participants to give yes or no answers to a few accessibility criteria questions.

There’s no 5-star rating system. “Everyone’s idea of what is accessible is different,” says McCann, who wants to add the ability to book accessible hotel rooms and restaurant reservations to Access Earth next. Check it out: [access.earth](#)



World’s First Accessible Water Park Gearing Up

If you’ve ever gone to a water park as a wheelchair user, you’ve probably realized accessibility is hard to find, which is why Morgan’s Inspiration Island in San Antonio, Texas, is so exciting. Scheduled to open during spring of 2017, this unprecedented water park will feature an accessible riverboat adventure ride and five water-play areas.

Learn more at [morganswonderland.com/morgans-inspiration-island](#)

Spice Up Your Life, Boost Your Immune System

The immune system is a complex collection of cells, organs and systems found throughout the body. This dynamic system is responsible for protecting your body against infection and disease. It is well documented that people with a spinal cord injury and other chronic neurological conditions have compromised immune systems, which contributes to increased risk of bacterial and viral infections. Furthermore, studies show that people with quadriplegia or complete SCIs tend to have greater immune suppression than people with paraplegia or those with incomplete SCIs.

A recent trip to Puerto Vallarta, Mexico, and many servings of salsa, reminded me how incredibly healthy this Mexican meal accompaniment is for the immune system. While there are endless ways to make and enjoy salsa, there are a few key spicy ingredients that act to stimulate and support immune function.

Coriander, also known as cilantro, is considered both an herb and a spice. This deliciously fresh tasting plant is a powerful antioxidant that contains antibacterial compounds.

Chili peppers have a high content of beta carotene or provitamin A. Just two teaspoons of red chili peppers provide more than 10 percent of the daily value for vitamin A. Vitamin A helps maintain the mucosal surfaces of the gastrointestinal, respiratory and genitourinary tracts, which act as protective barriers to microorganisms.

Onion has sulfur-containing compounds that also help provide antibacterial benefits.

On the sweet side, pineapple is one of the best natural sources of Vitamin C, which is vital for the proper function of the immune system, too, thanks to its antibacterial and anti-viral properties. This vitamin is found in higher concentrations in white blood cells and is quickly utilized and depleted during an infection.

Studies demonstrate that Vitamin C can help increase the circulation of certain antibodies in the body, increase neutrophil functions, destroy bacteria, reduce the length of chronic illness and protect cell membranes from free radical damage. Vitamin C also helps to increase hormone secretions by the thymus gland and improve the integrity of the lining of the mucous membranes.

This yummy salsa recipe includes all of the above immune boosting nutrients — enjoy it with chicken, fish or on top of a salad! *Buen provecho!*

Fresh Pineapple Salsa (Salsa de Piña)

- 2 cups finely chopped fresh pineapple
- 1/2 cup finely chopped cilantro
- 1/2 cup fresh lime juice
- 1 tsp sea salt
- 4 serrano chiles, minced (optional)
- 1 small red onion, minced

Place all ingredients in a large bowl, and toss until evenly combined. Let sit at room temperature to meld flavors, at least 30 minutes.



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



SCUBA DIVING IN COZUMEL

BY BOB VOGEL
PHOTOS BY JANICE STRAYVE

Immersed and weightless

in the warm Caribbean water, I'm drift-diving, riding the current that runs along a colorful coral reef teeming with sea life that unfolds in front of me as I flow by. The amazing water clarity gives a dreamy flight-like quality to the dive, complete with being able to "think" where I want to go — a breath in from the regulator and I slowly ascend, exhale to descend, and a gentle wave of webbed finger gloves provides propulsion.

I had joined six other participants with Adaptive Adventures — a nonprofit that offers a wide variety of adaptive recreation programs ranging from skiing to scuba diving — at the second annual scuba trip to the island of Cozumel, held December 5-12.



Above: The dive master assists Bob Vogel into his gear and onto the swim step.

Below: Suited up and happily drift diving, Vogel waves at the camera.

Left: Matt Feeney relaxes in the disability-friendly underworld.

Right: Jim Munson looks for lobster in a coral nook.

Below: These drift divers flow with the water, controlling their ascent with a breath and their descent with an exhale. Gently waving their hands is all that's necessary for them to navigate their accessible underwater environment.



Cozumel is a mecca for divers who love the clear warm water, rich coral and marine life, but are primarily attracted by "drift diving." On a drift dive, the dive master and your group exit the dive boat, descend to the reefs and drift with the underwater currents, which can range from mellow and meandering to exciting and swift. The result is effortless diving that feels akin to flying, or taking a breath to rise over a mound and exhaling to swoop down into a valley or canyon. The dive boat follows the group's bubbles and is waiting when you surface.

The operation we dove with is Dive Paradise, and our boat accommodated five wheelchair users with room to roll around. Some of Dive Paradise's dive masters have been trained by the U.S. nonprofit Diveheart to work with adaptive divers. On each dive, our dive master and his crew would assist us to the swim step, hold us as they strapped on our gear and ease us into the water. Upon exiting, they would remove our gear in the water and lift us to our chairs.



Above: Among the many cool creatures seen by the divers on this trip were spotted eagle rays like this one.

Left: John Nousaine, Axel Doerwald, Bob Vogel, and Matt Feeney drift over reef.



Top Left: John Nousaine spears a lionfish for the group's dinner — once the poisonous "feathers" are removed. Although beautiful, this is an invasive species.

Top Right: Jim Munson checks out a sea turtle.

Bottom Right: The divers relax, letting the water hold them up.

Bottom Left: The group gathers for a night dive.



The island of Cozumel is laid back and tropical and the main areas are accessible, including our all-inclusive accommodations at Hotel Cozumel, located right across from the dive shop and boat dock.

Divers in our group ranged in experience from John Nousaine, a single leg above-the-knee amputee who has over 1,500 dives and has been certified since 1974, to Jim Munson, a T10 para, and Rich Cunningham, a T12 para, both of whom had recently earned their scuba certifications. Both Munson and Cunningham made their first ocean dives on the Cozumel trip.

Because you are weightless underwater, scuba diving is a great equalizer and adaptive sport — and can be practiced by people with higher injuries, including mid-level quadriplegics.

When asked about their favorite memories of the trip, the same answers came back — doing the night dive and seeing larger sea life — including large sting rays, nurse sharks, and sea turtles. But the top of the list was hanging out with friends and making new ones. Adaptive Adventures will be making this a yearly trip, and everybody agreed they will return.



Training Organizations For Divers With Disabilities

- Diveheart, www.diveheart.org
- Handicapped Scuba Association, www.hsascuba.com

Resources

- Adaptive Adventures, adaptiveadventures.org
- Dive Paradise, www.diveparadise.com
- Hotel Cozumel, www.hotelcozumel.com.mx



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Mark Zupan

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Getting the EQUIPMENT YOU NEED & *Learning to Self-Advocate*

BY KENNY SALVINI



The Here and Now events give participants a safe place to discuss issues like obtaining equipment.



No stone was left unturned by Jesse Collens in his search to fund upgrades to his second wheelchair.



Bill Miller says he has the most luck getting his needs met by dealing directly with a local seating technician.

Prior to the snow skiing accident that rendered me a C3-4 complete quad in 2004, I knew about as much about power wheelchairs as the next nondisabled guy. I thought they were sold between Showcase Showdowns on *The Price is Right*. I woke up from my injury inside a confusing new world with very little guidance on how to navigate, feeling isolated with nowhere to turn for help. Now I needed my own wheelchair (in addition to a bunch of other expensive stuff) and there was no Showcase Showdown for me to win. Like many of us, I was forced to learn to survive the hard way.

It all started when I was in rehab dealing with a particularly insensitive sales rep from a major mobility company who seemed far more concerned with an upcoming Hawaiian vacation than properly outfitting me with my first wheelchair. A brief moment of clarity when the fog of my injury lifted helped me realize that I wouldn't settle for that kind of treatment at a car lot; my new pair of legs deserved a far better effort.

The day I was discharged, I contacted a DME provider halfway across the state. Their salesperson showed up at my house with two wheelchairs and built me a usable trial chair in my living room. The experience taught me that if I wanted to get my needs met, I would have to learn to advocate for myself.

Build Relationships Within the Industry

When you have to fight for every shred of adaptive equipment, there is nothing more infuriating than dealing with peo-

ple who seem tone deaf to your needs. The unfortunate reality is that it's rare to find someone as passionate about their job as you are about living a full and independent life, so self-advocacy requires a constant level of vigilance that can be uncomfortable at first. It can mean a lot of repeated phone calls and emails with awkward conversations, but this can help separate the nine-to-fivers from the people who care.

In those interactions, sometimes what you say matters less than how you say it. As great as it has felt to vent my frustrations at a receptionist or delivery driver, I have found I get much further with polite persistence than bitter complaints. Your energy is better spent cultivating solid connections than burning bridges you may need later.

"If you can find a good tech, they are worth their weight in gold," says Bill Miller, an entrepreneur living with a C1-2 injury in Leesburg, Florida. Miller, who has almost 20 years of experience in a power chair, says he has the most luck getting his needs met by dealing directly with the seating technician at his local mobility branch. Working closely with his tech has helped educate Miller on the proper fit of his equipment, making it easier to communicate his needs to others within the industry.

Getting to know the local representative of your equipment manufacturers (Quantum, Permobil, etc.) gives you another option. You'll often meet these representatives at expos and trade shows, or when trialing their chairs when it's time for your new one. Not only will they have in-depth knowledge of the idiosyncrasies of their products,

they are not tethered to one specific DME provider, so you can work with them even if you decide to break away from the one you use now.

In desperate times, it's not what you know, it's who you know. When my chair was sparking in the Philadelphia Amtrak station last summer and the local mobility outfit was closed, I called my Invacare rep hoping for a miracle. Within minutes, I was on the phone with his local counterpart who graciously left happy hour to come bail me out.

Connect With the Community

Of the first six years of my post-injury life, I spent exactly half that time on bed-rest battling pressure sores because my skin could not seem to cooperate with the seemingly infinite permutations of ROHO cushions clinicians and I tried. If it weren't for a random encounter at a Kiwanis fundraiser with a C5 quad named Dan McConnell, I may have never gotten healed and rejoined the world.

McConnell introduced me to the

RIDE Designs custom cushion and soon after, I got my own. Meeting him showed me how crucial peer connections are when it comes to navigating the system as a whole. Getting wheel-to-wheel with people who advocate for themselves on a daily basis expedites your own evolution from frustrated patient to informed customer. Whether it is the pros and cons of specific equipment, or which local providers are better than others, you get the benefit of all their experience without having to suffer the kinds of setbacks that cost some of us months or even years.

It's an idea that spawned The Here and Now Project, a social support network for paralysis survivors and their supporters in the Pacific Northwest [see "Starting a Support Group," August 2016]. By securing free meeting rooms available at public libraries — all over Washington state — we've created safe spaces to discuss issues and learn from each other. Suddenly, a gathering of 20 or so individuals from all walks/rolls of life with wildly different perspectives coalesces into a group with hundreds of

years of collective strength and wisdom ready to be mined and put to use.

Get Creative with Funding

At some point, connections within the industry and community will only get you so far. The secret weapon in a self-advocate's toolkit is the tenacity to search out extra funds. Whether it is through your respective state's vocational rehabilitation, private grants or a simple car wash at your neighborhood gas station, money is the ultimate bargaining tool.

When it came time for Jesse Collens to order his second wheelchair last year, he left no stone unturned so that he could find a way to pay for upgrades not covered by state insurance. The C1-2 quad, an outdoorsman and live music lover who lives in Federal Way, Washington, had his sights set on upgraded motors for longer trail rides with friends, as well as seat elevation. "It looked like a handy feature for going to concerts or being in social environments with larger groups," he says.

By working closely with his therapists and social workers, he discovered the Northwest Access Fund, a nonprofit

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focused on helping people in the disability community acquire the assistive technologies they need most. Formally known as the Washington Access Fund, the NAF recently expanded its offer of low-interest loans, matched savings accounts, and other financial tools to Oregon residents as well. With the organization's help, Collens was finally able to assemble his ideal wheelchair instead of settling for whatever showed up. "To be able to see over walls and especially crowds at concerts, it's already been a huge help," he says.

Also, if you were injured before the age of 26, keep your eyes out for ABLE accounts in the very near future. As a result of the passage of the Stephen Beck Jr., Achieving a Better Life Experience Act of 2014 (better known as the ABLE Act), states will be rolling out tax-advantaged savings accounts for individuals with disabilities and their families that will allow them to save money for qualified expenses — big-ticket items like education, housing and transportation — without jeopardizing their eligibility for SSI, Medicaid and other public benefits.

Although currently only fully open for enrollment in a handful of states, almost all the rest have signed a version of the ABLE Act into law in the last year.

Remember, You are a Customer, Not a Patient

Getting the equipment you need and learning to advocate for yourself are not rocket sciences; they are skills developed over time. They can seem daunting when you are at the bottom of the hill looking upward, but they get easier. Whether it is insurance, a fundraiser, your own checkbook or a combination of them all, you are spending thousands, if not tens of thousands, and you need to make those dollars count.

By connecting with others in your community, you can educate yourself on the equipment that meets your needs and find resources outside of your primary funding, transforming yourself into an informed customer with plenty of negotiating power. When it came time to order my third chair a little over a year ago, I took my time. I knew what I wanted, and

I knew my budget, so I challenged my local manufacturer reps to sell me on why I should choose their model, and the more responsive DME provider in my area was rewarded with my business.

Standing up for yourself can be difficult at first, but the more you make a habit of it, the easier it becomes. Pretty soon that sense of empowerment will become less of a struggle and more of a lifestyle. Collens sums it up perfectly. "I feel more motivated to be independent every day, to take charge of what is going on in my life." **MI**

Resources

- The Here and Now Project, hereandnowproject.org
- Northwest Access Fund, northwestaccessfund.org
- ABLE National Resource Center, www.ablenrc.org
- United Spinal Association, www.unitedspinal.org

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Poor Wheelchair Service: *What's Really Happening?*

A Perspective from Inside the Industry

BY GERRY DICKERSON

Gerry Dickerson is a certified complex rehab technology provider with 40 years of experience in the design and custom fabrication of devices for people with disabilities. He advocates for a stronger provider-consumer alliance in the struggle against Medicare cuts.

The business of providing seating and wheeled mobility has always been a “moving target.” Since the advent of “Operation Wheeler Dealer” (a 2003-2004 federal program aimed at reining in widespread and costly fraud in Medicare payments involving durable medical equipment), sweeping changes have caused much confusion and harm. It is nearly impossible to keep track of it all when you are deeply involved in the onerous regulatory process, let alone when you are just trying to get a new wheelchair, or have your chair repaired.

While all the changes that have occurred over the last 20 years make it impossible to address all the issues within the limitations of this article, clarifying a couple of critical definitions can give us a good start at understanding the problem:

Complex Rehab Technology. CRT products include medically necessary, individually configured devices that require evaluation, configuration, fitting, adjustment or programming. These products and services are designed to meet the specific and unique medical, physical, and functional needs of an individual with a primary diagnosis resulting from a congenital disorder, progressive or degenerative neuromuscular disease, or from certain types of injury or trauma. In the context of NEW MOBILITY, CRT usually refers to individually configured manual wheelchair systems, power wheelchair systems, seating and positioning systems, and other adaptive equipment, such as standing devices and gait trainers. (For more, see NCART — www.ncart.us)

Competitive Bidding. The Competitive Bidding Program was mandated by Con-

gress through the Medicare Prescription Drug, Improvement, and Modernization Act of 2003. The statute required that Medicare replace the current fee schedule payment methodology for selected durable medical equipment, prosthetics, orthotics and supplies with a competitive bid process. The intent is to improve the effectiveness of the Medicare methodology for setting DMEPOS payment amounts, which will reduce beneficiary out-of-pocket expenses and save the Medicare program money while ensuring the beneficiary access to quality items and services.

However, competitive bidding is much more convoluted than that. More information can be found at the Competitive Bidding website — www.dmecompetitivebid.com.

The Main Problem

First, obtaining the appropriate CRT through a third party payer (Medicare, Medicaid and private insurance) is becoming harder in several areas: Medicare's processes required in order to obtain it, the regulatory hurdles and documentation requirements, and drastic reductions in the amount of funding Medicare and other payers allow for technology. Second, once the technology is provided, keeping it functioning properly becomes an even more difficult challenge. With both new equipment and repairs, the documentation burden must be satisfied in order to minimize the risk of non-payment, audits and recoupments.

For many people, access to repairs has become nearly impossible. The easiest scapegoats are the DME/CRT suppliers. After all, they are typically the ones delivering the “no.” However, it is important for all stakeholders, including end users, to understand the real issues blocking access — in order to come together and fight for meaningful change.

For repairs, the reimbursement levels

are devastating for equipment dealers. In many situations, the repair parts cost the supplier more than they would be reimbursed. This is caused by the same billing code being used when an item is provided at initial issue and when it is replaced as part of a repair. If you have purchased any retail item and then subsequently had it repaired, you understand that repair parts are routinely more costly than when the part was included in the purchase price of a complete product.

For years, suppliers would opt to repair an item they had provided as ongoing service to their customers, even if the reimbursement was inadequate. All the aforementioned changes have resulted in suppliers often absorbing losses in order to provide the initial technology, and this is reducing access to many technologies. Suppliers cannot afford to also absorb the loss associated with repairs. The CRT supply community has shrunk by nearly 40 percent. The remaining CRT suppliers are faced with deciding between selling their businesses or making major changes in order to remain viable. In addition, companies are being asked to serve more people because of the shrinking number of viable suppliers.

So, what do we do now? How can we work together to address the real barriers impeding access to new equipment and repairs? It may seem oversimplified, but the first and most important step is for end users of adaptive equipment to get involved and speak up.

A Few Great Places to Start:

- National Registry of Rehab Technology Suppliers, www.nrrts.org
- Access to Care, www.access2CRT.org
- People for Quality Care, www.peopleforqualitycare.org
- United Spinal Association, www.unitedspinal.org
- Or email the author at gdcrts@gmail.com

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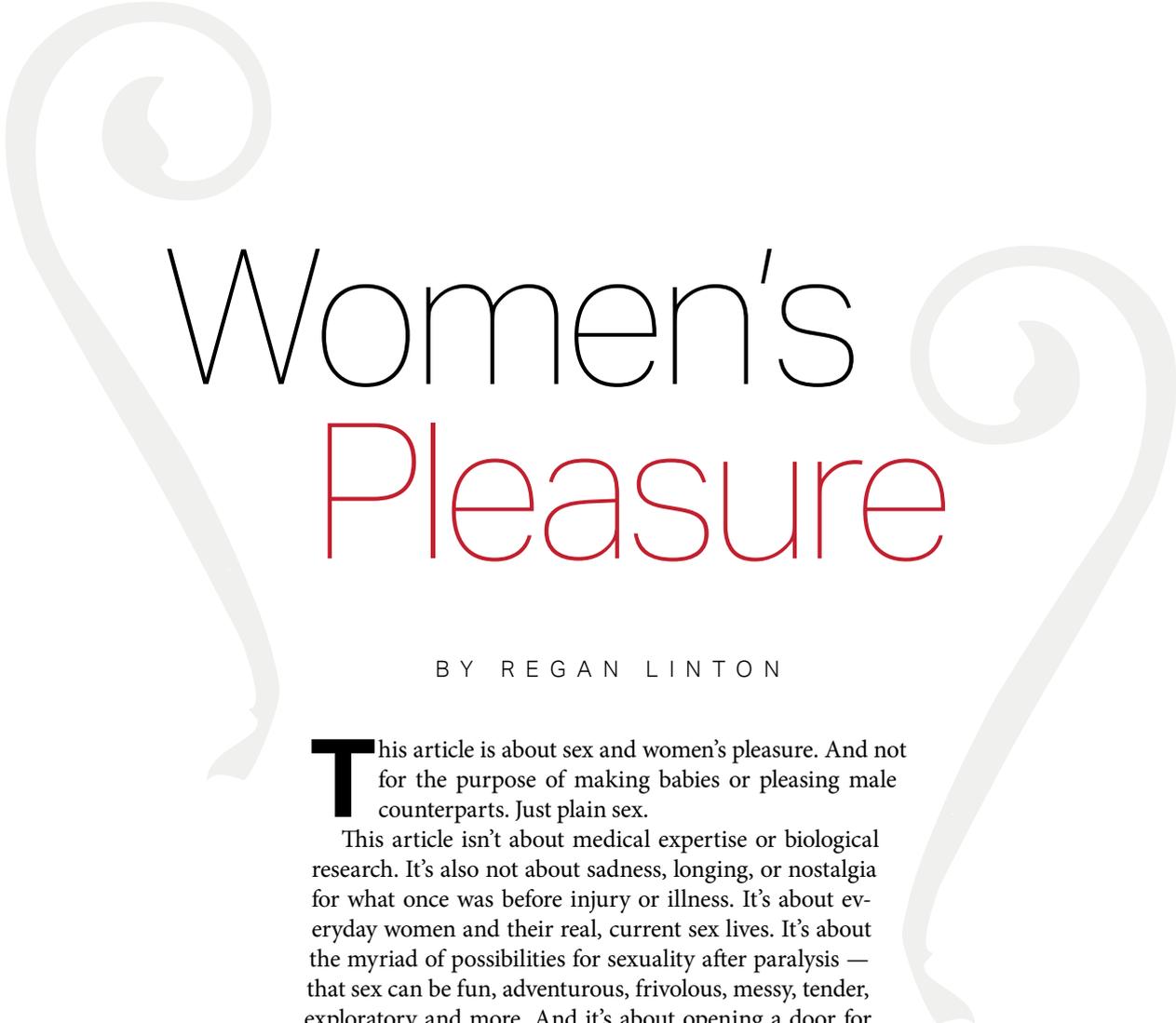
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Christine Selinger
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like to keep things
interesting in and out
of the bedroom. See
their story, page 30.



Women's Pleasure

BY REGAN LINTON

This article is about sex and women's pleasure. And not for the purpose of making babies or pleasing male counterparts. Just plain sex.

This article isn't about medical expertise or biological research. It's also not about sadness, longing, or nostalgia for what once was before injury or illness. It's about everyday women and their real, current sex lives. It's about the myriad of possibilities for sexuality after paralysis — that sex can be fun, adventurous, frivolous, messy, tender, exploratory and more. And it's about opening a door for communication.

I want to make a few things clear: I'm not a sex expert or medical professional. I also wouldn't consider myself "kinky," "weird," or "sex-obsessed" (whatever that even means). I'm simply a red-blooded woman who considers sex and sexuality to be one piece of my identity as a whole human being.

I'm also a T4 complete paraplegic, 14 years out from injury, who has discovered that there is a significant dearth of opportunities for women with paralysis to dialogue about our unique sexual lives and bodies. We especially don't get chances to talk about sex beyond how it relates to medical diagnoses, pregnancy, or relationships with men.

In America, our discussion of sex and sexuality is already stunted. Even though sex infuses much of what we see, hear, and buy, we don't actually talk about it, meaningfully and non-judgmentally. We especially don't talk about it when it involves "disabled" bodies.

Men with paralysis get an occasional opportunity since they account for more of the paralysis population. Products are geared toward men. Forums are often geared toward men. Heck, men can even talk about their erectile functions and orgasms without consternation because they can veil it in talk about virility for procreation. Still, even for guys, sex talk is often taboo (especially because there's an expectation that, if they're "real" men, they should have it all figured out).

I want to call bullshit. And I want to call it for my female comrades. We have a right to talk about our bodies, our

PHOTOGRAPH BY N MAXWELL LANDER

desires, and our experimentation without needing pregnancy as an excuse, and without feeling shame or embarrassment. (Frankly, I wish the same for our guys ... if they want to talk about using a vibrator because it feels good, they shouldn't have to disguise their desires in procreation cloaks.)

In writing this article, I wanted to reach out beyond my own contacts to ladies from a variety of backgrounds. Because there are limited forums to openly discuss this topic, I initially created an optional survey that I distributed through contacts, social media, and organizations for women with paralysis. Many thanks in advance to the ladies who responded, openly and honestly. (Some names have been changed.)

So, here we go. Let's talk about sex, bay-bee!

THE SURVEY: EXPLORING, EXPERIMENTING, STIMULATING

First and foremost, I wanted to know when ladies re-engaged with sex after paralysis, and how they did it. The experiences my respondents shared were diverse. Some had sex within a few months, others waited around a year or more. Some re-engaged with a partner they'd had before injury, others with a partner they met post-injury. It was common, though, that certain factors delayed sex for a few years, such as grieving for what had changed, fear about what it would be like, and uncertainty about what to try.

Lulu, a 60-year-old incomplete para from Florida, still hasn't really experimented with sex six years after her injury, mostly due to not having a partner. Still, she says the most surprising thing she's discovered about sex after paralysis is "the need." Through things like fantasizing, visualizing past experiences, and exploring her body with a mirror and touch, "I'm getting bolder about my need," she says.

But even with initial uncertainty, sex is very much still on our radars. "Life is different ... that doesn't mean you can't experience sex," says Jessica, a 34-year-old with permanent paralysis following surgery for spasms. And it's good to acknowledge that we're not going to be sexual dynamos right off the bat. Initial sexual experiences were "interesting," "comfortable," "different," or just plain "bad." But, things can only go up from there.

Our bodies become uncharted territory following paralysis. Everything is new again. In some ways this is frustrating, but it also gives us an opportunity that not many people get: to re-experience the novelty of our sexual bodies. Even if you've had sex a thousand times, with paralysis, it's brand new!

For many, paralysis is a reason to experiment in ways that maybe we didn't before injury. "I never had an orgasm (even before SCI) until I found BDSM," says Dawn, a 55-year-old T11. "When I became a para there were no good ways to learn about sexuality. I didn't know 'til I was 50 that my G-spot had sensa-

tion. And I didn't know the things I needed to enjoy sex. [Now] I have a winch in my garage and a massage table. Lots of fun."

Often, paralysis spurs creativity. Regardless of age and injury level or type, a majority of people I consulted had tried the following: masturbation (alone and with partners), giving and receiving oral sex, using toys, different sex positions, fantasizing, cuddling, kissing, stimulating other non-genital body parts, role playing, engaging other senses (food, oils, music, etc.), talking "dirty," and good ole' sex. Less common but still utilized were sensual massage, watching or reading "sexy stuff" (videos, pornography, erotica), sex therapy, sex clubs, relationship experimentation, and kink.

A pretty diverse menu of options! And experimentation and practice are important. Most of the ladies I queried initially didn't think they had any genital sensation, but now have discovered that they do. For some, it depends on what is being used to stimulate. "It takes a lot longer," says Jessica. Maggie, a 35-year-old T5 complete, says, "I have a Lelo vibrator with multiple settings. I like the setting with slower rumbles ... I can sense it more, whether it's inside me or by my clitoris."

Sensation isn't necessarily superficial, but instead feels activated by deeper muscles and nerves. "I feel more, depending on the partner," says Alyson, a 29-year-old C7-T2 incomplete. "If I feel connected and safe, I feel more. It's amazing how the mind and body work together."

Furthermore, "feeling" is subjective, and not the end-all-be-all. Stimulation is enhanced by "watching my partner touch me

where I can't feel," says Alyson. For Maggie, "I love having my guy go down on me. When I watch and think about it, it activates my genitals and feels good. It's psychological, but also physical ... like telepathic adrenaline."

Others have gotten creative about the type of stimulation they explore. "Rough breast and nipple play," says Dawn. "Breathing into my ear deep when coming, noises during sex, rubbing me," says Sandra, a 34-year-old C5-7 complete.

"I get just as excited by the stuff I do to my partner," says Maggie. "I love giving him a good blow job, or wrestling with him. I like playing with control, and using my tongue to tease."

ENDLESS POSSIBILITIES FOR PLEASURE

After my own injury, I felt like there was a common assumption that the enjoyment factor of sex is compromised following paralysis, or that sex has to look completely different in order to be enjoyable. But it's important to acknowledge that this is largely a fallacy perpetuated by people who aren't actually paralyzed themselves.

I remember one of the first things a close friend said to me after my injury: that she was sorry I had never experienced having an orgasm with someone before I was paralyzed. I thought,



“Most of the ladies I queried initially didn't think they had any genital sensation, but now have discovered that they do.”



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how do *you* know what it's going to be like? And why are you assuming that it's going to be worse?

I'm not alone in encountering these attitudes.

Yes, it might be different, but every human does it differently. And "different" doesn't mean it's all relegated to the mind, or takes the physical out of the picture. If anything, having paralyzed bodies creates potential for exploring physically where a majority of "normal" sex partners never venture.

For many of the women I spoke with, doggy style is one of the preferred possibilities. Dawn says she likes it because "it hits the G-spot." Tara, a 35-year-old L2 adds, "The submissiveness of doggy style really turns me on."

On the flip side, Alyson loves being on top. "I feel so powerful and capable," she says. "My partner holds my hips or my butt and I move my upper body. Every position is totally creative, and that's the fun of it."

Of course, positioning can take a little more preparation. "The first time I got on top, it was a little tricky. I didn't want to hyperextend my knees," says Maggie. "Now I know how to take it slowly, and my partner and I kind of roll together to get me on top. I watch my knees to make sure they're OK."

Having the right tools can help, too. "I recently saw something called the Body Bouncer that was a little bouncy seat you can sit on, while your partner lies underneath. Depending on your strength and stability, it might be a good option for being on top or trying other positions," says Maggie.

"We have a wedge called the Liberator that helps us with different positions," says Tara. "My husband may assist me by

helping hold up one of my legs, by helping me turn over and position my legs correctly, or by wrapping his arm around my lower stomach to pull me closer into him."

As for different types of supports, Jessica enjoys using a beanbag ("He helps position my hips and legs"). Other favorites included firm pillows and a headboard to grab on to. "I use my arms to help move my body, since my legs don't work like most people's."

Multiple people suggested trying different locations. "I've tried it on the floor, the couch, even in a bathroom stall where I could use the grab bars for support. But I think I like a good old-fashioned bed the most," says Maggie.

Lastly, the right clothing (or lack thereof) can make a difference. Maggie likes when her man stays dressed and she gets naked. Tara's husband prefers her in satin lingerie.

No matter what you try, communication is key. "Talking and expressing myself to my partner even when it's hard and painful has been the only way to find freedom and pleasure!" says Alyson. "If they're uncomfortable that's OK — it's not your job to make them comfortable."

And, of course, safety with skin, bladder, bowels, and contraception are important. "I'm always careful with my skin," says Dawn. Tara emphasizes the necessity of "emptying bladder and bowels beforehand and making sure to clean myself and empty bladder afterwards."

"I make sure to have lubricant in case my body isn't wanting to lubricate itself," says Maggie. "And I make sure to clean my vibrator and myself really well."

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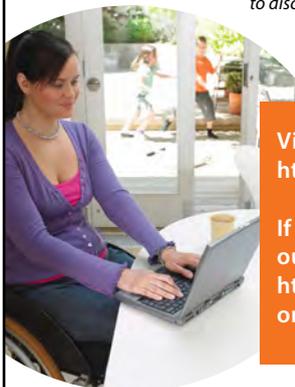
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“Birth control is so important. It takes the anxiety out of sex about getting pregnant and allows you to be in the moment,” says Alyson.

FINAL WORDS

Taken altogether, our frank sex talks boiled down to this: Whether you’re 29 or 60, live in Tennessee, New Jersey, or Colorado, whether it’s injury or illness, complete or incomplete — sex after paralysis can be awesome.

Heck, you’re already having to focus a lot on your body, why not make it enjoyable? Tara recommends finding a way to connect with your body, other than just medical means. “I found dancing, working out and stretching very helpful. Take care of yourself — for example, eat well, stay as active as you can, and treat yourself to a new outfit that makes you feel sexy. The more comfortable and confident you are with yourself, the better sex will be.”

“Start slow. Use a mirror, or take pictures of yourself, just for yourself. Be curious and open,” says Maggie. “And make sure you honor your own needs and wants as much as your partner’s. Mostly, don’t write off sex because of the unknown.”

“It’s going to be fun, awkward, and special,” says Sandra.

“Relax,” says Lulu.

“Don’t take 25 years to learn your body like I did,” says Dawn. “Figure out what you like, what you want. Life is too short not to enjoy sex.”

Multiple women commented on how empowering their

sexual reawakenings have been. Many, like Alyson, have grown to love the uniqueness of their bodies. “It makes me feel like a unicorn!” she says.

So go ahead, ladies. Get yourself a mirror, a vibrator, a wedge, a beanbag, a partner, and venture into something new. Don’t stop talking or sharing. Be a unicorn!

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Christine Selinger: Conversations About Sex

BY MARY TOLAN

Here are two topics that often make people uncomfortable: sex and disability. Put them together, and it's likely to make your Aunt Charlotte blush and reach for her cuppa. Add into the mix "sex toys" and she'll likely be topping off her hot tea with a shot of whiskey. Make that a double, please.

For one young Canadian woman, however, those words all go together like macaroni and cheese — or penises and vaginas — and the combination ought to be celebrated.

"I'm a bit shocked at how little people know about disability and sex," says Christine Selinger. A former Paralympic canoeist, Selinger teaches people with disabilities, as well as health care workers, about sex. "To me, sex is part of daily life. We should talk about this. And I'm more than happy to help people do that. I want to help make that conversation not awkward."

When she was first injured, though, she wondered about her own sex life. "I thought no one was going to want to have sex with me," she says. "It took a long time for me to have enough self-confidence and self-worth to pursue that. There are a lot of barriers — like people in general not seeing us as sexy. And this belief is even found among those with disabilities."

Now Selinger, 29, is an educator for Spinal Cord Injury Ontario, based in Toronto. The organization helps people with spinal cord injuries and other physical disabilities achieve independence and self-reliance as they rebuild their lives after an accident or illness. She leads sessions on a number of subjects for people with spinal cord injuries, and much of her work is currently through online education. Lately, she's been specializing in sex ed.

"I cover what to expect after a spinal cord injury, especially for people with brand new injuries," says Selinger, who in 2011 earned two bachelor degrees from University of Regina, Saskatchewan, one in education and one in science. "To hear about sexual health and subjects like bladder and bowel issues from someone who's actually gone through this — and not all in medi-

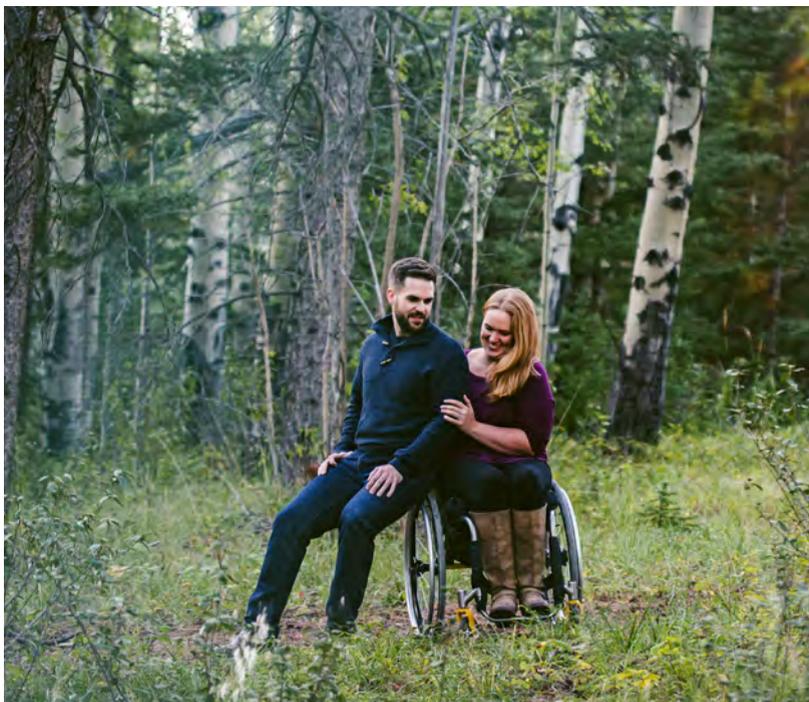


Photo by Sarah Pukin

Christine Selinger and her husband, Jerrod Smith, have become communication pros.

“Sex is part of daily life. I want to help make the conversation not awkward.”

cal jargon — makes a big difference.”

Her boss, Diana McCauley, senior manager of employment services and knowledge enterprise at SCI Ontario, says Selinger is a star employee, skilled facilitator, and an “enthusiastic advocate for people with disabilities.” She praises her for developing courses and presenta-

tions. “Sex is an important part of adult life, but often people are reluctant to ask about it,” McCauley says, adding that the classes have been very well-received, with people from across the globe reaching out for more information and resources. “Christine tells it like it is, and approaches the subject with a positive attitude, offer-

ing helpful tips in a respectful way that puts people at ease.”

ADAPTING SEX FOR YOUR BODY

Sex following spinal cord injury can be complicated and often requires adaptations. Since sexual function is enervated

CHRISTINE AND JERROD: LEARNING WHAT WORKS

“I tried online dating,” says Christine Selinger, “but it was just excessively complicated. When do you disclose you have a disability? Sometimes when I did, I’d never hear from them again. But then there were people interested in having sex with me only because I did have a disability ... that was even more weird.”

So she took a couple of years to figure out her new body, and then met her future husband.

“Jerrod was my first sexual experience with someone else after my injury,” she says. But as a 19- and 20-year-old, she undertook sexual experimentation by herself to find out what felt good — and what didn’t. “What feels good and doesn’t changes, too, because of your level of feeling,” after a spinal cord injury. “Erogenous zones can completely change.



Photo by N Maxwell Lander

“Because we’d known each other for so long, Jerrod and I had had the awkward conversations about the bladder and bowel accidents that might happen. He prepared for it. But I don’t think either of us were really prepared for it when we started having sex.”

She says she now usually prepares by voiding before sex, but

accidents can still occur. “It doesn’t often happen, but when it does happen, I still feel very embarrassed, but Jerrod makes me very comfortable with all that.”

She recalls their first time: “I didn’t know what was going to work or not going to work. I didn’t know what I’d feel or not feel. We had to get creative with it.”

Jerrod agrees: “We tried to read to each other what was working and what wasn’t working. Some things are good and some not good. After dating and living together, and now being married, we’ve figured a lot of that out.” He pauses. “You just have to practice a lot.”

They both laugh.

Christine was not dating anyone at the time of her life-changing rappelling accident.

“I wasn’t in a relationship when I sustained my injury,” she says, adding that she now knows many people who were. Those people had to figure things out in a new way in their sex life and their couplehood. “One woman I knew drew a body map, labeled what she could and could not feel. That gave them a place to start.”

“The biggest thing for me? Think of it as an adventure instead of an ordeal. We can figure this out together how to have fun, adventurous sex, instead of thinking, ‘I don’t know how to get off, and I guess I can just do what works for them.’ We’re trying to have fun and then branching out. We found what works for us,” she says. “We have a select few things in our repertoire.”

“And we know how to go back to the well if we need to,” Jerrod adds, meaning using the sexual basics in addition to new ideas and positions.

For this couple, the main sexual challenge is holding in a position. “The biggest thing is the positioning,” Christine says. “Realistically, it’s never going to be in ‘ride ‘em’ cowboy style, but we can simulate that in some ways.”

They laugh again.

“Christine on top doesn’t work so well for us. So that’s something we’re trying to do better,” Jerrod says.

“We’re always still playing with different toys and finding out what works,” she says. “I can get on top, but I can’t do any movement up there, so that kind of lacks the pizzazz. We try to find the in-between spot of rolling.”

For Christine, her inner thighs are hyper-sensitive since the accident, and not in a positive way.

“It’s not good to touch them. Jerrod had to learn that’s a no-go zone. Normally it’s an erogenous zone for someone else.”

“With Christine, it’s a good way to get a left hook,” Jerrod adds, smiling.

at the very bottom of the spinal cord, “everyone is affected somehow,” Selinger says. “It depends on the degree of your injury — complete or incomplete — and what nerves are affected.” For example, she adds, “I can feel interior sensations, just not exterior.” People with injuries at T6 and above may experience dysreflexia. Some people have orgasms, some haven’t figured out a way to get there yet.

As a counselor she often recommends sex toys to increase pleasure. “When people think sex toys, it tends to be more taboo, like only kinky people buy toys. But that’s part of what we’re trying to change in terms of talking about people with disabilities and sex. Not that there’s anything wrong about kinky. But it’s about using pillows or love bumps or things like that to help you position in a way that your body can’t hold any more.”

She says people with SCI may have minimal or hyper-sensitivity due to their injuries, so feathers or vibrators may also increase pleasure. “It’s about adapting sex, making it work for your body,” she says. “There’s nothing wrong with that.”

Her sex ed talks also include the topic of erections and condoms. Men want to know how you can keep a condom on if you can’t retain an erection. “Well,” she says, “there are female condoms. So if you’re having penetrative sex, you can insert a female condom, and you don’t have to worry about pregnancy and STDs, while also not having to worry about your erection coming and going.”

Selinger, a passionate speaker with a sense of humor and a sparkle in her eyes, says one of the first questions men new to disabilities ask is about sex, whereas most women are initially more timid on the subject. “Girls! We really need to talk about sex more,” she declares. “We need to have those conversations. Because it’s an important part of life. It’s not something you need to shy away from.” [See “Women’s Pleasure,” page 24.]

ALWAYS PERSISTENT & DRIVEN

Selinger was 19 in December 2006 when a rappelling accident in British Columbia resulted in her sustaining an incomplete L1 injury. For her, this means she has slight sensation and movement below her abdomen.

She recalls her family buoying her up after her accident, but her inborn nature



Photo by Sarah Pukin

Married in 2016, the “Smelingers” take joy in keeping romance alive.

was vitally important as well. “At first it’s really embarrassing because you tend to have a good number of accidents. And, remember, I was just 19,” she says, a smile in her voice. “I said to my mom, ‘I bet you didn’t think you were going to change diapers this late in the game.’”

Her sense of humor is one coping mechanism. Christine’s older sister, Chel-

sea, says Christine was born with other characteristics that also helped her adjust to the dramatic change in her life.

“She’s always been persistent. I’d call her a stubborn redhead,” Chelsea says, laughing. “That’s been a trait she’s had her whole life. What might have been an annoying trait as a child — to me as her older sister — has, I suppose, turned

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One way Christine learned about her body — and her resilience — was through competitive paddling.

to an admirable trait. And the accident definitely didn't stop that. Her attitude and approach to life has always been that. She's an optimist, has a sunny outlook on everything. She's persistent and driven, very driven, always driven."

This persistence and drive became more apparent when, after her injury, Selinger was paired with a mentor, Clayton Gerein, a quad who nudged her toward water sports.

FROM MENTEE TO CHAMPION

Although she did go for outdoor adventures before the accident, she wasn't into organized sports. "I wasn't actually an athlete before my injury at all. I didn't like sport, anything having to do with a ball," she says with a contagious laugh. "I was always chosen last on teams." But under Gerein's tutelage this quickly changed.

"I was introduced to him by my social worker when I started asking about travel," she recalls. "He was wonderful. He taught me everything I knew. He was the 'me' of me." Gerein, who was inducted into the Canadian Paralympic Hall of Fame in 2011 for his role as coach and mentor as well as his athleticism, died in 2010.

He guided Selinger to competitive kayaking and canoeing, where she could meet others with spinal cord injuries and learn what her post-injury body could do. She went from not being able to balance in a kayak without tumbling out into the water, to becoming a dominant competi-

tor, winning 10 international medals, including the first-ever Women's Paracanoe V1 World Championship in 2010.

That same year, she was the first paraplegic to go on an expedition along the Nootka Trail, a rugged backcountry 22-mile-long trail in British Columbia.

Selinger, whose paddling nickname was "Sully," is a retired paracanoe sprint champion and mentor in her own right. Known for being a coach and adventurer as well, she has been instrumental in promoting adaptive paddling. According to the World Paddle Awards website, "her efforts undoubtedly aided getting paracanoe into the Rio 2016 Paralympic Games."



Photo by Sarah Pukin

Jerrod thinks it's sad when people run away from a date because of something like a wheelchair. "It may be the love of your life," he says.

A TURN TOWARD INTIMACY

While still competing in paracanoe, Selinger returned to her studies at the University of Regina, Saskatchewan, where her life took a turn toward romance. That's when she met her future husband Jerrod Smith in an algebra class.

"Jerrod was the one I figured it out with," she says, regarding intimacy. "It helped that we were friends before we started dating. We had a lot of conversations." Jerrod and Christine finished their undergrad studies and moved across the country to Toronto in 2011 after dating for just six months. They were married in June 2016.

Jerrod says while he appreciates that his wife's drive enabled her to win championships, he knows sometimes people put her up on a pedestal, which is not what she wants.

"That's something Christine deals with, the attitude that as a disabled person you are either inspirational or you're sad. Either you're a Paralympian or you don't leave your basement," says Jerrod. "Christine gets lumped into the inspirational category. She sometimes just wants to be Christine."

Like when they're relaxing at home. "We're sitting together on the couch watching Netflix just like other couples are," says Jerrod. "Once we do end up in the bedroom, Christine's taller than me, and it's just more an even playing field."

With one exception, he admits.

"If I lean over and tickle her, she's going to beat me," he says because her upper body is stronger than his.

Jerrod encourages people to keep an open mind about relationships between nondisabled and disabled people. "You hear lots of stories about someone set up on a date with someone in a wheelchair ... and they turn and run. I think that's sad. It may be the love of your life who just sits a lot, uses a wheelchair, or has another disability. Openness is important and valuable."

Clear communication helps from the male perspective, too, he says. "I think Christine would probably like more communication from me than there is. Being a mathematician, I can be pretty focused. It probably takes a little longer for things to sink in with me than Christine would like," he admits. He is working on his Ph.D. in mathematics at the University of Toronto.

And it also takes time for the disabled person to feel comfortable in his or her

“We can figure this out together, how to have fun”



Photo by N Maxwell Lander

own “new” body, especially in that critical period following onset of disability. Christine says at first she experienced a siege of “what-ifs.”

“What if the rope had been long enough? What if I had fallen in a different way, and just broken a leg?” she recalls, adding that she knew, of course, that it could have also been much worse.

“But I forcibly stopped that kind of thinking pretty quickly,” she says, looking back on her 19-year-old self. “It’s so easy to get caught up in that. It’s just ... it’s not helpful. And I kept thinking, ‘I

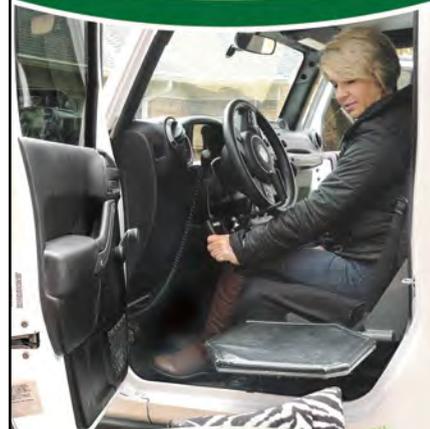
need to get rid of the things that aren’t helpful. There’s too much on my mind already. So I need to focus not on ‘what if,’ but ‘what is.’ And make the best of what I’ve got.”

Like everyone, Christine Selinger doesn’t know the specifics of her future. She may go back for a master’s or Ph.D., or she may take to paddling competitively again. But she is certain that she will continue to teach, as well as keep sex front and center in her life.

After all, sex is a natural part of living for all people — wheels or no wheels. **M**

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The Ruderman Family Foundation *and the* Fight for Inclusion



Photo by Niv Shank

Jay Ruderman awards Michael Stein, J.D., the first Ruderman Award.

"It is the largest minority in the world whose rights have not been realized. There is a vacuum in the philanthropic world on this issue and we can take a leadership role to make change."

— Jay Ruderman, President, Ruderman Family Foundation on people with disabilities

BY ALLEN RUCKER

A long-running and all-too familiar conundrum at the heart of the disability community is that the term "disability community" is at best a misnomer and at worst a grand delusion. There is no disability community, really, or only in the vaguest terms. The vast majority of disability groups — the National MS Society (not to be confused with the Nancy Davis Foundation for MS), the Reeve Foundation, the American Foundation for the Blind, and so on — have a single agenda and guard it like a mother hen. They are more like the assortment of grand duchies and fiefdoms in Central Europe before Otto von Bismarck came along and pounded them into Germany. And many are in open competition with others for medical research money, celebrity endorsements, and media attention. This is not a recipe for collective action.

There are ways, of course, that this disparate assortment of advocates can come together. The best example was the build up to the passage of the ADA in 1990. A political act that benefited all drew the activism of all. They can also

come together around social policy or when a presidential candidate — what is that guy's name? — blatantly mocks people with disabilities. It's like we have to be mocked to get any press these days.

All disability groups can cross party lines and join hands for the common good around one intractable barrier — the universal hobgoblin of inclusion. Everyone involved can join the fight. The guy in the chair and the deaf girl face the same invisible wall of exclusion. And there is one potent way to beat the drum for inclusion, and that's media.

This is where this story really begins. It's about a relatively new player in the disability arena that has made social inclusion and media awareness a principal mission. New players are rare in disability advocacy, especially new players who have the resources to foment change. Meet the Ruderman Family Foundation.

A Brief Backstory

The patriarch of a family in Boston, Morton Ruderman, made a ton of money in the health care technology business and



Photo by Pini Siluk

Jay Ruderman meets with Israeli film director and Paralympian Pascale Bercovitch.

decided to devote himself and his family's fortune to causes dear to him. Initially, the focus of his creation, founded in 2001, was strengthening the ties of understanding between the American Jewish community and the state of Israel. While early efforts involved programs directed at the



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Jay and Shira Ruderman enjoy an outing with their children.



Jewish community in the greater Boston area, in time they went international. This led to projects like establishing the first university curriculum focused on the lives of American Jews at Haifa University in Israel, called the Ruderman Program in American Jewish Studies.

The Ruderman Foundation is, in the eyes of its principals, a “family business” and is now run by Morton’s son, Jay, along with his wife and siblings. In working with the Boston Jewish school system, the Rudermans came in contact with the problem of accessibility for kids with disabilities. Jay Ruderman calls it “a fundamental issue of fairness.” As their mission statement reads, “guided by our Jewish values,” the foundation felt compelled to respond. Unlike most disability activists and fellow travelers, there was no one with a disability in the Ruderman clan that triggered this response. Only later did disability become personal when Jay’s nephew was born with autism.

By 2008, the Ruderman family saw the bigger issue of disability inclusion as a new direction for their efforts. They didn’t want to do something that just repeated what others were doing. They also decided that their work would be directed more toward the populace at large and not just “preaching to the choir.” If you have attended one or a hundred conferences on anything related to disability, you know that it’s usually the choir you see sitting around you. They know the sermon by heart.

So the Rudermans stepped in to fill what turned out to be a huge gap in the

broader disability game plan — public awareness. Those periodic six-o’clock news stories about a gutsy teen with a disability or Oscar-winning, feel-good movies like *Forrest Gump* weren’t getting the job done. This task required some savvy thinking and financial investment where real results can be seen. This isn’t run of the mill do-goodism. This is business.

But why does public awareness matter, especially awareness spawned by film and television? Because many millions of people out there, after decades of saturation, often take television as more real than reality itself. As Jay Ruderman so aptly put it, “Many of us in America relate more to people we see on television than we do with each other. Becoming comfortable with people with disabilities in

“I think sometimes producers and directors are scared of disabled actors because they think . . . we might not be able to do this or that or might make it complicated for them, and I just want to say. . . . Give us a chance. Please.”

— Micah Fowler, actor with CP, co-star of *Speechless*, at the Ruderman Roundtable on Inclusion

our favorite TV shows and films means we will be more comfortable with them in real life.”

Defining Diversity

I live in Media Central, USA, otherwise known as Los Angeles, and out here diversity is one hot topic of late. You will read this shortly before the 2017 Academy Awards. After last year’s debacle where the glittery stage was a cavalcade of straight, white males, I promise there will be many more black, gay, and female faces up there this time around. Will there be at least a token person with a disability as window dressing? Highly unlikely. When the president of the Motion Picture Academy, who happens to be a black woman, recently announced her bold new diversity initiative, she didn’t even mention people with disabilities. We didn’t even make the boiler plate press hype! Such obtuseness is a testament to how long and winding the road to full inclusion still runs.

The Rudermans saw this and took action. They first commissioned a “white paper” on the employment of actors with disabilities in television. The two authors of the report, noted dwarf actor, Danny Woodburn (*Seinfeld*) and Ruderman content specialist, Kristina Kopic, surveyed the 10 top-rated scripted dramatic



Speechless’ Cedric Yarbrough, Scott Silveri, Melvin Mar and Micah Fowler pose with one of three awards the show won at this year’s Media Access Awards.

Photo by Michael Hansel

shows on network TV, plus the top such shows on streaming services like Netflix. Their findings were insane: Out of all the characters with disabilities appearing in these shows, 95 percent of them were played by nondisabled actors.

Plus, there aren't that many roles to begin with. According to the latest annual report by the LGBT advocacy group, GLAAD, the percentage and number of series regular characters with disabilities has risen to 1.7 percent (15 characters) from last year's 0.9 percent (eight characters). That sounds like progress, until you realize how paltry 15 are compared to a disability public of 56 million — and the fact that a huge chunk of those roles go to nondisabled actors. It makes you want to scream.

Unpacking the Problem

The next step in the Ruderman campaign was to stage a convocation in Los Angeles called "The Ruderman Studio-Wide Roundtable on Disability Inclusion." Noted actors with disabilities like Academy Award winner Marlee Matlin, RJ Mitte (*Breaking Bad*), and the aforementioned Mr. Woodburn joined writer-pro-



ducers like Scott Silveri (*Speechless*) and Glen Mazzara (*The Walking Dead*) to lay out the sad reality of the situation. Marlee Matlin told a story about going up for a role specifically written for a deaf actor of her age, losing out to a non-deaf actor, and then being gobsmacked when asked by the idiot filmmakers if she could teach that actor "how to be deaf."

"It's still simmering with me," she said, "and people tell me to get over it, but I can't."

Woodburn said he was turned down for

a role as a doctor because, he was told, that "he could never be a doctor." He cracked up the crowd when he confessed that he had been asked, more than once, to get a laugh on camera by biting another actor on the butt. He now has in his standard contract, "no biting on my character's part."

Writer-producer Mazzara got to the heart of the matter in this brief exchange with activist and agent, Gail Williamson.

Mazzara: I don't know if there is malice [in Hollywood] or a system that peo-

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ple grew up in, and there will have to be a painful pulling apart of that system as we go forward. ...

Williamson: How would you go about pulling it apart?

Mazzara: White guys need to get their shit together!

Honoring Inclusion

Yet another important way that the Ruderman Foundation is fighting the fight for inclusion is an annual monetary award called the Ruderman Prize in Inclusion. Now in its fifth year, five organizations were chosen as recipients out of over 400 applicants from around the world. Each winner receives a \$50,000 grant to build upon the work they are already doing. This year's honorees came from Germany, Brazil, Israel, and the U.S. and underscore the foundation's commitment to new technology and media outreach.

Sozialhelden, a group from Berlin, will use the money to educate journalists in how to present people with disabilities as more than inspirational "heroes." Egalite, from Brazil, will grow its online platform to connect job-seekers with disabilities with potential employers. The Jerusalem-based Bezalel Academy of Arts and Design will expand its program in inclusive design and accessible environments for people with disabilities.

The two American honorees this year may be familiar to NEW MOBILITY readers. One is the tech innovator, AXS Lab, created by filmmaker/entrepreneur Jason DaSilva, the 2015 NEW MOBILITY Person of the Year. Jason and his wife, Alice, invented an app called AXSMap.com that allows wheelchair users to check out locations for accessibility before they leave the house. Started on their home turf of New York, the service now draws tens of thousands site ratings from people all over the world. Next time you're in Sydney, check out AXSMap to find an accessible boozier, mate.

The other U.S. recipient was the Media Access Awards, the annual Hollywood ceremony celebrating disability in film and television. [Full disclosure: I am involved in this event, though I didn't know about winning the prize until after I was assigned this story. I was as surprised as the next guy.] After going dark for three years, the Media Access Awards, originally created by Norman Lear and others

in 1979, came roaring back to life with the help of four big Hollywood union/guilds and the Christopher Reeve Foundation. The aim of this program is in lockstep with the aim of the Ruderman Foundation: promote inclusion by honoring those Hollywood storytellers who see people with disabilities as an integral part of whatever they create.

Revisiting 'Community'

When you attend events like the Ruderman conference where the agendas of single-disability groups disappear, you do feel like you are part of a community greater than the sum of its individual letterheads. It's healthy to mingle with people who are both like you and unlike you at the same time. You may even be forced to confront your own bias, implicit or otherwise, towards those whose disability makes you nervous, whether you want to admit it out loud or not. What do you say to someone who is deaf and you don't sign? Are you impatient and maybe even embarrassed around someone who has difficulty speaking? That kind of thing.

So maybe it's good to keep up the notion of a community and as the Ruderman Foundation is doing, make inclusion a community-wide effort. One of the participants at the roundtable, activist and actor Jason George (*Grey's Anatomy*), laid out the future:

"This work of inclusion," he said, "it is slow, it is like watching concrete dry, and it is painful ... but to say we are close to done is like saying I got rid of three out of my five forms of cancer. There is, however, movement, and this [event] is part of it."

Hats off to the Ruderman Foundation for entering the fray and bringing new passion and vigor to a prolonged fight. Are there other inclusion go-getters out there? Well, step up. No matter your disability, we are all in this together. **MI**

Resources

- Ruderman Family Foundation, www.rudermanfoundation.org
- Sozialhelden, www.leidmedien.de
- Egalite, www.egalite.com.br
- Bezalel Academy of Arts and Design, www.bezalel.ac.il/en
- AXS Lab, www.axslab.org
- Media Access Awards, www.mediaaccessawards.com

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OUTDOOR TRACKS

Navigating Paved Trails in the Canadian Rockies



By Kary Wright

“How far is the lodge?” asks Jim. “Seven or eight miles,” I reply. “Can your chair make it there and back?” asks he, a little too concerned, methinks.

“I think so, I’ve done it before,” I say, reassuringly.

“There is that hill with switch-backs you know,” he says, not feeling reassured.

“I mean, what could possibly go wrong?” I say.

“Oh not much, just getting stuck down hill, miles from camp, late at night, in grizzly country, with about 400 pounds of dead weight on wheels,” Jim points out, sounding like someone who has had to push one of these things at one time or another.

“True ... but a vehicle could rescue us if need be ...” I offer.

Jim laughs. He is getting accustomed to anticipating what can go wrong when a member of the party must rely on electric-mechanical items for mobility. It is one of the harsh realities of wheelchair life, and as our equipment ages and declines, the chance of something breaking down rises — inevitably at the farthest point in the journey.

We gaze around at the amazing scenery while waiting for our wives at the trailhead. I never get tired of the Rocky Mountains. You can stare at them over and over and still find something new. Sometimes you’ll see a bear, an elk, a deer, or even a waterfall.

My wife and I and friends are camping in the Rocky Mountains for a couple of weeks in September to celebrate our wedding anniversaries. This area is a favorite of my wife’s, and mine, and we even got married on this trail ... oh ... would you believe a year or two ago? It also has a special connection as my



There are miles and miles of wheelchair-accessible paved bicycle pathways throughout the Canadian Rockies. Kary Wright loves exploring the mountains so much that he chose his wheelchair based on whether it could keep up with a bicycle.

grandfather and grandmother operated a coal hauling business nearby in the 1950s, and my mother and her brother were here with their parents as kids. There are miles of paved bicycle paths to explore, and today we are choosing to tour to the Kananaskis Lodge, eight miles away. The sun is shining on the mountains towering above us, bordering the valley. Cool crisp air with a sweet hint of the fermenting vegetation so characteristic of our autumns fills our lungs. I love it!

Grizzly Bears, Bees and Banter

One of the things I truly enjoy is exploring trails. My first criterion when choosing an electric wheelchair was top speed. I wanted to participate in bike rides without the hassle of needing to be transferred into a faster unit. I find that less dicker-factor



means more fun, more often. My chair does about 8.5 mph and can last up to 25 miles or so, just fast enough for bike rides. I do know from experience that as batteries age, the range is drastically reduced, and I’ve even been begrudgingly towed home by another wheelchair user after such a miscalculation.

Since we are in grizzly bear country, Jim has equipped us with pepper spray and loud horns. Many people also carry bear bells. If you make noise, the bears will hear and most likely avoid you. Of course there is the obligatory pre-ride bear-encounter bantering.

"Do you know the difference between grizzly-bear poop and black-bear poop?" I ask.

"Grizzly poop has bells in it and smells like pepper," laughs Jim. "Those bells are really just dinner bells to bears."

"You don't have to be the fastest ... you just don't want to be the slowest," I say.

"I guess we know who that'll be." Jim looks at me.

"That's not nice to speak of the girls like that," I tease, looking sideways at my wife.

She counters: "I've even heard one friend tell her husband with a laugh, 'I can run faster healthy than you can with a knife stuck in your leg.'"

All kidding aside, you do want to be prepared for an encounter. Although these bears probably see a lot of people, there are rare instances when they become aggressive, and with their speed, you want your pepper spray and noise-makers handy. On a drive earlier in the season, we had close encounters with grizzlies on three separate occasions, but were fortunate to be in a vehicle.

And off we go, zooming down the trail, weaving among the pine trees, occasionally cha-chinging the bell on the handlebars. It is downhill for miles and I struggle to keep up. "Slow-poke" comments are duly noted. At one point we stop to admire the vast expanse of the mountains silhouetted against the blue sky, a fast moving river snaking down the valley, crashing past. The next instant we notice a honeybee fly up to a yellow flower. Upon closer inspection there were many flowers covered by equal numbers of bees. It was a fascinating world to observe, one that busily carries on unnoticed most of the time. The beauty of their world was equal to the vast mountain expanse around us, a real eye opener. We observed for several minutes, got some great shots, and were on our way.

Soon we were on a steep incline, complete with switchbacks. This is where

the guy in the wheelchair gets even, and therefore must fully exploit the advantage. I easily zoom past and wait at the next rest stop. Not wanting to overdo it, I keep the heckling to no more than necessary.

"Nice hill, eh? What took so long? How come your face is red?" I say with my best innocent look.

Some of the responses are beyond PG-13, but suffice it to say that they seem to take exception to my mocking. Oh well, off I zoom up the trail whilst they soak up

oxygen and perspire profusely.

Soon we are at the top, taking in the sights of the lodge. There are spectacular hotels, restaurants, pubs, and shops. In the center is a crystal clear pond, a waterfall, and trout swimming around. Then just down the path is the spectacular lookout where my wife and I were wed so many years ago. It will always be a special place to us.

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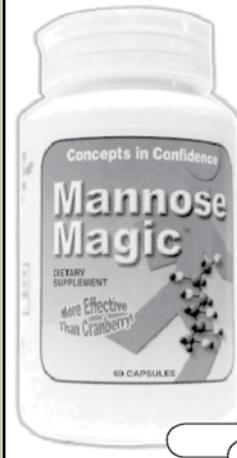
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Our Mission

VetsFirst leads the way in advocating for veterans living with disabilities and ensuring they achieve the highest level of independence and quality of life.

Our History

As a program of United Spinal Association, VetsFirst has a long and illustrious history assisting and representing veterans and their eligible family members. United Spinal—a VA recognized veterans service organization—strives to ensure the organization remains an instrument for veterans.

About VetsFirst

VetsFirst brings to bear seventy years of expertise in helping America's veterans with disabilities, their spouses, dependents, survivors and other eligible family members receive health care, disability compensation, rehabilitation and other benefits offered by the U.S. Department of Veterans Affairs. We supply direct representation, proactive legislative and regulatory advocacy, individual support and counseling services, guidance on education and employment, timely news and information and valuable self-help guides.

VetsFirst advocates nationally for all generations of veterans, including individuals living with post-traumatic stress disorder and traumatic brain injuries. Our advocacy efforts go far beyond offering words of support and encouragement. We take this fight to Capitol Hill to bring attention to issues that matter most to the men and women who proudly served our country.

Timely Support

We connect with thousands of veterans and active military servicemen and women annually through our call center and online help desk, **Ask VetsFirst**. Our staff takes the time to address each inquiry, offering guidance with questions on military separation, claims appeals, and state benefits. Visit <http://helpdesk.vetsfirst.org/> to submit your questions and receive quick response from our knowledgeable staff.

Valuable Resources

In addition to providing individual support and counseling services, VetsFirst offers timely news and information across the spectrum of issues presently impacting the veterans community, including state benefits, separating from the military, as well as exclusive feature stories on military health care and VA funding and compensation.

Our Core Beliefs

VetsFirst's priorities are based on three core principles that will improve the lives of veterans with disabilities.

Community Integration and Independence— We support policies that help veterans with disabilities reintegrate into their communities and achieve independence.

Timely Access to Quality VA Health Care and Benefits

We support improved access to VA health care and compensation and pension benefits that are the lifeline for many veterans with significant disabilities.

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PARSING MERYL'S SPEECH

Millions of people watched Meryl Streep's Jan. 8 Golden Globe acceptance speech in which she condemned Donald Trump's "instinct to humiliate."

"There was one performance this year that stunned me. It sank its hooks in my heart," said Streep. "Not because it was good. There was nothing good about it. But it was effective and it did its job. It made its intended audience laugh and show their teeth. It was that moment when the person asking to sit in the most respected seat in our country imitated a disabled reporter, someone he outranked in privilege, power, and the capacity to fight back. It kind of broke my heart when I saw it. I still can't get it out of my head because it



wasn't in a movie. It was real life."

Although many with disabilities appreciated Streep's heartfelt words, Rooted in Right's Emily Ladau disagrees that having a disability means we're powerless. "The outrage over the mocking

stems from a perception of disability that is stigmatizing in and of itself: We're a defenseless group, already leading pitiable lives. Never mind that Serge Kovalski is a successful, established reporter." If the media could move beyond denouncing superficial ableism and dig deeper into life-and-death disability issues, that might be something to celebrate, she explains in her article found on TheEstablishment.co, "I'm a Disabled Woman Who's NOT Celebrating Meryl Streep's Speech."

EXCERPT: 'MY LIFE WITH PARALYSIS, IT'S A WORKOUT'

We, the disabled, encourage one another to demand that society accept us for who we are, and not change our routines to accommodate how the general public feels we should look. But I want to stay healthy, and I want to keep my body ready for the future. I believe strongly that everything should have been made accessible yesterday, but I also would choose an abled version of myself over my current self any day — it's easier and more time-efficient to manage. Does spending so much time maintaining my body make me an inspiration, or a disability rights failure? Can I choose a lifestyle that won't be judged?

Perhaps not. And so I've taken on a small but meaningful act of resistance, by changing the way I talk about the life I now lead. I've sought to explain my regimen to others as health maintenance, which is an accurate, although thoroughly unsexy, description. My FES cycle workouts and standing frame (a machine that is exactly what it sounds like) sessions keep my muscles and bone density intact, my circulation going, and my health at a level such that I am less likely to require hospitalization.

I don't want to come off as angry, hopeless or inspirational, because my life may end up defined by one of those adjectives if I provide the slightest description of my day. But let me, just for now, take control of my story and tell you that I have a disability, and it takes time and effort to both maintain my health and live my life.

— Valerie Piro, www.nytimes.com/2017/01/11/opinion/my-life-with-paralysis-its-a-workout.html



What on earth would compel so many wheelchair users to bounce down so many steps at the same time? Well, it's a good way to draw attention to accessibility barriers such as steps. The video this screenshot was snipped from was posted to Todo Disca's Facebook page on Jan. 4.

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